

TRANSITIONS

ACROSS THE LIFESPAN

AN OCCUPATIONAL THERAPY APPROACH

EDITED BY

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DEDICATION

This book is dedicated to

*Our mentors who saw in us future therapists and scholars and who
provided us with support and guidance in our careers;*

*The many individuals and families who have shared their stories of transition,
change, and hope and who enabled us to deepen our knowledge and skills; and*

Our families for all their support and love.

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—Meira L. Orentlicher
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INTRODUCTION

*Meira L. Orentlicher, PhD, OTR/L, FAOTA; Sandra Schefkind, MS, OTR/L;
and Robert W. Gibson, PhD, OTR/L*

A *transition* is a passage from one life state, stage, or place to another. People experience planned and unplanned transitions throughout their lifespan. To transition successfully, they may need supports from a variety of social institutions such as government or state benefits for education, employment, and community living. *Transitions Across the Lifespan: An Occupational Therapy Approach* covers the transition needs of people throughout their lifespan.

This text is directed to occupational therapy students, educators, and practitioners to advocate for occupational therapy's role in transition services. It may also be a helpful resource for external audiences such as health administrators, special education directors, and other decision makers who help to allocate funds for programs and services and service providers.

How This Text Is Organized

This text begins with a "Prologue" that tells the personal story of a family that experienced an unplanned and traumatic transition when their son suddenly had cardiac arrest and anoxic brain injury at age 14 years. The story, told by his mother, provides a platform to review both opportunities and challenges brought upon by expected and unexpected life changes. Additional case examples are presented throughout the book to illustrate the specific transition areas highlighted in each chapter.

In Part I, "Understanding Transition," two chapters explore what transition is and occupational

therapy's role in transition. Part II, "Transition Across the Lifespan," devotes chapters to early childhood, school, postschool, employment, and aging. Part III, "Universal Considerations in Transition," discusses transition supports across all age groups, including health care, emotional well-being, environmental support, and prevention.

Also included are five official documents from the American Occupational Therapy Association (AOTA): *Specialized Knowledge and Skills for Occupational Therapy Practice in the Neonatal Intensive Care Unit* (Appendix A); *Occupational Therapy Services in Early Childhood and School-Based Settings* (Appendix B); *Occupational Therapy Services in Facilitating Work Performance* (Appendix C); *Occupational Therapy's Perspective on the Use of Environments and Contexts to Facilitate Health, Well-Being, and Participation in Occupations* (Appendix D); and *Occupational Therapy in the Promotion of Health and Well-Being* (Appendix E).

Throughout the text, chapters discuss relevant laws, regulations, and benefit programs; theories and tenets that guide practice; the unique contributions occupational therapy practitioners can make in each transition area; and suggested strategies for evaluation and intervention. Questions are included in each chapter to challenge readers to reflect and learn.

This book highlights three major premises:

1. Transitions can be examined broadly as both a conceptual and practical approach for service across many settings and systems.

2. Occupational therapy practitioners, on the basis of their unique and holistic knowledge and skills, can be key contributors to transition service delivery.
3. Our health care and educational systems are currently undergoing many changes, making now an opportune time for occupational therapy practitioners to embrace transition as a basis for communicating, planning, and documenting. In other words, practitioners can use transition outcomes as a measure of accountability to provide occupation-based, visionary service that aligns well with occupational therapy principles.

This text supports these premises by presenting framework and practice considerations on transitions across the lifespan for occupational therapy practitioners. It also offers important case studies that ask readers to seriously consider the complex navigation of life events.

Transition and Occupational Therapy

Life changes and transitions are experienced by all people. Therefore, addressing transition needs is

applicable to many—if not all—of the clients occupational therapy practitioners serve. By preparing clients and families for next steps and situations—and then meeting desired outcomes associated with the expected or unexpected changes—practitioners have great opportunities to impart their knowledge and skills to better the lives of those served. In addition, a focus on transition will help secure the profession by demonstrating its value in establishing functional goals and meaningful activities to increase participation.

Each of us has an opportunity to connect this transition focus to our own knowledge base and to our practices. This journey must be individualized. It could start with reading more literature cited throughout this book. It might begin with downloading existing AOTA resources. Finding a mentor might be an important step. Conversations could ignite between partners in schools or in clinics. Groups could form to continue dialogue and activity. A simple question of “What’s next?” might generate thoughtful planning among stakeholders.

Occupational therapy practitioners can be transition leaders by starting this exploration and by initiating these discussions. The right time is now.

PROLOGUE.

RENZO'S STORY

Cheryl Dougan

Thursday, May 21, 1998, began as a gloriously beautiful day with brilliant blue skies, spring warmth, and abundant satisfaction with life. After breakfast, Tony left for work and our 14-year-old son, Renzo, set out for school. Within weeks, Renzo would be graduating from eighth grade, a milestone we were planning to celebrate with a cross-country camping trip. He was establishing his independence, at least in his mind, and was eager to grow up.

By early afternoon, interrupted by the relentless ringing of the phone I had been trying to ignore, the upstairs answering machine echoed an unfamiliar voice relaying that Renzo was at St. Luke's emergency room (ER) and that I should come immediately. Several more recorded missed calls were from Renzo's school, and one was from the police department; all repeated the same message. Knowing that Tony would be home soon, I scribbled a note on a scrap of paper, taped it to the door, and left for the ER.

Renzo had been a frequent visitor to the ER, once for appendicitis, once for a mild concussion from falling out of a tree, and a few times for stitches to injuries incurred on the playground or in sports. Perhaps this was just another, not too serious, ER visit.

The director of the school waited at the door to the ER. Someone guided me into a small waiting room and suggested I sit on the couch to wait for the hospital chaplain. Fearing the worst, I refused, and

insisted on seeing Renzo immediately. They warned me that the sight of him could be disturbing, that he had suffered a cardiac arrest. As the curtain was drawn open, I saw my son, his body seizing violently. He lay unconscious but never still. The pant legs of his school uniform were cut open through his leather belt, and his turtleneck lay open, exposing his bare chest, wired with electrodes.

I clutched his bare feet, the only space left unattended, and spoke reassuring words, hoping my voice would reach him, calm him, and return him. Although stunned by the intense activity surrounding him—someone hand-pumping a mask held to his face, another holding his head still, the cacophony of voices, buzzing monitors, the blinding bright lights—I didn't dare show my emotions, fearing I'd be taken away from him if I lost control.

At last Tony arrived, confused and trying to comprehend the unbearable, asking questions I couldn't answer. A pediatric cardiologist quickly determined Renzo's condition was too serious to be handled in our area hospitals and arranged for a helicopter transport to St. Christopher's Children's Hospital in Philadelphia, an hour's drive away from our home. Despite our pleas, neither Tony nor I were allowed to travel with our son. What if he regained consciousness and we weren't there for him? Silently, we feared he might die. Renzo was strapped to the gurney and rolled away to the waiting helicopter. We drove in near silence to the hospital.

Reality, the Unavoidable Truth

After an interminable hour and a half in transit and admission procedures, we were finally allowed to be with Renzo. He lay resting, peacefully sedated, and isolated within a glass-fronted cubicle directly across from the nursing station in the intensive care unit. We sat with Renzo throughout the night, dazed, whispering, and wondering.

For the next month, we continued to hope that Renzo would wake from this profound but restless sleep. His brain had been robbed of oxygen when his heart stopped; the extent of injury remained unknown. Between frequent doses of sedating drugs, every muscle in Renzo's body was tormented by a central nervous system seriously out of whack. He writhed uncontrollably, flinging one arm upward as his body twisted and arched in opposition, clenching and grinding his teeth until it seemed they would crumble.

We wondered what had caused his heart to fail him, a strong and healthy 14-year-old, while performing the Presidential Fitness Test at school. Among several possibilities was the mention of *Long QT syndrome*, something we had never heard of. We would learn more over the next few months about this silent killer that most often affects adolescents, many of whom are athletic and show no discernible signs of a heart condition.¹

Overnight accommodations for grieving parents were dismal. I shared a room with up to three other mothers in what felt like an abandoned corridor of the hospital. Down the hall, Tony roomed with up to seven fathers, in four pairs of bunk beds. None of us slept well. At various hours, the phone rang, awakening fear in all of us; only one would

be called away to attend the bedside of their critically ill child. When we encountered other parents in our rooms or in the lounge assigned for parents and family only, it was enough to nod. No one ever made a serious attempt at conversation. Each parent bore his or her burden alone, never seeking to share the pain and anguish.

Although Renzo remained in a coma, we made certain that everyone should assume he could hear and understand. We made it clear that no disparaging conversations should occur in Renzo's presence, going so far as to escort the doctors into the hallway to suffer their dire reports.

Tony stood guard over Renzo during most of the day, ensuring good care by the nursing staff and being available to meet with the doctors and specialists who dropped by. I consigned myself to the hospital library to research the ramifications of anoxic brain injury. I needed to learn a new language to get by in the strange world we now inhabited, where words such as *anoxic encephalopathy*, *hypo-ischemic encephalopathy*, and *hypoxic ischemia* bewildered us. The hospital librarian sat with me for hours, patiently entering key words into the medical network search, printing out abstracts for me to review, and ordering complete articles.

I learned about hyperbaric oxygen therapy (HBOT), which suggested Renzo's brain cells might not be dead, that they could be in a stage of "neuronal lethargy" or be "idling neurons" or "metabolically lethargic neurons." I soon accumulated an impressive number of documents from around the world on the efficacy of this treatment.

Of all the research I had found, including that about pharmacological treatments, natural alternative medications, and more, HBOT seemed most

¹The American Heart Association (2015) describes *Long QT syndrome* as follows:

[Long QT syndrome] (LQTS) is an infrequent, hereditary disorder of the heart's electrical rhythm that can occur in otherwise healthy people. It usually affects children or young adults.

When the heart contracts, it emits an electrical signal. This signal can be recorded on an electrocardiogram... and produces a characteristic waveform. The different parts of this waveform are designated by letters—P, Q, R, S, and T. The Q-T interval represents the time for electrical activation and inactivation of the ventricles, the lower chambers of the heart. A doctor can measure the time it takes for the Q-T interval to occur (in fractions of a second), and can tell if it occurs in a normal amount of time. If it takes longer than normal, it's called a *prolonged Q-T interval*.

People with LQTS don't necessarily have a prolonged Q-T interval all the time. At the time that they have an electrocardiogram (such as during a routine physical examination), the Q-T interval may actually be normal. People with LQTS may not have any symptoms. People who do have symptoms often exhibit fainting (syncope) and abnormal rate and/or rhythm of the heartbeat (arrhythmia). People with this syndrome may show prolongation of the Q-T interval during physical exercise, intense emotion (such as fright, anger, or pain) or when startled by a noise. Some arrhythmias are potentially fatal, causing sudden death.

logical and least likely to harm Renzo any further. Absent any physician-proposed medical interventions, Tony and I began to consider how we could get Renzo into this unconventional treatment as soon as possible. We were desperate to improve Renzo's chances, to have him open his eyes, smile, and resume living.

I left Renzo for the first time on his 16th day of coma to return home to gather belongings for our continued stay at the hospital. The debris of our lives lay strewn about our house, just as we had left it—Renzo's worn-out shoes kicked off just inside the kitchen door, his shirt hanging on a doorknob upstairs. I escaped to his upstairs bedroom. I clung to his soft leather shoes, shaped by wear to a perfect fit, and nestled into his pillow, free to scream and cry as loud and long as I wished before slipping into an exhausted sleep.

Tony's desperate call from the hospital awakened me barely an hour later. His words were so difficult to hear and impossible to grasp. He had been waiting beside Renzo's empty bed for him to return from the testing lab when the neurologist phoned to deliver devastating results from a brain function test. The doctor said that the SPECT (single-photon emission computed tomography) showed "global, diffuse damage with very little likelihood of any significant recovery." More pointedly, he said that if Renzo survived, he was likely to remain in a persistent vegetative state.

I raced back to the hospital and found Tony sitting alone in the dark beside Renzo, who for the moment lay peaceful under the aftereffect of anesthesia. Tony sobbed as he tenderly smoothed Renzo's hair back from his forehead. His strength was drained, his heart devastated. We escaped to a nearby conference room to talk.

Finally, we were forced to touch the depth of our despair, kept initially at bay as we clung to hope for our son's future. But our natural store of hope was exhausted, depleted by time, medical tests, and loss. We talked for hours about what we should do, even considering whether we could let our son die, as obliquely suggested by his cardiologist. We came to realize that we needed to forge a different hope for our son's future—for our future with him. This was to be a new kind of hope, one that required diligent work to create a level of optimism that did not come naturally.

We arranged for a face-to-face appointment with the neurologist who had so insensitively delivered

such distressing news to Tony by phone, rather than in person. We intended to dismiss him from Renzo's care and request another, more compassionate, neurologist.

The next morning, Tony and I waited in the small conference room just outside Renzo's room, trying to keep our sadness and anger contained so we could attempt a rational discussion with the neurologist. He arrived and sat opposite us, concerned and confused about why we were so upset. As it turned out, the doctor thought he was being helpful by relaying the news of the SPECT test so quickly, saving us from having to wait over the weekend for the test results.

We explained our point of view and asked the doctor whether he had a child—he did. Framing the discussion parent to parent, we asked the doctor to imagine what it would be like to receive this devastating news by phone, without appropriate emotional support. With defenses diminished, the doctor asked how he could best help us.

We wanted more information about experimental pharmaceuticals. I had come across several possibilities, including human growth factor and amantadine. I had also acquired research saying that, for unexplained reasons, zinc was metabolically decreased when the brain was injured. The article suggested that zinc deficiency led to progressive neuronal injury and that it should be supplemented immediately following a brain injury. The doctor agreed to order the necessary blood tests to check Renzo's zinc level and, indeed, found it to be extremely low (Lin, Howng, Hu, & Huang, 1992). Finally, we asked the doctor to review the research I had gathered on HBOT and advise us whether it was a plausible treatment.

Despite what Tony and I thought to be a productive discussion, the doctor continued his attempt to help us "accept reality" and acknowledge that our son's prognosis was hopeless. With profound strength, Tony contained his rage and heartache to reprimand the doctor saying, "Hope isn't yours to give or take away. It belongs to us! Your job is to help us forge our path to the future, outside of this hospital."

For the first week or so of hospitalization, Renzo breathed well on his own. After repeated intubations for various tests, he lost that ability. We spent hours trying to hold Renzo's jaw in a particular way that would keep his airway open, hoping he would

regain this once innate skill. However, Renzo was scheduled for a tracheostomy and insertion of a feeding tube.

Needing a clear plan of action, we drafted our own agenda and called a meeting of all the professionals involved with Renzo's care. Our aim was to gather and cross-reference information from the physical and occupational therapists, nutritionist, nursing staff, psychologist, cardiologist, and two neurologists, thus beginning to map our way toward the future.

On June 12, before the meeting formally convened, one of the neurologists entered the room without acknowledging anyone. He grabbed a marker and quickly charted textbook expectations for Renzo's recovery on a white board. He noted that after 30 days in a coma, Renzo would have a 13% chance of any meaningful recovery; after 3 months, that chance would reduce to 3% (in studies, only one person regained consciousness).

The brutality of this graphic presentation was crushing. We had to hope that Renzo would be in that 3%–13% recovery zone. Clinging to each other's hands under the table, we regained our composure to begin the planned agenda.

Desperate to understand both the full nature of Renzo's injury and the ways we might best help our son, we framed the discussion to support true collaboration. All of the professionals, from the nutritionist to the neurologists, were afforded equal time and respect without a hierarchy of opinion.

As the meeting continued, we were particularly impressed by the partnership between Renzo's occupational and physical therapists. They were the first professionals to offer any measure of encouragement, saying they had observed amazing progress in patients after they left critical and acute care. Earlier, during therapy sessions, they had stressed the importance of stimulating all of Renzo's senses—olfactory by having Renzo smell fragrant oils or herbs, auditory by playing his favorite music and constantly talking to him, and tactiley by brushing his skin with a soft brush.

Because of Renzo's extreme tactile sensitivity, it was impossible to comfort him, or ourselves, by holding him close. Instead, we practiced the joint rotations the occupational therapist taught us to prevent long-term contracture and deformity. We discovered we could soothe Renzo's body to stillness by rotating each individual finger joint in

his hands. At last, we felt empowered to ease our son's pain.

Concluding the meeting, Renzo's primary neurologist reported that he had reviewed the research about HBOT for brain injury and agreed it was worth trying. The health maintenance organization (HMO) approved 20 HBOT treatments for Renzo within hours of receiving the neurologist's Letter of Medical Necessity and an abundance of my research. Finally, we were on a path forward.

On June 23, a little more than a month after his cardiac arrest, Renzo was discharged from St. Christopher's and transported to the Hershey Rehabilitation Hospital, chosen because of its proximity to an independent HBOT treatment facility. Over the previous month, Renzo's only progress was that he had moved from a deep coma to a vigil coma, meaning his eyes could open but not track on a moving object; his body had forgotten how to eat or breathe.

I rode in the back of the ambulance with Renzo and the emergency medical technician (EMT) to the rehabilitation hospital while Tony followed in our car. The EMT largely ignored Renzo, so I struggled alone to contain Renzo's body while he flailed his arms and legs, agitated by the road vibration despite being sedated. His leg broke loose from its restraint, scraped against the storage shelves, and began to bleed. This was my beloved son, barely out of a deep coma, his rigid body unable to move to a sitting position, and he was being treated like cargo.

Re-creation Story

On the third day after admission to Hershey, Renzo was sedated and transported to the HBOT facility for his first 1-hour session. The treatment record for June 25 reads, "Rested quietly and listened to classical music during treatment. Afterwards, patient had eyes wide open and seemed focused on his parents. Turns head toward mother's voice." It was a remarkable moment when Renzo emerged from the HBOT tank to look at us, to clearly see us for the very first time in over a month (Figure 1).

After three electrophysiologists at Hershey reviewed all of Renzo's past electrocardiograms, they concurred that his cardiac arrest was probably due to Long QT syndrome. At last, we had an explanation for what happened but also the knowledge that Renzo could be at risk for another cardiac event.

Figure 1. Hyperbaric chamber.

Source. C. Dougan. Used with permission.

We were heartened to see our son in new surroundings with concrete therapy goals set toward a more promising future than had been predicted during critical care at St. Christopher's. From Day 1 at Hershey, Renzo was dressed in regular clothes; no hospital-issued pajamas allowed. This small but significant change from critical care fueled our expectation that Renzo would improve.

We watched in amazement as an occupational therapist and a physical therapist worked to slowly ease Renzo's rigid body into a sitting position, supporting him between them at the edge of his bed. Another therapist held his head and gently turned it from side to side. After some discussion, the therapists decided Renzo might be able to tolerate sitting in a reclining wheelchair fitted with both a strap to secure his head to a headrest and a vest to attach his body to the chair back. We were taken aback when the therapists suggested we take Renzo outside by ourselves to walk in the beautifully landscaped garden of the hospital. It had been more than a month since we had been alone with our son, without medical supervision.

Gradually, our fatigue lessened as Tony and I took turns getting an uninterrupted night's rest at the Ronald McDonald House. One of us always stayed the night with Renzo, available to calm him when he became agitated, or lie beside him in his narrow hospital bed to physically embrace him in an effort to restrain his body when we sensed it was about to torque into an out-of-control back arch. Someone needed to be there to place the black rubberized mouth guard between his clenching teeth. His lips and tongue already bore sores from being bitten.

Over the next few weeks, we witnessed small gains as physical and occupational therapists worked with Renzo daily. We learned the importance of keeping his muscles and tendons stretched, the necessity of weight-bearing exercise, and safe ways to transfer Renzo from bed to wheelchair. Progress in oral therapy was slower, almost imperceptible. We felt a glimmer of hope when the speech pathologist decided to insert a Passy Muir valve into Renzo's tracheal tube, intended to facilitate speech. She taught us how to stroke Renzo's cheeks and throat, purse his lips together, and encourage him to swallow tiny spoonfuls of Italian ice. He made tasting movements and exhibited a slight swallow reflex, but not much more.

On one of our daily walks in the garden, we were delighted when a baby rabbit and its mother kept Renzo's attention for nearly 3 minutes before they disappeared under a bush. Another day, he moved his head and eyes to follow a soccer ball being tossed between a father and son for nearly 5 minutes. Most astonishing was when I made a drumming noise on a metal light pole. He smiled brightly, a fleeting expression that would not return for many weeks.

We were adamant to have Renzo breathe on his own before being discharged from the hospital. Our determination defied the consultation of an ear, nose, and throat physician who insisted that he never removed the tracheal tube from patients with brain injury until at least 6 months after injury, when they were more neurologically stable. We tenuously capped Renzo's tracheal tube for minutes at a time while he made valiant efforts to breathe through his nose. When he seemed frightened at not being able to breathe, we uncapped the tube and let him fill his lungs with air. Minutes of Renzo's breathing on his own grew into hours; those hours eventually totaled the 48 hours required before the doctor would agree to remove the tube. Before discharge from the intermediate care unit, Renzo was breathing on his own for the first time in almost 2 months.

Tony and I felt oddly positive about Renzo's progress and more certain every day that he would not only survive, but would also improve. We grew used to him as he was and rejoiced at each small improvement. However, undermining our optimism, the neuropsychologist's discharge report to the school district for special education services read, "The patient most likely does show flashes at times, but this does not necessarily mean

that he has a mental life." Those words remain painful to read.

Looking back, I realize that no consideration had been given to Renzo's medication schedule. Because he was on high doses of Valium and chloral hydrate, his fragile mental status was probably even more severely depressed by the drugs. To our disbelief, after only 1 month in rehabilitation, plans were initiated to discharge Renzo as needing only "custodial care." We were strongly advised to place him in a long-term-care facility. Instead, we chose to bring him home.

Nurses taught us how to bathe Renzo, shampoo his hair, and care for the still-fresh wounds caused by his tracheotomy and gastrostomy. We learned how to chart and measure his many daily medications and crush them so they could dissolve in liquid and pass directly into his stomach through his percutaneous endoscopic gastrostomy (PEG) tube. We learned how to replace the PEG tube in the event Renzo accidentally yanked it out of his stomach, as he had already done. Sensing Renzo's humiliation, we contained our tears when changing his diapers. It was hard learning how to parent our teenaged son in what promised to be a perpetual second infancy.

One thing seemed certain: Renzo would never be the person he was before. As we wrestled with our new reality, Tony found words to clearly define our common goal: "Our job as parents is to help our son achieve his full potential. His potential has changed; our job is the same."

Homecoming

In advance of our homecoming, more than 2 months after injury, friends ripped up the carpeting in our living room to expose the hardwood floors that would make the room wheelchair accessible. They also dismantled and stored our dining room furniture.

Arriving home by medical transport, two men unloaded Renzo, strapped to his wheelchair, and pushed him up the steep incline of a makeshift wheelchair ramp. After depositing Renzo and our belongings in the emptied dining room, they offered forms for us to sign confirming that our son had been delivered without incident, wished us well, and left.

Our son could no longer walk, talk, eat, or maintain any control over his body. He couldn't

even smile. Neither could we. With Renzo officially deemed as needing only "custodial care," a less-than-benevolent health insurance company agreed to pay for a mere 8 hours of night nursing, presuming that we could actually sleep while our son was cared for by strangers in our home. Renzo's daily care was to be left to Tony and me to manage, assuming we could separate from our emotional attachment and overcome our exhaustion to become competent caregivers. More of our lives slipped into the past as our dining room filled with an adjustable hospital bed with railings, a machine that would control the dispensing of liquid food directly into Renzo's stomach, an oxygen tank, and a cardiopulmonary pulse oximeter that measured the oxygen saturation of his blood while marking the rhythm of his pulse.

Tony and I took turns preparing Renzo's numerous medications, crushing them into a fine powder so they could be administered through his PEG tube. We charted when and how much medication we gave him, the ounces of liquid pumped into his body, when he urinated or had a bowel movement, and when he slept.

Without an accessible first-floor bathroom, we used an oversized stainless steel salad bowl as a bathing basin. Renzo's body flailed and seized out of control during grooming activities such as bathing and teeth brushing. Water sloshed everywhere, and at times, the entire basin was knocked to the floor. Too often, Tony and I wept through this daily baptismal ritual. Always exhausted and alternately angry and very sad, we slowly acquiesced to the revised patterns of our existence. Never was there a single moment of joy or happiness. We felt abandoned.

Renzo's condition seemed to worsen in the next 3 weeks. The pupils in his eyes dilated, and he looked terrified, as if he were seeing things, and his darkened tongue rhythmically protruded from his mouth. His posturing became so intense one night that the nurse eased him out of bed and onto an exercise mat to sleep more safely on the floor. Seeing him there in the morning, we felt the futility of our struggle.

Because Renzo's needs were now so complex, his former pediatricians declined to treat him. It took almost 2 weeks before I could find a new primary care physician who agreed to see Renzo. She gently but thoroughly examined Renzo before asking why we thought we could possibly manage the

complexity of his care at home. Feeling defeated, we spoke the truth: we couldn't. She comforted us with words of encouragement, the first that we had heard from any of his doctors. She said, "He is in there. Don't give up hope." With that advice, she arranged to have Renzo admitted directly to Good Shepherd Rehabilitation Hospital as an inpatient.

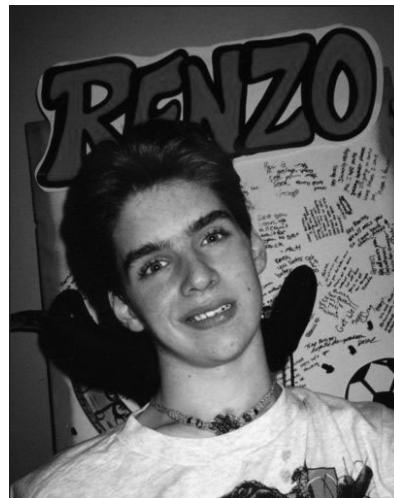
Rehabilitation

It was a huge relief to have Renzo competently cared for in the brain injury unit at Good Shepherd, only a 20-minute drive from our home. His doctor, a psychiatrist, believed it was important to wean Renzo from all sedating medications to evaluate the degree of his brain injury. Surprisingly, Renzo calmed and began to show more improvement with this round of intensive occupational, physical, and speech therapies. Almost 4 months after injury, Renzo finally passed his barium swallow test and was allowed to try eating pureed food.

A neuropsychologist agreed to meet with a group of Renzo's dedicated middle school friends to explain brain injury, answer fearful questions, and help them feel more at ease interacting with a dramatically different Renzo. After observing him during therapy sessions, these friends devised their own therapeutic activities, based on Renzo's interests. The guys were more inclined to engage in physical activities in the recreational therapy department, using hand-over-hand assist with Renzo to play games like air hockey. The girls concentrated on cognitive skills and more subtle exercises. Knowing Renzo's love of music, one friend brought her keyboard to the hospital; we watched in amazement as Renzo slowly unclenched his fists and attempted to play.

Another intuitive friend placed her palms on Renzo's cheeks to stretch a smile into place; that tactile stimulation pasted a smile on his face that soon became real (Figure 2). We discovered Renzo could read when one of these amazing friends made large-print cards with phrases such as "Look at Mom" or "Raise your arm"; his eyes tracked the words, and he obliged with the directive. As his speech became more understandable, we could discern his correct answers to simple math problems. My heart almost stopped on October 4 when he quietly spoke, "I love you, Mom."

Figure 2. Renzo's first smile.



Source. C. Dougan. Used with permission.

During the month Renzo was an inpatient at Good Shepherd, Tony and I had more free time to reimagine our future as a family. We kept in mind the wise advice of Renzo's neuropsychologist at Good Shepherd never to give up on our dreams but instead to consider ways we might accomplish them differently.

Reinventing Life

Remarkable friends joined forces to form the Have a Heart for Renzo committee. Together, they anticipated and met our every need, including raising enough money to construct an accessible addition to our home and eventually to buy a wheelchair-accessible van. They did our shopping, helped with housekeeping, provided some of Renzo's care, and even arranged to deliver dinner every night—for the entire next year!

Granted medical leave from work through December, Tony coordinated the design and construction of an accessible bedroom and bath for Renzo. In addition to raising funds, the committee also secured donations of time and materials from area plumbers, electricians, and contractors, who agreed to supervise volunteers. Construction progressed quickly. We were determined to have Renzo in his new room by the 1-year anniversary date of his cardiac arrest. The demolition of our backyard and the construction of Renzo's new room seemed a metaphor for our lives. We adapted to our

circumstance and began the arduous task of constructing life after the annihilation of our dreams.

After filing a formal appeal to medical insurance, we were granted an additional 8 hours to bring the total nursing care up to 16 hours per day, allowing us more time to plan and do the work needed to establish new patterns of life. I assumed the remaining 8-hour day shift so I could escort Renzo to therapy appointments and learn from watching and working with the therapists. Most were patient with my many questions; some seemed annoyed that I continued to hope and press for significant improvement.

Normalizing

Soon after Renzo's return home from Hershey Rehabilitation and before his unexpected inpatient stay at Good Shepherd, Rick Agretto, the Bethlehem Areas School District director of special education, came to our house for an intake interview. When he arrived, Renzo was strapped head and torso to his reclined wheelchair. Although still unable to smile, he attentively followed our conversation with his eyes. As Rick stood to leave, shaking Tony's hand and mine, Renzo ever so slowly, and with tremendous effort, raised his hand toward Rick, wanting to shake hands also. Reduced to tears

by Renzo's determination, Rick assured us he would pull together a dynamic team of therapists and educators to individualize Renzo's education needs.

Because of significant neurological injury, Renzo could not tolerate over-stimulating environments, so his individualized education program (IEP) provided for home-based special education supports, including all therapies, for the first year after injury. This was a great opportunity for Tony and me, and Renzo's home nurses, to learn from the teacher and therapists. To maximize Renzo's progress, we reinforced all skills and goals daily. He also continued with the medical-based therapies at the rehabilitation hospital.

At one point, frustrated and confused by the strict parameters of medical- versus school-based therapies, I requested that all therapists from both providers begin meeting together on a monthly basis to formulate complementary goals. Meetings alternated between the hospital and the school district offices. This was a first-time experience, valued by all of the therapists; the results of their collaboration were realized in Renzo's accelerated progress (Figure 3).

As Renzo improved, we began visiting the district's special education classrooms to assess where his needs might best be served. In researching education law, I learned that Renzo was eligible to

Figure 3. Home-based (a) occupational and (b) physical therapy.



(a)



(b)

Source. C. Dougan. Used with permission.

receive a "free and appropriate" education until age 21 years. We felt strongly that Renzo would benefit from being among familiar friends in small class sizes at his former private school. These friends, particularly those who had witnessed his sudden cardiac arrest, also needed an opportunity to reconcile their complex feelings of loss by becoming reacquainted with Renzo and adapting to his limitations. He needed his friends to inspire him and to give him reason to fight for his own existence.

Ultimately, the district agreed to support Renzo's return to his smaller private school, where, accompanied by an instructional aide, he could audit one or two classes per semester. The district also supported him with transportation services and continued physical, occupational, and speech therapies. As we watched our son heal with the love and support of his childhood friends, we knew the right decision had been made.

On June 1, 2002, 4 years after his injury, Renzo's two best friends helped him rise from his wheelchair and walk arm-in-arm to center stage, amid a standing ovation, to receive his diploma, which read, "Certificate of Attendance." Like his friends, Renzo was ready and eager to be independent.

Transition to Adult Life

Around the time Renzo was completing his high school experience, I trained with Michael Smull, one of the key innovators of person-centered planning and proponent for system change, to become certified as a facilitator of Essential Lifestyle Planning (ELP), a tool that continues to guide the evolution of Renzo's life.² As part of the coursework, I facilitated development of Renzo's first plan with Tony, members of Renzo's direct support staff, and chosen friends. Renzo's plan acknowledges his varied interests before brain injury and considers ways to connect his past with his

current life, lessening the sense of loss as he moves forward with life.

Physical, occupational, speech, and cognitive therapy goals specific to brain injury rehabilitation are embedded within every focus area of his plan. Renzo's ELP clearly defines what is important *to* and important *for* him; sets and revises specific goals with action plans; and contains information about his evolving health care, how he communicates, and what people need to know to best support him. Through this life-affirming process, Tony and I began to see our son as a whole person again, living life now with different abilities and able to make his own choices, develop personal relationships, and participate fully in his community.

With Renzo symbolically graduating from high school, we began more focused work on the transition IEP that would prepare him for final graduation out of district services in June 2005, at age 21 years. We were fortunate to have Terry Myers, supervisor of special education at the high school level, guiding the process. Like me, Terry had become an avid proponent of person-centered planning,³ still a relatively new concept in our area at the time. Looking back, she recalls, "The key to Renzo's unique transition program is that we did person-centered planning. It was a huge team, comprising family, friends, psychologists, teachers, therapists... basically everyone integrally involved in Renzo's life. We could not have conceived this alone."

Truly, I didn't know just how lucky we were back then. I have since learned from other parents that many school administrators discourage participation from people outside the education system in the development of an IEP. Too often, it is simply required legal paperwork for administrators; they neglect to acknowledge the important role of the individual student and the knowledge and understanding that parents, family, and friends might contribute.

²*Essential Lifestyle Planning (ELP)* is a guided process for learning how someone wants to live and developing a plan to help make it happen. It began in the late 1980s at the University of Maryland, where Michael Smull and Susan Burke-Harrison were asked to help people return to their home communities from institutions and residential schools. For more information on ELP, see <http://www.helensandersonassociates.co.uk>.

³*Person-centered planning* is a collection of tools and approaches based on a set of shared values that can be used to plan *with* a person, not *for* him or her. Among the person-centered planning approaches are Making Action Plans (Forest, & Lusthaus, 1990), Group Action Planning (Turnbull & Turnbull, 1992), and Planning Alternative Tomorrows With Hope (Pearpoint, O'Brien, & Forest, 1993). The Centers for Medicare and Medicaid Services (CMS) has highlighted person-centered planning and is promoting its use through its Home- and Community-Based Services Waivers.

For Renzo and his team, the transition IEP experience was one of celebration. The walls of the meeting room were decorated with oversized paper banners that soon filled with photographs of Renzo's life along with words and drawings describing his hopes and dreams in a confetti of bright-colored markers.

Renzo's transition IEP, informed by his more comprehensive ELP, established the foundation for the life he currently enjoys. He now works at a part-time clerical job at the Martin Guitar factory, volunteers at Easter Seals with preschool children, periodically takes continuing education classes, and enjoys an active social life. All this wasn't the result of the spontaneous miracle most parents in our situation hope for; it was the outcome of a well-conceived and carefully implemented transition IEP, a true person-centered plan. The transition team invested their time to get to know Renzo, consider his interests and abilities, and explore options within four categories identified as important to him: (1) continuing education, (2) meaningful employment, (3) community volunteering, and (4) an active social life.

Whenever Terry agreed to one of our many unusual requests of the school district, she always weighed, "If we do this for Renzo, can we equitably provide the same for other students?" As a result, more students transitioning into adult life are now realizing their dreams and maximizing their capabilities while becoming contributing members of the community.

I drafted a vision statement and job description defining the responsibilities of a single person who could integrate all four categories of Renzo's transition IEP in a holistic approach. Ed, an inspiring and creative person, was assigned to the position we eventually titled, Life Associate, to more aptly describe work that extended well beyond that of an instructional aide or a job coach. He was responsible for integrating educational goals—functional math and reading; therapeutic goals set by physical, occupational, and speech therapists; and life skills training within every aspect of Renzo's plan. Ed became Renzo's advocate and friend, someone with whom Renzo could imagine life dreams and make them happen.

Continuing Education

As time went by, Renzo expressed his wish to go to college like his friends. Traditionally, students with

significant disabilities are based in a special education classroom, usually within the high school building, until age 21 years. It seemed inappropriate that Renzo should be in a high school building while his peers without disabilities were on college campuses or building independent lives in community settings. I convinced our local community college to permit Renzo to audit one carefully chosen class, with his assistant. To make this more financially feasible for the district and flexible for Renzo, we provided a vehicle for transportation.

To begin, Renzo preferred to audit lecture-style classes in history or social sciences; he later moved on to take courses in art and, surprisingly, a dance class (with mostly girls) as a pleasant alternative to exercising in the college gym. In keeping with education goals, Ed chose one or two facts from each class for Renzo to memorize. Renzo joined The Impact Club, a group for students receiving special accommodations for learning disabilities. Like students in many campus clubs, they organized fundraisers; volunteered for events such as the Special Olympics; and spent time together bowling, going out to dinner, and having parties. I learned that Renzo even skipped class on warm spring days to hang out with new friends, or simply rest in the shade of a nearby tree. Typical college student!

Meaningful Employment

The year before his injury, Renzo purchased a guitar and spent long hours setting his poetry to music he composed while teaching himself to play. When the team proposed the idea that Renzo might find a job at nearby Martin Guitar, Ed helped him complete the job application and practice skills for the interview, after which they wrote a thank you note. He was hired and works there still.

The school-based occupational therapist evaluated Renzo's work area and established methods that would enable Renzo to do his 2-hour-a-week job collating paperwork for building custom guitars. After completing his work, Renzo often lingers to strum one of the Martin guitars that hang on the wall over his desk. What a great place to work! His office mates are always happy to see him and welcome him to work by playing Renzo's favorite Sixties music when he walks in the door.

I did say *walk*. Ed used every opportunity to work on Renzo's physical goals, including helping

him walk from the parking lot into the workplace. When Renzo receives his paycheck, he works on speech goals while transacting business with the bank teller. Renzo is encouraged to count his money, thereby integrating functional math skills. Imagine Renzo's pride when his employer, Chris Martin, personally awarded him a \$300 holiday bonus one year, acknowledging his hard work and contribution to the company. Renzo is paid a fair wage and also receives his share of quarterly dividends. He proudly earns almost all of his personal spending money.

Community Volunteering

Realizing that it was important for Renzo to validate his self-worth while learning to accept his disabilities, the transition IEP team agreed it might be helpful if he participated in community volunteer work. Before his injury, Renzo showed an interest in working with children and, on his own, arranged to take a course at a local hospital to become a certified babysitter. He talked about becoming a pediatrician when he grew up. So, we thought Renzo might enjoy volunteering with preschool children with disabilities.

Renzo was accepted as a volunteer at Easter Seals, where his main responsibility was to clean the children's toys. With methods established by his occupational therapist, Renzo soon acquired the skill to spray disinfectant on the toys and then, sometimes with hand-over-hand assist, dry them with a cloth. After completing this task, Renzo assists the children with their learning activities. Renzo's work at Easter Seals was celebrated when he was awarded the 2004 Volunteer Center of the Lehigh Valley bronze plaque for outstanding and dedicated service to the community.

Active Social Life

After graduation, most of Renzo's friends moved away to attend college. We knew that many would not return. With Renzo now dependent on paid staff to attend to his needs, Tony and I feared he would never again have friends who were there for him simply because they cared about him. To complete Renzo's transition plan, we felt it was important to provide opportunities for him to meet new people, forming casual relationships and

Figure 4. Renzo enjoying life.



Source. C. Dougan. Used with permission.

participating in activities typical of his peers, even somewhat challenging experiences.

Like any parents, we had to learn to let go, despite our fear. For instance, we watched him float down the Schuylkill River in a kayak he couldn't paddle; his friend Matt did all the hard work. One of Renzo's education professionals, an avid kayaker, also paddled beside them. The broad grin on Renzo's face as he returned to the dock silenced our fears and filled us with pride. Embracing unlimited possibilities, we've found ways for Renzo to enjoy experiences such as watching hawks migrate from the edge of a cliff, traveling to Hawaii as an invitee to the Pacific Rim Conference on Disabilities; and joining us on several trips to Italy, his father's ancestral home. These opportunities continue to enrich his life and the lives of those who share his joy of accomplishment (Figure 4).

Self-Directed Supports

Knowing school-based services were ending soon, I began to survey existing home- and community-based services offered through the Office of Developmental Programs (ODP) in the Pennsylvania Department of Human Services. I was disheartened to realize that the life we'd so carefully built on principles of person-centered planning might be impossible to continue.

As I interviewed provider agencies, what I heard brought me to tears. Their words neutralized Renzo to being only a "client" or "consumer," and there was much discussion about what "program" he would fit into. Restricted by licensing regulations and encumbered by reporting requirements, no agency in our area seemed capable or willing to

support Renzo, a unique individual, to continue the pattern and quality of life he was currently living. It became apparent that we would need to circumvent the established, fragmented system that was so firmly defined according to disability labels rather than designed to support an individual's wants and needs. I decided to explore the rarely used but flexible option of helping Renzo to self-direct services.⁴

Previously, I attended a conference session by Patti Scott of Neighbours, Inc., about ways her organization supported people with disabilities living in their own homes, hiring and training their own support staff, working, and otherwise enjoying the same freedoms as any other citizen, with minimal government intervention. She described her success in moving people out of institutions, where they had spent most of their lives without family or friends, to living on their own with the assistance of a Circle of Support.⁵ Each person's Circle, composed of people from the greater community, agreed to meet regularly to help the person in transition develop meaningful and supportive relationships and manage his or her own resources. I met several such people and was in awe of the richness of their lives in the community.

I invited Patti to our home to meet Renzo, and before long, she was enthusiastically involved in his life, freely sharing her expertise on ways we might enable Renzo to exert more choice and control. Within a few weeks, we hosted a gathering to discuss what might be expected of members of Renzo's Circle of Support in terms of time and level of

commitment. Although no longer responsible for supporting Renzo's education plan, both the school district's director of special education and the supervisor of special education at the high school level asked to join Renzo's Circle to share in the realization of a pretty amazing transition plan, one they hoped to duplicate for other local students.

Using the facilitated person-centered planning process, Making Action Plans (MAPS; Forest & Lusthaus, 1990), an action-oriented approach, Renzo and his Circle began to define, evolve, and seek ways for him to achieve *his* vision for *his* life. During a question-and-answer session, we learned specifics from Renzo, such as he wanted to share meals with friends, perhaps have breakfast in bed on occasion, sleep later in the morning, stay up late, increase his work hours at Martin Guitar, make art, have friends over for beer, and so on. Renzo's vision of "interdependent" living has come true for the most part, with support from friends in his Circle, his parents, and staff.

Borrowing from the equity in our house, we purchased a small house for Renzo. His Circle worked together on remodeling the fixer-upper, so that Renzo could move into his own home on his 22nd birthday. Contractors paid through state-allocated funds widened doorways, brought the bathroom up to Americans With Disabilities Act (Pub. L. 101-336) standards, and built an entrance ramp. As a young adult now living on his own, Renzo became eligible for and reliant on government programs, such as Supplemental Security

⁴The CMS (n.d.) describes *self-directed services* as

An alternative to traditionally delivered and managed services such as an agency delivery model. Self-direction of services allows participants to have the responsibility for managing all aspects of service delivery in a person-centered planning process.

Self-direction promotes personal choice and control over the delivery of waiver and State plan services, including who provides the services and how services are provided. For example, participants are afforded the decision-making authority to recruit, hire, train, and supervise the individuals who furnish their services. CMS calls this "employer authority." Participants may also have decision-making authority over how the Medicaid funds in a budget are spent. CMS calls this "budget authority."

⁵The *Circle of Support* is defined as a group of

people who care about change happening for the focus person and choose to give their time and resources to working for change. They see themselves as an action-oriented group that exists with and for the person, commit themselves to working alongside the focus person and meeting from time to time for as long as it takes to assure that the person has a secure and interesting community life. The more diverse the group's skills and connections the more they can get done. The better they are able to listen and see things from the focus person's point of view, the more the focus person will be strengthened by their support. (Mount, O'Brien, & Lyle O'Brien, 2002, p. 3)

Income, food stamps, and Low-Income Home Energy Assistance. ODP pays for his support staff. As long as we can, Tony and I will do our best to supplement funding provided by government agencies, not only to enhance his quality of life but also to reduce his dependence on scarce public resources.

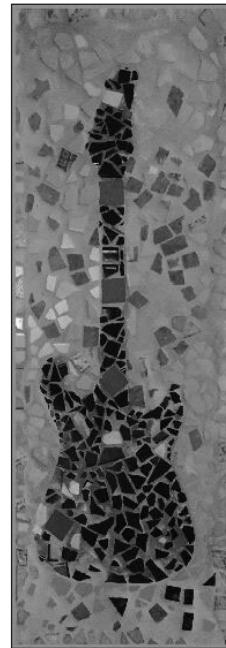
Renzo's housewarming celebration lasted late into the night and included old childhood friends and new ones from the community college. I knew our decision to help Renzo self-direct his life had been right when a few months later, as I was visiting at his house and apparently overstaying my welcome, he sweetly said, "Mom. Go home." He was proud to have transitioned to living on his own.

Emotional Transition

In still photos and the narrative I prefer to convey of Renzo's existence, he is living an "everyday life." He seems dramatically improved. He looks so "normal." In reality, the average person cannot understand his speech, uttered without enunciation through his beautiful smile; he cannot feed himself efficiently (after help to get the food on his fork, he can, however, get it to his mouth); he cannot tilt his head back to drink (he uses a straw); and he needs assistance to shower and toilet (he remains incontinent) and participate in all activities of daily living. He is weight bearing, able to walk like an out-of-sync robot, but he cannot balance to get anywhere on his own. He is getting better at controlling his power scooter, although new gouges mar the door jams of his house. He seems happy, most of the time. He rarely begs us to kill him anymore.

Over a 2-year span, Renzo was obsessed with wanting to die. During more quiet and reflective moments, he often asked us, or one of his staff, to kill him. On one particular Saturday, he begged for hours, struggling to say things like, "Get a knife. Kill me. My mind is broken! I can't think." We were devastated and at a loss as to how we could help our son through his emotional pain; it was so linked with our own. Because his speech ability was severely limited, traditional talk therapy was impossible. Eventually, we found Charlotte, a remarkable art therapist, who helped Renzo visually express his anguish. Some of the most profound work she did with him stemmed from a brief but poignant poem,

Figure 5. Guitar mosaic.



Source. C. Dougan. Used with permission.

entitled *Broken Boy*, he had written with the help of his former seventh-grade English teacher:

Big Boy
He is good thinking
Bad heart in the boy
Goodbye to you

Exploring Renzo's perception that he was broken, Charlotte helped him break tiles, design an image, and create beautiful mosaics. The life lesson: Broken pieces when reassembled can be beautiful (Figure 5).

Having become familiar with Elisabeth Kübler-Ross's (1969) stages of grief in her book *On Death and Dying* while coping with my mother's early death, it seemed a logical place to begin exploring the emotional consequences of Renzo's altered life. After surviving the initial shock about the severity of Renzo's injury, we easily slipped into the first three of Kübler-Ross's five predicted stages of grief: denial, anger, and bargaining. We frequently still revisit anger.

The fourth stage, depression, continues to linger, shading certain events like Mother's or Father's Day or the anniversary of Renzo's injury, or occasions such as when his peers celebrate college graduation, marriage, or the birth of a first child.

Every happy moment is tainted, touched by a deep sadness and longing for what should have been. We know now that the sadness we have grown accustomed to will remain forever, only just slightly buried, skin deep, erupting easily and suddenly, without warning.

I feel guilty about the sadness I feel and hide so well from Renzo. I've learned, from people with disabilities and advocates, that it is important to honor one's abilities, to accept the person. Nevertheless, I can't help but long for the son I knew for 14 years, before his injury, the one who might now be living a more enviable life.

People offer well-meaning words: "Well, at least he is alive," or "He is so much better than he was." Such comments, although true, are neither comforting nor relevant to the harsh reality of our present life. Renzo is alive, but he cannot do the least thing independently. He can't brush his teeth, blow his own nose, or easily readjust to a position of comfort in a bed or chair. He can't play the beloved guitar he holds in his lap every day. He can't speak about what he wants or how he feels without prompting. He couldn't defend himself against abuse or even report an incident. He can't even cry. In fact, the nature of his brain injury has left an almost constant smile on his face, comforting to those around him but belying real emotions that he is unable to communicate adequately.

I needed to find the right words to aptly express this seemingly lifelong sadness that is not always obvious to others, that oddly coexists with the pure joy of watching Renzo not merely thrive, but live a quality life among devoted staff and friends who love him and help him to imagine and fulfill his own dreams for his own future. I delved into research again, soon dismissing words like *posttraumatic stress*, *grief*, *mourning*, and *melancholia* because they simply did not describe the intricacy of what I was feeling. When I came across the term *chronic sorrow*, proposed by Simon Olshansky (1962), a rehabilitation counselor and researcher, I felt instant release. I'd found the words to explain the true nature of my malady.

Expanding on Olshansky's concept of chronic sorrow, Susan Roos, psychotherapist and a mother of two children with severe disabilities, reasoned,

Because the person has not died, there is usually no social recognition of the loss, and regrettably, often little recognition of the person

who is the source of the loss. There are no rituals, no customary social supports, and no acceptable ways to grieve the loss. The loss is a living loss. (Roos & Neimeyer, 2007, p. 93)

She also wrote the following about chronic sorrow:

Since the source of the loss continues to be present, chronic sorrow is about years upon years of living with the inevitability of loss, of continually negotiating reality demands required by the loss, and of contending with ongoing and resurgent grief responses. (Roos, 2002, p. 27)

Roos (2002) concluded, and I agree, "To lose a child is tragic; to lose a child who still lives is beyond comprehension" (p. 29).

All the years of Renzo's young life unexpectedly condensed to bestow the most incredible suffocating weight on my soul. A palimpsest of moments—my perfect and beautiful baby, my toddler, a teenager, the coma, the reality of who he is now, my memories, my feelings and hopes—all these obliterated any vestige of happiness. Videos and photographs were taken in anticipation of a future when we would look back at those moments with untainted joy. Those memories were being recorded to show our grandchildren, who will never be born. Those pictures were taken to sustain us in our old age. What is to be done now with those images of unfulfilled hopes and dreams?

I grudgingly acknowledge that we've entered Kübler-Ross's fifth stage of grief: acceptance. For Tony and me, and perhaps other parents of children living with disability, we've learned that acceptance does not imply closure. It simply means that we've managed to pick up the wreckage of our unexpected circumstance and adjusted to the best of our ability.

Barriers and Financial Implications

It is somewhat difficult to retrace the chaotic and unpredictable path toward securing appropriate funding and services to support Renzo's lifelong needs as an adult with significant disabilities.

We had a measure of security because Tony, a professor, had received tenure the month before Renzo's injury; at least he wasn't likely to lose his job in the near future. We would, however, be reliant on a single income while I devoted all of my time to Renzo's needs and securing resources to support him well into the future.

When we began preparations to transfer Renzo from the hospital to home care, the discharge social worker enrolled Renzo for services in the Pennsylvania ACCESS system, which provides Medicaid funding to cover medical expenses, such as Renzo's co-pay (not otherwise covered under our HMO), and accessible public transportation to medical appointments. The social worker knew of no available funding to cover Renzo's many other nonmedical needs, such as non-nursing respite care that might allow Tony and me a few hours together, relieved from being Renzo's primary caregivers.

I began to gather information about the human services system. I found that because Renzo's cognitive disability occurred before the age of 22, it was considered to be a developmental disability, thereby qualifying him for supports through the Office of Developmental Disabilities. I made an appointment for a county caseworker to come to our house to do an intake interview. With that single interview, the floodgates of government overregulation of a single human life opened wide to endless redundant paperwork that still continues year after year.

Throughout his school years, Renzo received a combination of funding. Medicaid's Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) services⁶ delivered behavioral health rehabilitative services, which employed staff to provide emotional support for Renzo as he struggled with depression and suicidal feelings. Limited funds through the Person/Family Directed Support Medicaid Waiver provided for respite care and some therapies.

As Renzo neared age 21, when he would no longer be eligible for EPSDT services, he was enrolled to receive ODP Consolidated Waiver funding, designed in theory to provide home- and community-based support based on assessed needs without an upper limit of funding. This waiver funding currently provides for round-the-clock staffing and limited

mileage reimbursement for Renzo's transportation needs. Renzo was extremely fortunate to have been approved for the Consolidated Waiver, because at that time more than 20,000 people were on Pennsylvania's waiting list for those needing, but not receiving, any waiver funding.

We were relieved to learn that Tony's employer-subsidized medical insurance would continue to cover Renzo as our dependent because his disability occurred before age 18. Medicaid would cover any medical costs, like co-pays, not covered by our insurance. Unlike the school system, which provided year-long weekly therapies, our health insurance limited occupational, physical, and speech therapy to only 30 visits per year, per condition, and only if documentation proved measurable steady progress.

Medical-based therapists seemed to grow weary of Renzo's slow recovery pace and often discharged him after only a few sessions. Although Renzo's transition to adulthood was well planned, we feared he would not receive the same level of intensive therapy the education system supported, therapies needed to retain his gains and continue his recovery from severe brain injury. Reluctantly, we began exploring the option of admitting him to a residential rehabilitation facility.

Because ODP was originally intended to meet the needs of people *born* with intellectual disabilities, it made no provisions for the very different functional and therapeutic needs of a person recovering from a severe acquired brain injury. Although I received approval from ODP to use waiver funding to pay for Renzo's residential living in a brain injury rehabilitation facility, he was ultimately denied admission because the facility's billing system was set up to receive electronic payment only through the Office of Social Programs (OSP) in the Pennsylvania Department of Human Services. Thoroughly confused, I arranged to bring representatives of both program offices to the table to openly discuss how Renzo's complex needs could be met.

I was dismayed to learn that the OSP CommCare Waiver was limited to people with traumatic brain injury. Because Renzo had an anoxic brain injury, he was deemed ineligible. How was it possible that a semantic difference could exclude Renzo from

⁶EPSDT services provide home health care, respiratory care, personal attendant care, private duty nursing services, prescription drugs, physical therapy, and prosthetic devices, that is, any medically necessary services prescribed by a pediatrician.

funding for rehabilitative therapies that any survivor of brain injury needed, regardless of cause?

We opted to cobble together a rehabilitation strategy with funding for traditional therapies and equipment provided by private health and Medicaid insurances. The ODP Home- and Community-Based Services Waiver funded Renzo's direct support staff, charged with implementing therapy goals and assisting in his daily activities. Tony and I worked extra part-time jobs when possible to pay for additional ineligible therapies, such as hippotherapy, aquatic therapy, and massage—interventions that have made the most difference in Renzo's rehabilitation.

Over the years, my home office has become crowded with filing cabinets filled with paperwork generated by a human services system that is splintered into various government silos that do not share information or resources. Although catchphrases such as *person-centered planning, self-determination, individual support plan*, and *everyday lives* are sprinkled liberally throughout human services documents and directives, the inherent inefficiency in the system undermines real efforts to implement an actual person-centered system of supports for people whose lives are already complicated by their disability.

As Tom Nerney, a strong advocate for self-determination for people with disabilities stated,

New types of service definitions need to be written, meaningless paperwork substantially reduced, and attention to the basic life goals of all individuals to be served are at the heart of self-determination [sic]. To continue the present system is not only fiscally unsound, it consigns those served to lives lost to loneliness, personal impoverishment, and full or partial exclusion from real community life; lives lost to regulations, program requirements, surrendering basic and ordinary freedoms; and lives lost to a sophisticated pretense at quality. (Thomas Nerney Center for Self-Determination, 2001, p. 5)

Final Thoughts

A snapshot of Renzo's life today, nearly 10 years after moving to his own home, shows a life fairly

typical of a 30-year-old: Someone who earns his own money, shops for groceries, exercises in a community gym, attends concerts and other events, votes, spends quiet time strumming guitar while listening to his Sixties favorites, or simply hanging out on his front porch where the 3-year-old boy next door might spot him and walk over with his German Shepherd and a batch of cookies to share. He dreams of finding the right woman to share his life with and has popped the question more than once, bearing rejection well.

For now, Renzo is content to be surrounded by a dedicated team of direct-support professionals who help him enact and fulfill his vision for life. These professionals often become his friends, remaining long after they've moved on to other careers, married, and had children of their own. Renzo is an "uncle" many times over.

May 21, 2015, marked 17 years since our universe shifted, since gravity reversed and our world shattered. Ever since that day, I've been consumed with finding and fitting together the fragments of our lives, hopes, and dreams. Unlike the beautiful mosaics Renzo composed in his attempt to feel whole again, my mosaic remains unresolved. Too many ill-fitting pieces, shards of broken bureaucratic systems, remain to be incorporated into the picture—or discarded.

References

- American Heart Association. (2015). *Types of arrhythmia in children*. Retrieved from http://www.heart.org/HEARTORG/Conditions/Arrhythmia/AboutArrhythmia/Types-of-Arrhythmia-in-Children_UCM_302023_Article.jsp
- Americans With Disabilities Act of 1990, Pub. L. 101–336, 42 U.S.C. §§ 12101–12213.
- Centers for Medicare and Medicaid Services. (n.d.). *Self-directed services*. Retrieved from <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Delivery-Systems/Self-Directed-Services.html>
- Forest, M., & Lusthaus, E. (1990). Everyone belongs with MAPS action planning system. *Teaching Exceptional Children*, 22, 32–35.
- Kübler-Ross, E. (1969). *On death and dying*. New York: Macmillan.
- Lin, C. N., Howng, S. L., Hu, S. H., & Huang, T. J. (1992). Assessments of nutritional status and immunological responses in head trauma: Alterations in zinc and C-reactive protein. *Gaoxiong Yi Xue Ke Xue Za Zhi*, 8, 195–201.

- Mount, B., O'Brien, J., & Lyle O'Brien, D. (2002). *Increasing the chances for deeper change through person-centered planning*. Syracuse, NY: Center on Human Policy.
- Olshansky, S. (1902). Chronic sorrow: A response to having a mentally defective child. *Social Casework*, 43, 190–193.
- Pearpoint, J., O'Brien, J., & Forest, M. (1993). *PATH: A workbook for planning possible positive futures*. Toronto: Inclusion Press.
- Roos, S. (2002). *Chronic sorrow: A living loss*. New York: Routledge.
- Roos, S., & Neimeyer, R. A. (2007). Reauthoring the self: Chronic sorrow and posttraumatic stress following the onset of CID. In E. Martz & H. Livneh (Eds.), *Coping with chronic illness and disability: Theoretical, empirical, and clinical aspects* (pp. 89–106). New York: Springer.
- Thomas Nerney Center for Self-Determination. (2001). *Filthy lucre: Creating better value in long-term supports*. Retrieved from <http://www.centerforself-determination.com/docs/sd/lucrPrint1.pdf>
- Turnbull, A., & Turnbull, R. (1992, Fall). Group action planning (GAP). *Families and Disability Newsletter*, pp. 1–13.

Part I.

UNDERSTANDING TRANSITION

CHAPTER 1.

FOUNDATIONS OF TRANSITION

Meira L. Orentlicher, PhD, OTR/L, FAOTA, and Robert W. Gibson, PhD, OTR/L

Chapter Objectives

At the completion of this chapter, readers will be able to

- ❖ Define *transition* and differentiate among developmental, natural, and systems transitions;
- ❖ Describe how transition is understood by various disciplines and how those disciplines' views of transitions contribute to occupational therapy knowledge;
- ❖ Explain occupational therapy philosophical approaches and their relationship to transitions, including inclusion, social model of disability, self-determination, family-centered care, person-centered planning, and universal design; and
- ❖ Provide guiding questions for preparing for and thinking through clients' anticipated transitions.

Key Terms and Concepts

- | | |
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| <ul style="list-style-type: none">❖ Actual transition❖ Anthropologists❖ Assistive Technology Act of 2004❖ Brief therapeutic interactions❖ Consolidation❖ Cultural embeddedness❖ Developmental/biological transitions❖ Educators❖ Family-centered care❖ Inclusion❖ Long-term therapeutic interactions❖ Medical emergency | <ul style="list-style-type: none">❖ Natural transitions❖ Person-centered planning❖ Preparation❖ Psychologists❖ Self-determination❖ Short-term therapeutic interactions❖ Social model of disability❖ Sociologists❖ Transition❖ Transition rites❖ Universal design❖ Vocational Rehabilitation Act of 1973 |
|--|--|

This book begins with a deeply personal story about a young man and his family who faced a series of life transitions related to a ***medical emergency***. The efforts of many people helped restore a life and a family and forge new expectations they shared as members of a community. Like Renzo's story in the "Prologue," such tragedies illustrate what happens when life does not go as expected or planned. The "taken for grantedness" of the flow of human life is exposed, and life transitions become very evident.

When disease, injury, or other life trauma interrupt the naturally occurring process of life transitions, it often becomes necessary to develop new or additional skills and extra planning to move successfully through the culturally defined stages of life. Renzo's story can be compared with the lives of people who have not faced trauma, disability, or physical or mental impairment, because everyone experiences transitions and may need support from others when adjusting to new circumstances. This chapter defines *transition*; examines philosophical tenets that affect transitions, including inclusion, social model of disability, self-determination, family-centered care, person-centered planning, and universal design; and introduces a role for occupational therapy in supporting people during transition.

What Is Transition?

Transition is a passage, evolution, development, or abrupt change that leads to movement from one life state, stage, or place to another. Throughout one's lifespan, some transitions are predictable, such as progressing from kindergarten to first grade, from high school to college, or from being single to being married. Other transitions are unpredictable and usually the result of a trauma or an unexpected change, such as transitioning to and from a hospital because of injury, from employment to unemployment when one is laid off, or becoming a widow or widower following the death of a spouse. All life transitions require preparation, new knowledge, and time to accommodate to the new situation.

Studying Transitions

Anthropologists, sociologists, psychologists, educators, and health care providers all study life

transitions. However, each discipline approaches transition from a unique perspective and for different purposes.

Anthropologists examine life transitions as a way of understanding cultural beliefs and practices with a focus on rites of passage or developmental processes within a cultural framework (American Anthropology Association, 2015). ***Sociologists*** often look for broad societal trends that reflect changes in populations' and subgroups' behavior (Lawson & Garrod, 2010). ***Psychologists*** seek to understand a person's behavior, mental processes, and reactions and responses to transition experiences and other life changes (Gerrig & Zimbardo, 2009). ***Educators*** observe the process of transition to, throughout, and from school, with a renewed focus on the success of transition programs to support young people in the move from high school to employment and independence (Wehman, 2013).

Health care providers primarily focus on the transition of youth from pediatric care to adult-oriented care but also look at transition in late adulthood and health systems transitions, such as transitioning from one's third-party private health insurance provided by one's employer to government-sponsored Medicare at age 65 years (Viola, Arno, Byrnes, & Doran, 2014).

Research on life transitions from these disciplines informs us about culturally significant life periods and the needs, beliefs, and expectations surrounding those transitions. It also informs us about how a person's participation in meaningful occupations throughout the lifespan may affect or be affected by transitions.

Developmental/Biological Transitions

Developmental/biological transitions are the physiological changes that occur as a human being grows, matures, and ultimately deteriorates and dies. These transitions are biological and provide the substrate to which societies assign significance or meaning within a cultural context. These stages of biological and developmental transitions include the many firsts of growing up, such as getting a first tooth, taking a first step, or saying a first word; include the start of puberty; and mark the declines of adulthood and old age.

Natural Transitions

Situated upon biological development are **natural transitions**, which can be understood as the social or cultural meanings ascribed to biological development. They encompass the social and cultural rules that direct human behaviors and inform behavioral expectations. An example of a natural transition is the celebration or acknowledgment of puberty. Many cultures mark important transitions with **transition rites**, which are activities expressed in cultural forms that guide, instruct, and help transform dependent members of societies into full, participatory adult members. These might include attending prom, graduating high school, attending college, or getting a first job.

Upon reaching adulthood, people have additional transitions and social opportunities available, such as living independently, getting married, starting a new family, and becoming empty nesters. They can also transition in other aspects of life, such as in employment or retirement. Most of these transitions typically occur in a particular sequence during a person's lifespan, are accepted as natural, and are reinforced by cultural practices.

Natural transitions are life transitions that are generally anticipated and prepared for and shared within a cultural context. For example, although the process of getting married has countless variations, the commonalities can provide insight into the three stages of natural transition and the **cultural embeddedness** of such transitions. The following are the three stages of natural transition:

1. **Preparation:** Time to prepare for the transition and practice the anticipated new social roles,
2. **Actual transition:** Actual time of transformation that is acknowledged or celebrated, and
3. **Consolidation:** Period of adjustment or establishment.

Societies share rules and expectations about what behaviors will change before transitions and what preparations are necessary. For example, it is possible to acquire a marriage license and be married with little or no fanfare, but a tremendous amount of preparation goes into even a simple wedding. It is typically planned and organized well ahead of the actual event.

A formal gathering usually acknowledges the transition and serves as a cultural marker that a transition has occurred. It often involves particular rituals. For

example, the process of getting married is achieved through a social action, the wedding ceremony. This ceremony usually involves rituals such as exchanging vows, dancing, and wearing special clothes.

The consolidation period usually signifies new social roles for the transitioning person or people. For example, after the marriage ceremony, the new couple is expected to behave differently than before the ceremony, engage in new activities, and bear new social responsibilities.

Similar observances of transitions are conducted in other developmental life events such as bar mitzvah or confirmation ceremonies to mark adolescence or parties to celebrate graduations or retirement. Each social setting, community, or religious group has guidelines or social rules for these observances. Adherence to these social rules varies according to how traditional or progressive the social group, family, or couple is. Natural transitions, possibly because of their relationship to biology, development, and cultural norms, tend to be one directional, that is, once the transition has occurred, there is usually no returning to the pre-transition state.

Challenging and Atypical Transitions

Most natural transitions are well established and anticipated within cultures and societies. This anticipation allows for planning and, in most instances, some measure of transition success for most of the population. However, trauma, illness, disability, and other factors can interrupt this natural process and make transitions more difficult or create unique transition processes that require more planning and support.

In the United States, legal, health, education, and social programs have been developed to assist in many of these challenging transitions. For example, a toddler diagnosed with a disability may receive early intervention services. In addition, the law mandates professionals working in early intervention to prepare and assist the family as the child ages out of early intervention services and transitions to preschool.

Laws That Shape Practice

Occupational therapy practitioners often support people during challenging transitions, but only two transition supports are mandated by law: (1) early

childhood transitions (Chapter 3, “Early Childhood Transitions”) and (2) the transition from school to adult life, including health care transitions (Chapter 5, “Transition From School to Adult Life,” and Chapter 8, “Health Care Transitions”). However, even when support for a specific transition is not mandated by law, other legal mandates may be used to help people at particular times.

For example, the *Vocational Rehabilitation Act of 1973* (Pub. L. 113–185) provides for vocational counseling for an injured worker seeking new employment. The *Assistive Technology Act of 2004* (Pub. L. 108–364) provides for assistive technology to an elderly person with stroke transitioning home after a long stay at a rehabilitation facility. Each chapter in this book includes a description of laws and funding programs relevant for the transition being discussed.

Philosophy of Practice

Occupational therapy practice is governed and guided by philosophical underpinnings that should also guide practitioners supporting people during transitions. Philosophical approaches, such as inclusion, the social model of disability (Oliver, 1990, 1996), self-determination, family-centered care, person-centered planning, and universal design directed the development of this text.

Inclusion

Inclusion means that people with disabilities have the right to full and fair access to activities, social roles, and relationships alongside typical community members, with the appropriate supports necessary for successful experiences (American Occupational Therapy Association [AOTA], 2014b; Bates & Davis, 2004). Beyond inclusion as a philosophical belief, research shows that people who learn, live, work, and receive services in inclusive settings have better outcomes in social interactions and participation in meaningful occupations and naturally occurring activities in their communities (Landmark, Ju, & Zhang, 2010; Ryndak et al., 2010; Spence-Cochran, Pearl, & Walker, 2013).

When people transition to new activities, programs, and places, planning and preparation for the

transition should include consideration of accommodations, systems of support, and activities to allow those people access to social, educational, recreational, and vocational opportunities in the new setting. As seen in Renzo’s story, Renzo participates in meaningful activities and is included in typical community settings, including a guitar company for employment, community college for education, and Easter Seals for volunteer activities.

Social Model of Disability

The *social model of disability* proposes that people with disabilities have difficulty participating in activities and community settings because of society’s failure to provide appropriate accommodations and services (Oliver, 1990, 1996). Thus, to support people with disabilities who are transitioning to new environments, programs, and tasks, the focus of intervention should also be on changing and accommodating the environment, tools, and tasks rather than trying to “fix” the person. In addition, the assessment of transition readiness should not only focus on the person transitioning but should also include the accommodations necessary to make the new setting “ready” for the person.

Self-Determination

Self-determination is defined as “volitional actions that enable one to act as the primary causal agent in one’s life and to maintain or improve one’s quality of life” (Wehmeyer, 2005, p. 117). The historical roots of self-determination can be found in the normalization, independent living, disability rights, and self-advocacy movements and in legislative protections ensuring equal opportunities for people with disabilities (Ward, 1996; Wehmeyer & Shogren, 2013). Within that context, self-determination is viewed as part of empowerment, with the argument that people with disabilities should be enabled or empowered to exert self-determination.

Self-determination is a recommended practice, specifically during the transition of students with disabilities from school to adult life because it has been identified as an evidence-based predictor of positive postschool outcomes in employment, independent living, and community participation (McDougall, Evans, & Baldwin, 2010; Test,

Fowler, et al., 2009; Wehmeyer & Shogren, 2013). Although people with severe physical or cognitive disabilities may not be able to perform activities independently or make complex decisions, supports must be provided to enable them to retain control over the decision-making process and choose the activities in which they want to engage. For example, in the Prologue, Renzo's mother, Cheryl, evaluates Renzo's well-being and looks for signs of general happiness and contentedness to ascertain his satisfaction with activities or direct service providers. Occupational therapy practitioners should enhance clients' self-determination and active involvement in transition planning by promoting goal setting, choice making, problem solving, decision making, and self-advocacy (Wehmeyer & Shogren, 2013).

Family-Centered Care

Family-centered care is an approach for service delivery in which service providers work with the family to make informed decisions about the amount and type of services and supports the child and family should receive. The strengths and needs of all family members are considered (Jeglinsky, Autti-Rämö, & Brogren Carlberg, 2012). Family involvement is a key component during transitions (Targett & Wehman, 2013).

For example, family involvement in the transition from school to adult life has been found to be a predictor of postsecondary success of young adults with disabilities (Kraemer, McIntyre, & Blacher, 2003; Test, Mazotti, et al., 2009). Specifically, young adults with disabilities work more hours, earn higher wages, live more independently, and have an overall higher quality of life when their parents are involved in their transition process (Davies & Beamish, 2009; Kraemer et al., 2003; Landmark et al., 2010; Powers et al., 2007).

Occupational therapy practitioners need to understand the challenges families may face during typical and challenging transitions, especially those surrounding accommodating the needs of the family member with disabilities. For example, families with a member who has a disability are more likely to have lower income, live in poverty, and be dependent on social security benefits and public assistance (Brault, 2012). The family member with disabilities may have difficulties fulfilling family roles and may face barriers to community living

such as inaccessible housing (National Council on Disability, 2010).

Caregiving for the family member with disabilities is a demanding role, often associated with stress and economic burdens (Anderson, Dumont, Jacobs, & Azzaria, 2007), many of which Cheryl experienced as she adjusted to her new role as Renzo's primary caregiver. In addition, many education, health, and disability services are typically not designed to address cultural differences and language barriers (Baker, Miller, Dang, Yaangh, & Hansen, 2010; Reichman, Corman, & Noonan, 2008). Family-centered care includes treating families with respect and dignity, responding to their unique needs, sharing information, and providing choice (Dunst, 2000).

Person-Centered Planning

Used by Cheryl to plan Renzo's transition to adult life, **person-centered planning** is an umbrella term that is used to describe a group of procedures and planning strategies that propose an informal but structured way of setting goals and implementing transition plans for people with disabilities (Clark, 1998). Although the various person-centered planning tools are slightly different from each other, in general, they all require professionals and unpaid people (e.g., family members, friends, community members) to follow specific steps to learn about the person with disabilities and his or her interests, preferences, and desired lifestyle; describe what needs to be done to help him or her move toward the desired lifestyle; and outline an action plan to achieve the desired goals (O'Brien, O'Brien, & Mount, 1997; Smull & Harrison, 1992).

Planning is used to learn about people with disabilities in more effective and efficient ways to design and create supports that can assist them in participating in and experiencing self-directed lives (O'Brien & O'Brien, 2002). The ultimate goals of person-centered planning are to reduce the person's social isolation, establish friendships, increase engagement in preferred activities, develop the person's competence, and promote respect for the person. A related goal is to place people with disabilities in leadership positions during the assessment, planning, and service delivery process (Austin & Wittig, 2013; Holburn & Vietze, 2002).

Person-centered planning emphasizes the person with disabilities making choices, taking initiatives, accepting responsibilities, and learning from his or her failures and achievements. It has been shown to improve social networks and family connections and to promote greater engagement in desired activities (Holburn, Jacobson, Schwartz, Flory, & Vietze, 2004; Orentlicher, 2008; Robertson et al., 2006; Wigham et al., 2008). Orentlicher (2011) identified potential roles for occupational therapy practitioners in person-centered planning, including assisting the person in breaking down long-term goals to manageable and achievable short-term objectives and suggesting accommodations and modifications to assist the person to participate in desired occupations.

Universal Design

Universal design is “the design of products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design” (National Institute on Disability and Rehabilitation Research, 2008, para. 16). With roots in architecture, universal design was introduced to create public spaces, buildings, and everyday items that are accessible for people with and without disabilities. Examples of universal design include curb cuts, ramps, levered door handles, software operating systems with options such as speech output, television and film captioning, ergonomic keyboards, voice-activated telephones, and buses with wheelchair lifts.

Occupational therapy practitioners are ideal team members in the universal design process because of their expertise in task analysis and environmental adaptation. They are able to evaluate tasks and environments and suggest adaptations to accommodate various needs of people with disabilities.

Transition and Occupational Therapy

Occupational therapy practitioners engage with clients during many transition experiences, some natural and others created by the circumstances of disability or injury or medical systems. These transitions can range in length of time:

- **Brief therapeutic interactions** (e.g., redirecting a child with autism’s attention from one task to another)

- **Short-term therapeutic interactions** (e.g., preparing a client to move from hospital-based care to home care)
- **Long-term therapeutic interactions** (e.g., preparing a young person with disabilities to move from adolescence and dependency to independent living and employment).

Although practitioners are often principally focused on the current needs of their clients, it is important for them to anticipate and prepare for clients’ transitional or future needs. Practitioners are uniquely qualified to support people with disabilities as they prepare for and engage in transitions across the lifespan. Practitioners understand human occupation and function as they relate to individual skills and interests, task demands, and environmental contexts and cues (Michaels & Orentlicher, 2004). They can perform analysis of anticipated roles and requirements, evaluate skills and needs in relation to specific tasks within these roles, and suggest environmental or task adaptations to increase function and participation (Orentlicher, 2013; Spencer, Emery, & Schneck, 2003).

Participation

Occupation-based theories describe the processes of selecting, accommodating, adapting, and participating in meaningful occupations. Transitions affect and are affected by occupational participation. Specifically, occupations in which a person participated before a transition may no longer be relevant in a new setting. For example, an elderly woman moving to a nursing home may no longer need to cook or clean, but if these were important tasks for her, it would be supportive for her health to find suitable substitutes for these activities.

Transitions may require the person to adapt to or acquire new occupations. For example, a child transitioning to preschool may need to learn how to take off his or her own coat, place personal possessions in a cubby, or open his or her own beverage container. A new occupational therapy graduate transitioning to a new employment setting will need to learn how best to document services and track one’s time for billing purposes.

Engagement in meaningful occupations can serve as a tool to support a person through challenging transitions. For example, the older adult woman who found gardening meaningful in her own home

may adapt easier to the nursing home if she can garden or tend to plants in the new setting. Transition can also involve the family in learning new ways to support the participation of a developing child or an aging family member by regulating the amount and type of support provided.

Occupational Therapy Practice Framework

The *Occupational Therapy Practice Framework: Domain and Process* (3rd ed.; the *Framework*; AOTA, 2014a) describes occupational therapy's scope of practice. On the basis of various occupation-based theories (e.g., Dunn, Brown, & McGuigan, 1994; Law et al., 1996; Nelson, 1997), the *Framework* guides occupational therapy practitioners to consider the person's factors, performance patterns, roles, and contexts when delivering services. Each chapter in this text describes the domains, contexts, and occupation-based theories relevant for a specific transition. More information on the role of occupational therapy in transitions is discussed in Chapter 2, "Occupational Therapy and Transition."

Guiding Questions

During transition co-planning, it is important for occupational therapy practitioners to recognize what questions they should ask themselves and their clients and families about function, occupational engagement, lifelong participation, and success. Practitioners must be aware of the transitions the client will face immediately and in the distant future. For example, if a client with a new physical impairment is expected to drive in the future, he or she will need the more immediate developmental experiences of powering, steering, and controlling various means of transportation to ultimately transition to the role of independent driver.

Understanding the client's long-term goals, unique qualities, and challenges helps practitioners identify the big picture and ensure that treatment decisions anticipate the transitions that will occur throughout the client's life. Therefore, after identifying the big picture, the practitioner considers all the major and minor transitions and challenges the client may encounter while

working toward his or her goals. Once each transition and associated challenges are outlined, the practitioner must consider what his or her role will be in helping the client overcome challenges and successfully navigate the transition. Questions to guide practitioners through anticipating and planning for transitions are included in Exhibit 1.1.

Exhibit 1.1. Questions to Consider When Anticipating and Planning for Transitions

Understanding Transitions in Relation to the Client

- What are the long-term goals or life expectations of this client?
- What are the client's unique cultural, social, and family practices or concerns and expectations that could challenge or drive future life transitions?
- What are the possible disease-related or physical complications that may affect transition, such as low cognitive functioning or life expectancy? How can these complications be ameliorated?

Anticipating the Next Transition

- Do these transitions involve changes in location of living or receiving services, such as moving to a new school or receiving services from a new provider because of aging out of the pediatric health services?
- Are there different structural, social, or behavioral expectations that will be involved after the transition (e.g., different schools may require different levels of independence in addressing personal activities of daily living)?
- Is there a need for change in the way family members support participation and independence? How might family support be modulated to foster participation and independence?
- What is the length of time between the awareness or acknowledgment of the anticipated transition and when the transition will occur? How can time in treatment be used to prepare for the transition?

Preparing for the Transition

- What are specific transition preparation activities that need to be incorporated into treatment to prepare for foreseeable transitions?

(Continued)

Exhibit 1.1. Questions to Consider When Anticipating and Planning for Transitions (Cont.)

- What roles or social skills should the client practice in the clinical setting to anticipate the behavioral expectations of the next transition?
 - What occupational tasks or skills are necessary for the next transition (e.g., when the client is transitioning from a preschool environment with low mobility demand to an elementary school where the ability to propel oneself with a scooter or wheelchair will greatly enhance independence)?
 - What occupations can the client already do? What occupations can the client learn to perform on his or her own?
 - What adaptations or accommodations can be made to the environment, tasks, or tools to enable the client to perform the anticipated occupations?
 - What assistance may be needed from others in the client's environment to help the client engage in the anticipated occupations?
 - What supports or training may be required to assist others to help the client prepare for the transition or to support the client's engagement in the anticipated occupations?
-

Summary

People experience many transitions throughout their lifespan, many of them naturally occurring and planned for. Other transitions are unexpected and may be a result of trauma. People with disabilities and their families experience additional transitions associated with the disability experience. Occupational therapy can uniquely support people in transition. Occupational therapy practice in transition is guided by philosophical approaches such as inclusion, self-determination, and universal design. As you read the following chapters, consider the new approaches and practice challenges and how your own practice can evolve to support people in transition.

References

- American Anthropology Association. (2015). *What is anthropology?* Retrieved from <http://www.aaanet.org/about/whatisanthropology.cfm>
- American Occupational Therapy Association. (2014a). Occupational therapy practice framework: Domain and process (3rd ed.). *American Journal of Occupational Therapy*, 68(Suppl. 1), S1–S48. <http://dx.doi.org/10.5014/ajot.2014.682006>
- American Occupational Therapy Association. (2014b). Occupational therapy's commitment to nondiscrimination and inclusion. *American Journal of Occupational Therapy*, 68(Suppl. 3), 341–342. <http://dx.doi.org/10.5014/ajot.2014.686S05>
- Anderson, D., Dumont, S., Jacobs, P., & Azzaria, L. (2007). The personal costs of caring for a child with a disability: A review of the literature. *Public Health Reports*, 122, 3–16.
- Assistive Technology Act of 2004, Pub. L. 108–364, 118 Stat. 1707.
- Austin, K., & Wittig, K. M. (2013). Individualized transition planning: Building the roadmap to adulthood. In P. Wehman (Ed.), *Life beyond the classroom: Transition strategies for young people with disabilities* (5th ed., pp. 95–119). Baltimore: Paul H. Brookes.
- Baker, D. L., Miller, E., Dang, M. T., Yaangh, C., & Hansen, R. L. (2010). Developing culturally responsive approaches with Southeast Asian American families experiencing developmental disabilities. *Pediatrics*, 26, S146–S150.
- Bates, P. E., & Davis, F. A. (2004). Social capital, social inclusion and services for people with learning disabilities. *Disability and Society*, 19(3), 195–207.
- Brault, M. W. (2012). *Americans with disabilities: 2010*. Retrieved from <http://www.census.gov/prod/2012pubs/p70-131.pdf>
- Clark, M. C. (1998). *Assessment for transition planning*. Austin: Pro-Ed.
- Davies, M. D., & Beamish, W. (2009). Transitions from school for young adults with intellectual disability: Parental perspectives on "life as an adjustment." *Journal of Intellectual and Developmental Disabilities*, 34, 248–257. <http://dx.doi.org/10.1080/1366825090310367>
- Dunn, W., Brown, C., & McGuigan, A. (1994). The Ecology of Human Performance: A framework for considering the effect of context. *American Journal of Occupational Therapy*, 48, 595–607. <http://dx.doi.org/10.5014/ajot.48.7.595>
- Dunst, C. (2000). Revisiting "rethinking early intervention." *Topics in Early Childhood Special Education*, 20(2), 95–104.
- Gerrig, R. J., & Zimbardo, P. G. (2009). *Psychology and life* (19th ed.). Old Tappan, NJ: Pearson.
- Holburn, S., Jacobson, J. W., Schwartz, A. A., Flory, M. J., & Vietze, P. M. (2004). The Willowbrook Futures Project: A longitudinal analysis of person-centered planning. *American Journal on Mental Retardation*, 109(1), 63–76.
- Holburn, S., & Vietze, P. M. (Eds.). (2002). *Person-centered planning: Research, practice, and future directions*. Baltimore: Paul H. Brookes.

- Jeglinsky, I., Autti-Rämö, I., & Brogren Carlberg, E. (2012). Two sides of the mirror: Parents' and service providers' view on the family-centredness of care for children with cerebral palsy. *Child: Care, Health, and Development*, 38(1), 79–86.
- Kraemer, B. R., McIntyre, L. L., & Blacher, J. (2003). Quality of life for young adults with mental retardation during transition. *Mental Retardation*, 41(4), 250–262.
- Landmark, L. J., Ju, S., & Zhang, D. (2010). Substantiated best practices in transition: Fifteen plus years later. *Career Development for Exceptional Individuals*, 33, 165–176. <http://dx.doi.org/10.1177/0885728810376410>
- Law, M., Cooper, B., Strong, S., Stewart, D., Rigby, P., & Letts, L. (1996). The Person–Environment–Occupation Model: A transactive approach to occupational performance. *Canadian Journal of Occupational Therapy*, 63, 9–23.
- Lawson, T., & Garrod, J. (2010). *A-Z sociology handbook: Digital edition* (4th ed.). London: Hodder Education.
- McDougall, J., Evans, J., & Baldwin, P. (2010). The importance of self-determination to perceived quality of life for youth and young adults with chronic conditions and disabilities. *Remedial and Special Education*, 31, 252–260. <http://dx.doi.org/10.1177/0741932509355989>
- Michaels, C. A., & Orentlicher, M. L. (2004). Capacity building evaluation and transition services: Implications for school-based occupational therapy practice in the United States. *Occupational Therapy International*, 11(4), 209–228.
- National Council on Disability. (2010). *The state of housing in America in the 21st century: A disability perspective*. Retrieved from <http://www.ncd.gov/publications/2010/Jan192010>
- National Institute on Disability and Rehabilitation Research. (2008). *Frequently asked questions (FAQs) about NIDRR*. Retrieved from <http://www.ed.gov/about/offices/list/osers/nidrr/faq.html>
- Nelson, D. L. (1997). Why the profession of occupational therapy will flourish in the 21st century [Eleanor Clark Slagle Lecture]. *American Journal of Occupational Therapy*, 51, 11–24. <http://dx.doi.org/10.5014/ajot.51.1.11>
- O'Brien, C. L., & O'Brien, J. (2002). The origins of person-centered planning: A community of practice perspective. In S. Holburn & P. M. Vietze (Eds.), *Person-centered planning: Research, practice, and future directions* (pp. 3–27). Baltimore: Paul H. Brookes.
- O'Brien, J., O'Brien, C. L., & Mount, B. (1997). Person-centered planning has arrived...or has it? *Mental Retardation*, 35, 480–488.
- Oliver, M. (1990). *The politics of disablement: A sociological approach*. New York: St. Martin's Press.
- Oliver, M. (1996). *Understanding disability: From theory to practice*. New York: St. Martin's Press.
- Orentlicher, M. L. (2008). *Striving for typical: Collective experiences of person-centered planning for young adults with disabilities during transition*. Unpublished doctoral dissertation, New York University.
- Orentlicher, M. L. (2011, January 24). Person-centered planning: An innovative approach for transition planning. *OT Practice*, 16, CE1–CE8.
- Orentlicher, M. L. (2013). Best practices in postsecondary transition planning with students. In G. Frolek Clark & B. E. Chandler (Eds.), *Best practices for occupational therapy in schools* (pp. 245–259). Bethesda, MD: AOTA Press.
- Powers, L. E., Garner, T., Valnes, B., Squire, P., Turner, A., Couture, T., & Dertinger, R. (2007). Building a successful adult life: Findings from youth-directed research. *Exceptionality*, 15(1), 45–56. http://dx.doi.org/10.1207/s15327035ex1501_5
- Reichman, N. E., Corman, H., & Noonan, K. (2008). Impact of child disability on the family. *Maternal and Child Health Journal*, 12, 679–683.
- Robertson, J., Emerson, E., Hatton, C., Elliott, J., McIntosh, B., Swift, P., . . . Joyce, T. (2006). Longitudinal analysis of the impact and cost of person-centered planning for people with intellectual disabilities in England. *American Journal on Mental Retardation*, 11, 400–416.
- Ryndak, D., Ward, L., Alper, T., Montgomery, S., Wilson, J., & Storch, J. F. (2010). Long-term outcomes of services for two persons with significant disabilities with differing educational experiences: A qualitative consideration of the impact of educational experiences. *Education and Training in Autism and Developmental Disabilities*, 45, 323–338.
- Smull, M., & Harrison, S. B. (1992). *Supporting people with severe reputations in the community*. Alexandria, VA: National Association of State Mental Retardation Program Directors.
- Spence-Cochran, K., Pearl, C. E., & Walker, Z. (2013). Full inclusion into schools: Strategies for collaborative instruction. In P. Wehman (Ed.), *Life beyond the classroom: Transition strategies for young people with disabilities* (5th ed., pp. 175–195). Baltimore: Paul H. Brookes.
- Spencer, J. E., Emery, L. J., & Schneck, C. M. (2003). Occupational therapy in transitioning adolescents to postsecondary activities. *American Journal of Occupational Therapy*, 57, 435–441. <http://dx.doi.org/10.5014/ajot.57.4.435>
- Targett, P., & Wehman, P. (2013). Families and young people with disabilities: Listening to their voices. In P. Wehman (Ed.), *Life beyond the classroom: Transition strategies for young people with disabilities* (5th ed., pp. 69–94). Baltimore: Paul H. Brookes.
- Test, D. W., Fowler, C. H., Richter, S. M., White, J., Mazzotti, V., Walker, A. R., . . . Kortering, L. (2009). Evidence-based

- practices in secondary transition. *Career Development for Exceptional Individuals*, 32, 115–128.
- Test, D. W., Mazzotti, V. L., Mustian, A. L., Fowler, C. H., Kortering, L., & Kohler, P. (2009). Evidence-based secondary transition predictors for improving postschool outcomes for students with disabilities. *Career Development for Exceptional Children*, 32, 160–181.
- Viola, D., Arno, P. S., Byrnes, J. G., & Doran, E. A. (2014). The postpediatrician transition: A life span care perspective. *Journal of Disability Policy Studies*, 24(4), 238–246. <http://dx.doi.org/10.1177/1044207313503684>
- Vocational Rehabilitation Act of 1973, Pub. L. 93–112, 29 U.S.C. §§ 701–796l.
- Ward, M. J. (1996). Coming of age in the age of self-determination: A historical and personal perspective. In D. J. Sands & M. L. Wehmeyer (Eds.), *Self-determination across the life span: Independence and choice for people with disabilities* (pp. 3–16). Baltimore: Paul H. Brookes.
- Wehman, P. (2013). Transition: New horizons and challenges. In P. Wehman (Ed.), *Life beyond the classroom: Transition strategies for young people with disabilities* (5th ed., pp. 3–39). Baltimore: Paul H. Brookes.
- Wehmeyer, M. L. (2005). Self-determination and individuals with severe disabilities: Reexamining meanings and misinterpretations. *Research and Practice for Persons With Severe Disabilities*, 30, 113–120.
- Wehmeyer, M. L., & Shogren, K. A. (2013). Self-determination: Getting students involved in leadership. In P. Wehman (Ed.), *Life beyond the classroom: Transition strategies for young people with disabilities* (5th ed., pp. 41–68). Baltimore: Paul H. Brookes.
- Wigham, S., Robertson, J., Emerson, E., Hatton, C., Elliott, J., McIntosh, B., . . . Joyce, T. (2008). Reported goal setting and benefits of person centred planning for people with intellectual disabilities. *Journal of Intellectual Disabilities*, 12(2), 143–152. <http://dx.doi.org/10.1177/1744629508090994>

CHAPTER 2.

OCCUPATIONAL THERAPY AND TRANSITION

Sandra Schefkind, MS, OTR/L

Chapter Objectives

At the completion of this chapter, readers will be able to

- ❖ Identify tenets within occupational therapy that relate to the concept of transition,
- ❖ Advocate for the valuable contributions of occupational therapy in transition planning and services across systems and populations,
- ❖ Identify AOTA's transition resources and activities, and
- ❖ Provide recommendations that increase occupational therapy practitioner engagement in transition services.

Key Terms and Concepts

- | | |
|--|--|
| <ul style="list-style-type: none">❖ 2020 Federal Youth Transition Plan❖ Activity and occupational demands❖ Areas of occupation❖ Client factors❖ Communities of practice❖ Context❖ Domain❖ Education pipeline❖ Environment❖ Healthy People 2020❖ IDEA Partnership | <ul style="list-style-type: none">❖ National Longitudinal Transition Study–2❖ Occupation❖ Occupational transitions❖ Outcomes❖ Performance patterns❖ Performance skills❖ Processes❖ Ready by 21 model❖ Results-driven accountability❖ Self-determination❖ State performance plan indicators |
|--|--|

Change and adaptation are fundamental concepts to the practice of occupational therapy. People who are prepared to face life's challenges are more adaptive and so more likely to succeed. ***Occupational transitions*** can be viewed as the movement between daily life sequences, shifts in functional abilities, and changes in the environment or programming. Successful transitions occur when the person shifts smoothly to the next stage or situation, which may be aided by adequate preparation, planning, and support.

Occupational therapy can assume a leadership role in preparing people for transition because occupational therapy practitioners serve people with and without disabilities throughout their life scope and ready clients for the next step. Transitions may include a return to employment, home, or community; a move from inpatient to outpatient; or a shift toward independent living and greater participation in occupation.

Occupational therapy takes a holistic approach of examining the occupational needs of the person within the context and environment where he or she participates and in anticipation of his or her life routines, goals, and stages. Transition occurs in almost every system: health, education, rehabilitation, and employment. Occupational therapy practitioners provide services within all of these systems, and they can be instrumental in examining the client's needs as he or she navigates within and between these systems throughout his or her lifespan.

As a transition looms for a client, the occupational therapy practitioner should ask the following questions:

- Is the next setting ready to receive the client?
- Are the client and the family prepared to assume new roles?

Early preparation and planning are key elements to successful transition. Because occupational therapy practitioners are activity experts, they can be visionary leaders in the transition process.

Nancy's Story: Reflections on Transition

Nancy Davis, OTD, OTR/L

As a school-based occupational therapist working mainly with elementary and middle school children, I had limited experience with high school students,

and even less experience with their needs for transitioning to the community. It was not until working with Brandon, a bright, dedicated, honors high school junior, that I gained insight into the occupational therapy's contributions and perspective in the process of transitioning to the community.

When Brandon shared with me that he did not believe his dream to attend college would come to fruition, I realized my focus on supporting his technology needs was very limited in scope. I expected that Brandon was concerned about his substantial physical limitations as a result of cerebral palsy. However, it was when Brandon relayed that his parents, who had not attended college, did not understand the transition process, nor supported his vision, that I understood his concern.

I was unaware that Brandon's other challenges—limited mobility and motor skills—resulted in the necessity for a personal needs assistant. I felt compelled to broaden my view of transition and to help Brandon realize his dream. Through increased collaboration with Brandon, his parents, his individual education program (IEP) team, and outside agencies, we forged his path. Brandon received the supports he needed and successfully attended a local community college, with plans to transfer to a university.

Shortly after working with Brandon, I began my own transition to doctoral studies. It was through serendipitous events stemming from a doctoral course that I had the honor of representing the American Occupational Therapy Association (AOTA) at a Community of Practice on Transition annual meeting. The community, convened and facilitated by the IDEA Partnership, is composed of diverse local, state, and national stakeholders coalesced with a common goal to solve complex issues on transition. This experience continued to spark my flame of transition interest, and Sandy Schefkind, AOTA's pediatric program manager, graciously agreed to be my mentor for one of my doctoral rotations.

I joined the AOTA Transition work group and collaborated with a highly talented group of occupational therapists, developing transition resources for internal and external audiences. Concurrently, I continued to represent AOTA on Community of Practice on Transition, sharing information from the community meetings with the AOTA Transition work group to help identify focus areas. Additionally, I shared transition information at

the local level, passing on relevant resources to internal stakeholders within my district, presenting on the role of occupational therapy in transition at the departmental level, and developing a transition resource book for our occupational therapy resource library.

The information flow through collaboration and networking has resulted in increasing awareness of the value of occupational therapy in the transition process and creating new venues, opportunities, and resources to support students. My own journey has been a transition and a transformation—from narrowly focusing on voice recognition software for a high school student to viewing the transition process with a broad lens and a greater understanding of the valuable contributions that occupational can provide to help support adolescents to reach their dreams.”

(*Note*. Used with permission.)

Questions

- How do you define *transition*, and what is its significance?
- What is the role of occupational therapy in promoting successful transition?
- What are some success stories around the country?
- What are some AOTA transition resources and activities, and what are their relevance?

Renzo's Story

Renzo's Story, in this text's Prologue, is a compelling personal story of transitions within and between the systems of education, health, work, and rehabilitation. Renzo's neurological and functional status slowly improved after his initial trauma, and he and his family needed to navigate changes in health systems from critical care to rehabilitation. They had to adjust to transitions in service providers, approaches, and settings. Renzo's parents continuously struggled to navigate within a complex health system to secure financial and community supports for their son.

In addition to practical and logistical matters, both Renzo and his family had to cope with the emotional stress of trauma while developing advocacy skills during the recovery process. The family and health team worked to recognize Renzo's strengths and challenges and propose realistic short- and long-term

goals. Each transition in ability and setting presented new possibilities and challenges. With high-quality team involvement, medical care, and environmental modifications, Renzo made improvements in his mobility, self-care, and work skills.

The family had to adjust to Renzo's struggles with depression and shift their expectations as his status and needs fluctuated. Community support was essential to the family's ability to cope. The perspective of Renzo's mother resonates with all parents who hope their child will lead a meaningful and productive life, well integrated into the community.

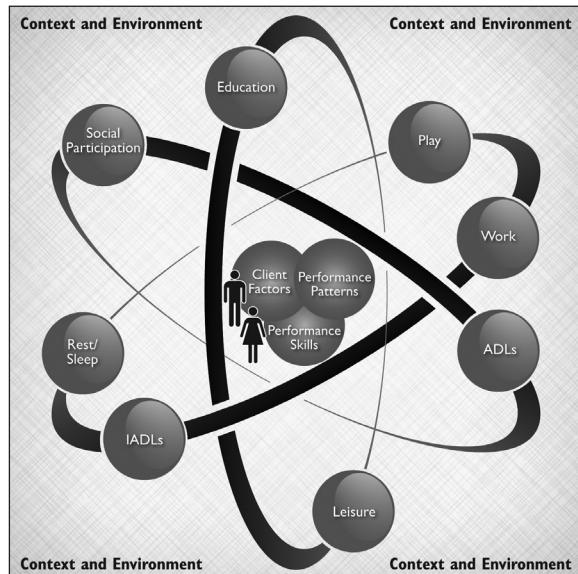
Practice of Occupational Therapy

According to the *Occupational Therapy Practice Framework: Domain and Process* (3rd ed.; AOTA, 2014), “Only occupational therapy practitioners focus on the use of occupations to promote health, well-being, and participation in life” (p. S11). **Occupation** refers to “daily life activities in which people engage” (AOTA, 2014, p. S6). **Areas of occupation** or activity include activities of daily living (ADLs), instrumental activities of daily living, rest and sleep, education, work, play, leisure, and social participation (AOTA, 2014). Clients are identified broadly as individuals, within groups, or as a population (AOTA, 2014).

Everyday occupations are fundamental to our existence and help define us. With activity, people secure their identity and achieve meaningful, productive lives. Occupational therapy practitioners examine the client's past, current, and anticipated future occupations. The practitioner and client then collaborate to determine the necessary steps to promote client participation in activity. This preparation helps the client better integrate into his or her community and to become more independent and participatory in daily routines. Occupational therapy supports people to maximize their occupational performance as they adapt to personal or situational challenges.

Occupational Therapy's Domain and Process

“Achieving health, well-being, and participation in life through engagement in occupation” is occupational therapy's domain and process (AOTA, 2014, p. S4).

Figure 2.1. Occupational therapy's domain.

Note. ADLs = activities of daily living; IADLs = instrumental activities of daily living.

From "Occupational Therapy Practice Framework: Domain and Process," 3rd ed., by the American Occupational Therapy Association, *American Journal of Occupational Therapy*, Vol. 63, Suppl. 1, p. S5. Copyright © 2014 by the American Occupational Therapy Association. Used with permission.

The **domain**, or purview, of occupational therapy includes occupations, client factors, performance skills, performance patterns, and context and environments (AOTA, 2014). All domain aspects interface to support engagement, participation, and health (AOTA, 2014; Figure 2.1). A client's current level of activity, personal values, sociocultural background, habits, routines, and other influences affect his or her current identity, health, well-being, and participation in life (AOTA, 2014).

Activity and occupational demands

The client must also be ready for next steps. The client is continuously entering a new stage or situation, and he or she must be ready to face novel or challenging **activity and occupational demands**, which are "the specific features of an activity and occupation that influence its meaning for the client and type and amount of effort required to engage in it" (AOTA, 2014, p. S12). Occupational therapy practitioners have expertise in activity and environmental analysis and modification to graduate tasks; build skills; and maximize the fit among

person, environment, and occupation. Occupational therapy can help the client anticipate and accommodate activity demands, supporting clients as they prepare for and reach desired short- and long-term occupational goals.

Performance skills

Performance skills are "goal-directed actions that are observable as small units of engagement in daily life occupations" (AOTA, 2014, p. S7). Client performance skills, consisting of motor, process, and social interaction skills, are continuously tested by activity and occupational demands (AOTA, 2014). Injury, disease, or aging may have contributed to the deterioration of the client's abilities. Will the client be prepared to meet the challenges to his or her occupational performance? If a client suffers a stroke, his or her self-care abilities may shift because of changes in visual perception, strength, or coordination. Occupational therapy practitioners can collaborate with the medical team to customize a service plan on the basis of the client's priorities, shifts in abilities, and future goals. Occupational therapy can be instrumental in maximizing the skills and abilities of this client and helping identify the necessary accommodations to promote participation and independence.

In contrast, a client's performance skills may advance as a result of growth and development or therapeutic intervention. For example, the occupational therapy practitioner may provide highchair modifications to promote the young child's self-feeding capacity. As the child's performance skills advance, he or she becomes more participatory in family mealtime routines. The client, which includes both the child and family, may transition to new levels of independence and roles, and occupational therapy can help to identify and support these future steps and opportunities.

Client factors

It is important to consider client factors and performance patterns within occupational performance. **Client factors** are "specific capacities, characteristics, or beliefs that reside within the person and that influence performance in occupations" (AOTA, 2014, p. S7). They include values, beliefs and spirituality, body functions, and body structures. **Performance patterns** are "habits, routines,

roles, and rituals used in the process of engaging in occupations or activities that can support or hinder occupational performance" (AOTA, 2014, p. S8).

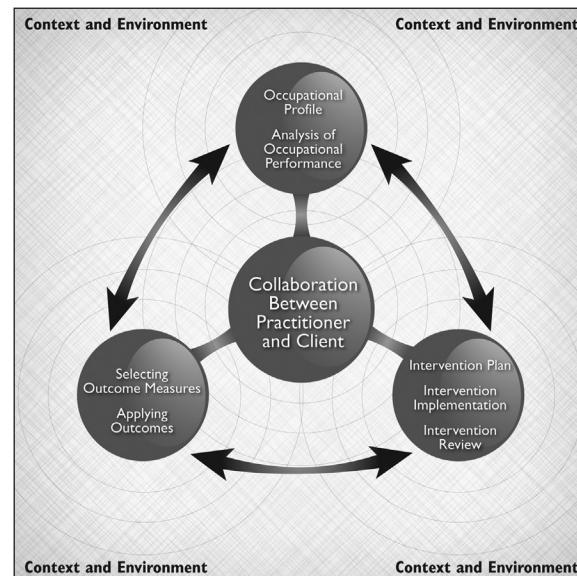
The client may harbor certain values and beliefs that reflect his or her cultural upbringing, so occupational therapy practitioners must examine the client and family values and concerns with sensitivity when facing a disability that conflicts with a family's beliefs and existing routine. For example, knowledge of the client's belief that only a wife should prepare the family meals is key for the occupational therapy practitioner to help ready the homemaker for transition from hospital to home. Occupational therapy can help build the homemaker's skills to re-establish her role in the family and cope with her shifting abilities and self-identity. The practitioner can help the client during times of occupational transition to promote independence and foster self-esteem.

Context and environment

The **context**, which is "cultural, personal, temporal, and virtual," and **environment**, which is both "physical and social conditions," are always changing (AOTA, 2014, p. S28). A student must adapt to new classrooms, curricular demands, and educators each school year. A person in transition may face a divorce or the loss of a job or loved one. Each change or transition presents new challenges, opportunities, and barriers to participation. How will the client cope with a new situation or stressor? Occupational therapy practitioners possess unique knowledge and skills in activity and occupational performance, environmental and task analysis and modification, assistive technology, sensory systems, and mental health that can support clients.

For example, an older adult experiencing macular degeneration may face vision loss and, subsequently, difficulty with driving. The practitioner can recommend driver evaluation and remediation when appropriate. The practitioner can suggest alternative methods of transportation (e.g., senior transit shuttles, taxis) and encourage reducing the need for driving by shopping through catalogs and using delivery services for groceries and medicines. When driving is no longer feasible, the practitioner can collaborate with the client to formulate a plan that preserves as much of his or her independence as possible. Emotional and physical components must be addressed.

Figure 2.2. Occupational therapy's process.



Note. From "Occupational Therapy Practice Framework: Domain and Process," 3rd ed., by the American Occupational Therapy Association, *American Journal of Occupational Therapy*, Vol. 63, Suppl. 1, p. S10. Copyright © 2014 by the American Occupational Therapy Association. Used with permission.

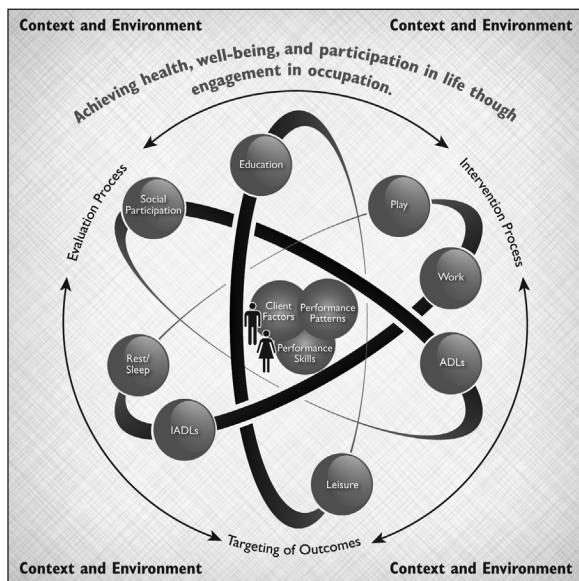
As the aging client struggles to cope with changes, the practitioner helps to ease transition by providing strategies to enhance community participation.

Occupational Therapy's Process

The therapist, client, and intervention **processes** and interactions are continuously linked and modified as demands, needs, and abilities change. Service delivery, within context and the environment, is modified according to the level of collaboration, analysis of occupational performance, intervention, and outcome measures (AOTA, 2014; Figure 2.2). The transactional relationship between occupational therapy domain and process reflects this constant movement (AOTA, 2014; Figure 2.3).

For example, the client–therapist relationship and interactions shift as the client transitions from inpatient to outpatient rehabilitative services. As the client moves forward on the continuum from illness and disability to wellness and recovery, occupational therapy can support incremental steps toward independence and increased occupational role performance. The intensity and frequency of

Figure 2.3. Occupational therapy domain and process.



Note. ADLs = activities of daily living; IADLs = instrumental activities of daily living.

From "Occupational Therapy Practice Framework: Domain and Process," 3rd ed., by the American Occupational Therapy Association, *American Journal of Occupational Therapy*, Vol. 63, Suppl. 1, p. S5. Copyright © 2014 by the American Occupational Therapy Association. Used with permission.

occupational therapy service match the client's abilities and needs.

Occupational therapy's domain reflects transition because shifts are continuously occurring at all levels: within the client's needs, performance, and abilities; activity demands; conditions; and environment. Transition occurs within the occupational therapy process because of the interactive nature of service delivery and the ongoing collaboration between the client and practitioner. Throughout the life course, the client must successfully navigate through continuous challenges to and opportunities for engagement in occupation.

Addressing Transition in Practice

Occupational therapy practitioners can be leaders in addressing the client's transition needs because they examine the client holistically, asking who he or she is, what his or her needs are, where he or she will be going, and what he or she will be doing in the

future. Practitioners should consider transition as an innate concept of occupational therapy practice, using transition outcomes to assess accountability, infusing transition language within conversations, examining client needs and service delivery during transitions within the context of IEP and state requirements, and collaborating with hospital and rehabilitation team members to successfully transition clients from facility to home or community. Additionally, by correlating their service to achieving positive transition outcomes, practitioners advocate for the profession and secure its future.

Results-Driven Accountability

During financially challenging times and rising accountability standards, occupational therapy practitioners must articulate the value-added benefit of occupational therapy to any service plan and link occupational therapy to positive transition outcomes. With this current **results-driven accountability**, the U.S. Department of Education (ED; 2015) will be monitoring educational results and outcomes for students with disabilities more critically. The trend toward rising accountability in education raises the bar for state special education programs (ED, n.d.b). Practitioners must self-examine to ensure that practices are measurable, evidence- and occupation-based, and related to function. Transition outcomes are a specific measure to examine accountability.

Transition Language

Practitioners must learn the language of transitions. They need to be comfortable with terminology, such as **self-determination**, which supports the belief that people have the right to direct their own lives. Chapter 1, "Foundations of Transition," reviews common language used in transition. Practitioners should particularly consider the term **outcomes**. When transition goals are met, the client meets an outcome related to his or her current and anticipated needs, which is a way to measure occupational therapy accountability and value.

State Performance Plan Indicators

School-based practitioners should become familiar with the 20 **state performance plan indicators** that

measure state efforts to implement the requirements and purposes of Part B of the Individuals With Disabilities Education Improvement Act of 2004 (IDEA; Pub. L. 108–446). For example, Indicator 12 discusses early childhood transition for children who are found eligible for early childhood special education and who have an IEP developed and implemented before their third birthday (20 U.S.C. 1416[a][3][B]). Indicator 13 collects data related to postsecondary transition outcomes for students with disabilities ages 16 years or older. It includes appropriate measurable postsecondary goals based on an age-appropriate transition assessment, transition services, annual IEP goals related to transition service needs, and evidence that the student was invited to IEP team meetings where transition services were discussed (20 U.S.C. 1416[a][3][B]).

Practitioners should consider broadly how their individual service contributes to advancement of the client, specifically addressing transitions—within an IEP plan and goals and an overarching state plan and goals.

Medically Based Practitioners

Medically based occupational therapy practitioners must establish an intervention plan and documentation in anticipation of the transition to home or other setting. They must be familiar with hospital home care procedures and share information about the patient's current and projected occupational needs with other professionals and the family, relevant to the discharge plans. For example, occupational therapy service that includes training in daily living skills and falls prevention may reduce the likelihood of costly rehospitalization and help the client achieve a safe and sustained transition from hospital to home.

National and Federal Initiatives

Transition planning is a forward-thinking, visionary process that projects to future needs and goals. This planning can be examined for an individual or a population. Healthy People 2020 (Centers for Disease Control and Prevention [CDC], 2011), developed for the population as a whole, and the 2020 Federal Youth Transition Plan (Federal Partners in Transition Workgroup, 2015), developed for youth with disabilities, are two frameworks that consider the transition for groups of people toward greater health, independence, and function.

Healthy People 2020

Healthy People 2020 was first developed by the U.S. Department of Health and Human Services in 1979 in collaboration with other federal agencies and public stakeholders and an advisory committee (Koh, 2010). The vision of *Healthy People 2020* is to create a society in which all people live long, healthy lives, increasing quality of life and eliminating health disparities. Leading health indicators for Healthy People 2020 include physical activity, tobacco use, responsible sexual behavior, injury and violence, immunization, overweight and obesity, substance abuse, mental health, environmental quality, and access to health care (Koh, 2010). In 2010, the framework was revised to track approximately 1,200 objectives organized into 42 topic areas, each of which represents an important public health area (CDC, 2011).

Occupational therapy promotes physical and mental health for all people and can support the Healthy People 2020 goals. Its role in primary care teams to adopt and maintain both physical and mental health through occupational engagement supports the objective of successful transition throughout all life stages by

- Anticipating situations and environments,
- Promoting healthy routines and settings,
- Providing play and leisure coaching throughout all life stages,
- Contributing through initiatives (e.g., obesity and bullying prevention, recess and friendship promotion),
- Providing life coaching, and
- Supporting adoption and maintenance of a healthy lifestyle.

2020 Federal Youth Transition Plan

Federal partners formed a workgroup to develop a strategy for inclusive service delivery for transitioning youth with disabilities from school to postsecondary education, the workforce, and independent living called the *2020 Federal Youth Transition Plan*, which consists of an executive summary of interagency coordinated goals and strategies. The workgroup examined the findings of the *National Longitudinal Transition Study–2*, which was commissioned by ED (n.d.a) and

showed that youth with disabilities lag behind their peers without disabilities in finding a job.

The study results have important implications for occupational therapy practitioners working to meet the occupational needs of students with disabilities to achieve future career and education goals and the life skills necessary for community integration. For example, school practitioners can coordinate services and forge partnerships to develop student work skills in anticipation of graduation and future employment. In-school partners may include playground monitors, the librarian, the principal, and the Parent–Teacher Association, who can provide opportunities for students to engage in meaningful volunteer work, such as taking inventory of playground equipment or library books, working in a school store, or assisting in a school fundraiser. Such job rehearsal helps the student build a portfolio of work experiences.

Practitioners can also seek out opportunities for students to participate in life skills programming. Transition skills must be developed constantly and consistently, beginning in the early years—if this process begins at age 14 or 16 years, when mandated services are instituted, it is too late.

Systems-Based Transition and Relationship to Occupational Therapy

Occupational therapy practitioners have a unique perspective that fits well in analyzing, planning, and addressing short- and long-term transitional steps and goals between and within systems. Practitioners can help to coordinate and plan care within multiple systems through strong communication and partnerships.

As a client grows and develops, he or she navigates within and between health and wellness, medical, educational, and rehabilitative systems. For example, under Part C and Part B of IDEA, a child with a disability can navigate through a path of receiving mandated transition services in both early childhood and high school.

Education Pipeline

Occupational therapy practitioners support the young child and his or her family when he or

she transitions from early intervention services to preschool, kindergarten, and school services and during high school transitions as he or she moves toward college or a career in what is sometimes called moving from “cradle to college and career.” The child navigates through the education system and copes with changes in setting, approach, and service providers.

The **education pipeline** conceptualizes the pathway to adulthood as a continuum from preschool to age 21 years (Forum for Youth Investment [Forum FYI], 2010a, p. 21). Known as the **Ready by 21 model**, it recognizes the complexity of transitioning into adulthood and notes that multiple stakeholders, including related service providers, must participate in the process (Forum FYI, 2010a).

The education pipeline suggests strengthening the links among preschool and elementary, middle, and high school to prepare young people for college, work, and community integration. A group of national partnerships helped to develop numerous free tools on the Ready by 21 website, developed through an initiative of the Forum FYI (2010b). But, what if the child must navigate health concerns that additionally threaten the smooth passage through the education pipeline?

Health Concerns in the Educational Pipeline

If the school-aged child experiences substantial health difficulties, hospitalizations likely affect his or her capacity to participate in education and with peers. Additionally, as in Renzo’s story, the family faces financial and emotional hurdles. When the student re-enters school, he or she faces social and academic challenges and health concerns of endurance, risk of infection, or relapse.

In this scenario, the child faces transition within and between both the educational and medical systems. Adequate staff preparation and support will ease the child’s return to school. With parental consent, the hospital, community, and school-based occupational therapy practitioners can share important information about the child’s occupational performance. Practitioners in schools can then promote the student’s participation in school routines by collaborating with other school personnel.

Modifications to the child's school day may reduce fatigue and build endurance. A shortened school day may accommodate health concerns, and extracurricular activities with less physically demanding opportunities for participation may be appropriate. A designated buddy may offer support for social engagement. Collaboration among the occupational therapy practitioner, school nurse, and the rest of the education team can help to shift the student's recent identity as a patient to that of an active member of the school community.

At-Risk Populations

Clients continuously confront work, health, social, environmental, or educational demands that affect participation in occupation. Certain populations are at greater risk for unsuccessful transitions, such as returning soldiers and their families, who face systemwide transition challenges as they both try to navigate medical, educational, and social changes. Foster care children are another vulnerable population because their family structure and routines are threatened.

Examples of Best Practice

Across the country, many outstanding occupational therapy practitioners address the transition needs of their clients, through research, education, or practice. The examples in this section can serve as models and inspiration for others.

Occupational Therapy in Secondary Transition Services in Arkansas

Tina A. Mankey, EdD, OTR/L, is an associate professor in the Department of Occupational Therapy at the University of Central Arkansas in Conway. She has been actively developing and advocating for the inclusion of occupational therapy services in secondary transition services, which prepare students for life after high school, in Arkansas. Mankey codirected a grant-funded summer program for adolescents with disabilities, which initiated a collaborative effort among local agencies and a state university. Its purpose was to prepare adolescents with disabilities and their families for the transition into adulthood, set goals and priorities on the

basis of their individual capabilities and interests, and provide them with opportunities to participate in their chosen activities. Feedback from the program revealed positive outcomes by the families, adolescents, and the occupational therapy students (Mankey, 2011b; Mankey & Acre, 2010).

Mankey (2011a) also conducted a preliminary statewide research study to examine the involvement of occupational therapy in secondary transition services. Her research explored whether occupational therapists in Arkansas public schools are involved in secondary transition planning for students with disabilities and what types of services are being provided.

The study also examined occupational therapists' feelings about their role in secondary transition planning. Finally, it explored challenges for and supports to occupational therapy service in transitions (Mankey, 2011a). This research laid a foundation of evidence and strengthened previous literature findings that indicated low involvement of occupational therapy in secondary transition in Arkansas. Occupational therapists in Arkansas believed they have the expertise to play an active role in this process but indicated numerous limitations toward their involvement. Further research is needed to explore the limitations, identify solutions, and support efforts within Arkansas.

Mankey (2012a, 2012b) explored the educators' perceived role of occupational therapy in secondary transition in Arkansas and conducted focus groups throughout the state to ascertain the perspectives of transition team members regarding occupational therapy services in the transition process (Mankey, Canizares, Krehel, & Warner, 2014). Themes emerged to indicate how the transition team members view the roles of occupational therapy and the factors that influence the participation of occupational therapy in transition planning. In addition, the results revealed the type of support needed for occupational therapy to be involved in their teams.

As a result of her research, Mankey has continued to strive to enhance occupational therapy's presence in transition services in Arkansas. Previous research on transition services had identified reimbursement as one of the contributing factors that hinder involvement (Kardos & White, 2005; Mankey, 2011a). Mankey (2014) established that availability of revenue has affected the involvement of occupational therapy within the state. Her research

sought to find possible funding solutions for those who want to create change and provide invaluable input into the transition process.

Mankey has worked in conjunction with AOTA to promote transition services within the profession (Orentlicher, Schefkind, Pierce, & Mankey, 2011) and is actively involved in transition at the state and national levels (Pierce, Summers, & Mankey, 2011). She has greatly affected occupational therapy in transition services within Arkansas and has educated parents, caregivers, educators, and administrators on the importance of occupational therapy's presence in transition planning.

Transitions to Work and College in Georgia

Charles Berstecher, OTR/L, ATP, CAPS, worked as an occupational therapist in the Assistive Work Technology Unit of the Georgia Vocational Rehabilitation (VR) Agency. He noted that many of his clients, particularly those with mental health and cognitive disabilities, were ill-prepared for transition to the workplace and local community because of insufficient skills or acquired dysfunctional patterns in daily living such as self-care and home management. These clients also demonstrated poor organizational and time management skills. Berstecher developed an occupational therapy life skills program and encouraged rehabilitation counselors to refer to the program their most challenging clients regarding transitioning into the workforce.

The program's client-centered approach focused on promoting health and participation in performance areas of daily occupations, including ADLs, work, and education. The program used integrated assistive technology to reduce barriers and facilitate performance, leading to client empowerment and community integration. Although the program provided individual evaluation and treatment services, its sessions were primarily in a group format to inspire participation and facilitate the social skills necessary for expected work environments.

Berstecher's advocacy for the inclusion of occupational therapy in VR services and team collaboration has led to an increased number of referrals and a deeper understanding of the role of occupational therapy within the team. Berstecher stated that VR staff is now more cognizant of the effects of a disability on occupational performance, which

he believes is critical in the development of an effective vocational plan and subsequent transition into a successful and valued job role.

Advocacy Efforts in Wisconsin

Judith Werbel Sage, MSE, OTR, served children with disabilities for 38 years. She recently retired from her position as a school-based occupational therapist in four rural school districts in west central Wisconsin. Her leadership has improved transition planning and transition activities for students with disabilities and their families.

Since 2007, Sage actively participated in the Wisconsin Community of Practice on Transitions. Through activities conducted by a community-based, interagency group, she assisted in developing the 2009 version of a newly revised resource entitled *Transition Health Care Checklist: Preparing for Life as an Adult* (Wisconsin Community of Practice on Transition Practice Group on Health, 2014). She also teamed with a special education teacher to develop a brochure about transition so family members would be more prepared to be active participants in the IEP transition planning process. Throughout her career, Sage advocated for state networking and disseminating national and state transition resources and tools to local school districts.

Transitioning Youth and Adults With Autism in Maryland

The number of children diagnosed with autism spectrum disorder (ASD) is increasing exponentially (CDC, 2012); therefore, greater numbers of youth with ASD are transitioning to adulthood. Although services for school-aged children and youth are mandated, supports and services to promote community participation are often not available when these youth transition to adulthood.

To begin to address this gap, with donated funds, the College of Health Professions at Towson University in Maryland charged Lisa Crabtree, PhD, OTR/L, with developing the Center for Adults With Autism (later named the Hussman Center) on the university campus. The center's mission is to provide educational experiences for students and professionals and conduct faculty-student applied research and outreach activities that support adults with ASD

in living meaningful lives as fully engaged members of their communities.

Crabtree's background in school-based occupational therapy and her research on the social participation of youth with ASD led her to incorporate constructs of inclusion, presumed competence, and empowerment into the development of the center. Using the Person–Environment–Occupation Model (Law et al., 1996), Crabtree considered how social context influences participation of young adults. Therefore, the center's programs partner university students with youth and young adults with ASD to support mutual learning through leisure activities such as rock climbing and art and social activities such as dinners, games, and parties. University students learn firsthand about people with ASD and advocacy for the ASD community, and transitioning youth and young adults with ASD can engage with peers in a supportive, engaging context that promotes skill development and community integration (Crabtree & Sherwin, 2011). The programs also include evaluating outcomes and disseminating results.

Preliminary research suggests the center's mission has been successful (Crabtree & Demchick, 2015). Students involved in the programs have reported that they have learned more about ASD from their partners with ASD than they ever had in the classroom, and participating youth and young adults with ASD have reported they felt equal to and accepted by their peers for the first time in their lives.

Data analysis before and after assessments of program participants identified substantial positive changes in perceptions of leadership and social competence by the youth and young adults with autism. University students' attitudes about and knowledge of ASD also showed great changes through participation in the program.

Transition Research Through Job Matching in Ohio

Andrew Persch, PhD, assistant professor of occupational therapy at The Ohio State University, established the Transition, Employment, and Technology (TET) Lab in 2012. The long-term goal of the TET Lab is to improve postsecondary employment outcomes for people with intellectual and developmental disabilities through the adaptation,

development, and deployment of systematic assessment and intervention strategies.

The lab created the Model of Systematic Job Matching, which combines assessment of the person and occupation using the Vocational Fit Assessment, and implemented intervention through use of the Job Matching Report (JMR; Persch, 2014), a decision support system designed for special education and vocational rehabilitation. Systematic job matching begins with assessment. Key stakeholders (e.g., client, parent, professional) complete web-based assessments of worker abilities and job demands. The TET Lab then uses a comparative algorithm to compare abilities with demands.

The results of this process are presented electronically in the JMR, a tool that displays the pros and cons of each potential job match. The JMR also shows key stakeholders where to intervene to improve worker abilities or modify work demands. Recent TET Lab research on current practices in job matching has demonstrated that job matching is a collaborative process, stakeholders consider many different types of data when job matching, current practices in job matching are variable and lack consistency, and outcomes of the job-matching process are poorly defined (Pesch et al., in press).

Evolving Transition Practices: An Arizona Success Story

Linda Rudd is an Arizona occupational therapist who began exploring secondary transition in 2008. After learning about the mandatory requirements for transition services in IDEA, Rudd began to rethink her approach to school-based therapy. Armed with an understanding that children with disabilities should not only be receiving a free appropriate education but also an education that prepares them for adult living, she began to implement several personal practice changes. Additionally, as the lead occupational therapist for her school district, she worked to evolve departmental practices for all occupational therapy practitioners.

Rudd first made simple changes to service delivery by providing contextually relevant interventions in the settings where students needed to demonstrate skills, meaning not pulling kids out of class for occupational therapy appointments. Additionally, although much of occupational therapy service was focused on fine motor skills development, Rudd understood that many students with special needs

required more opportunities to practice life skills. So, in collaboration with her certified occupational therapy assistant and a junior high special education teacher, she established a life skills room and student-run store at a campus with a program for youth with intellectual disabilities.

As the lead occupational therapist, Rudd advocated for a position on a districtwide committee for transition services. This position presented an opportunity to increase her knowledge of the process and documentation requirements of transition and to educate other staff members about the unique education and skill set of occupational therapy practitioners. This experience prompted major changes in how occupational therapy was interpreted and implemented, including increased allocation of occupational therapy staffing at each of the district's seven high schools. Changing the perception and expectations of occupational therapy in the district required practitioners to gain additional knowledge and awareness of current best practice for school-based occupational therapy, so Rudd engaged her department in several book studies and literature reviews using AOTA resources.

To deepen her knowledge and expertise in transition services, Rudd routinely sought out training available at the state and national levels. Eventually, she began to provide professional development training to other transition personnel and occupational therapy practitioners across Arizona to advocate for increased occupational therapy participation. In 2014, the transition services coordinator position at Peoria Unified School District became available, and Rudd was selected to fill this role. She continues to promote occupational therapy involvement in transition services by collaborating with the Arizona Department of Special Education, AOTA, and the National Technical Assistance Center on Transition.

Transition Resources and Activities

AOTA and the IDEA Partnership both offer multiple resources and activities related to transition services.

AOTA Resources

AOTA has dedicated staff to promote transition practices and support the development of

transition resources and activities. Two key results of these efforts include a dedicated area of transition resources on the AOTA website (<http://www.aota.org/Practice/Children-Youth/Transitions.aspx>) and the creation of an AOTA Transition Community of Practice. Both entities act as supports and advocates for the profession.

Many AOTA resources refer to transition, including AOTA official documents. AOTA's (2010) *Standards of Practice for Occupational Therapy, transition* is defined as "actions coordinated to prepare for or facilitate a change, such as from one functional level to another, from one life [change] to another, from one program to another, or from one environment to another" (p. S107). Several AOTA resources review key points of transition found within IDEA. AOTA members and nonmembers may access the AOTA (2008b) fact sheet entitled *Transitions for Children and Youth: How Occupational Therapy Can Help*. Sharing this document with consumers, administrators, and policymakers can promote occupational therapy's role during early childhood and school-based transitions.

Practitioners can advance their knowledge and skills by accessing several AOTA Frequently Asked Questions (FAQs). These member-only resources were created by content experts and are geared toward practitioners. They provide a brief overview of the topic and suggest resources and action steps. The goal is to inform practitioners and to advance transition practice. Two FAQs include *Occupational Therapy's Role in Transition Services and Planning* (AOTA, 2008a) and *What Is the Role of Occupational Therapy in Supporting Employment of Young Adults With Disabilities?* (AOTA, 2013).

Several books published by AOTA Press devote content to early childhood or school transitions (check store.aota.org for new or revised publications and continuing education). *Occupational Therapy Services for Children and Youth Under IDEA* (Jackson, 2007) contains a chapter on transitions, "Transition From School to Adult Life" (Orentlicher, 2007). Frolek Clark and Chandler's (2013) *Best Practices for Occupational Therapy in Schools* contains two chapters that focus on transition: "Best Practices in Transition Planning for Preschoolers" (Myers & Podvey, 2013) and "Best Practices in Postsecondary Transition Planning With Students" (Orentlicher, 2013). Kuhaneck and Watling's (2010) *Autism: A Comprehensive*

Occupational Therapy Approach includes a chapter dedicated to transition, “Transition From School to Adult Life for Students With an Autism Spectrum Disorder” (Orentlicher & Olson, 2010).

AOTA also provides several continuing education transition resources, including *Creating Successful Transitions to Community Mobility Independence for Adolescents: Addressing the Needs of Students With Cognitive, Social, and Behavioral Limitations* (Monahan & Patten, 2009), and an online course, “Best Practices in Transition Planning for Preschoolers” (Myers & Podvey, 2014).

Other continuing education focuses on transition for students with ASD, *Occupational Therapy Service Provision in an Educational Context, Topic 4: Transition From School to Adult Life For Youth With ASD* (Olson & Orentlicher, 2012). A continuing education article was published in *OT Practice*, “Person-Centered Planning: An Innovative Approach for Transition Planning” (Orentlicher & Dougan, 2011).

AOTA also offers new pediatric virtual chats for occupational therapy practitioners and students. These quarterly topic-specific discussions, led by content experts, provide an opportunity for learning, dialogue, and member engagement. Recordings of these chats on both early childhood and high school transitions are available for playback at <http://www.talkshoe.com/tc/73733>.

Other resources on transitions can be found on AOTA’s website (<http://www.aota.org/Practice/Children-Youth/Transitions.aspx>). AOTA offers OT Connections, which includes a Transition forum that focuses on adolescent transition services and occupational therapy, an excellent resource for discussing with colleagues throughout the United States the topic of high school transitions for students with disabilities. Appendix 2.A provides information on AOTA resources on transitions. AOTA also continues to sponsor several conference presentations on transitions. Educational sessions on transition sessions have been offered at AOTA’s Annual Conference & Expo each year since 2010.

Developing a Transition Community of Practice

AOTA is an active member of the IDEA Partnership (discussed in the next section) and has developed volunteer pediatric workgroups that align with a community of practice approach. *Communities of*

practice are “groups of people who share a concern, a set of problems, or a passion about a topic, and who deepen their knowledge and expertise in this area by interacting on an ongoing basis” (Wenger, McDermott, & Snyder, 2002, p. 4).

Understanding communities of practice

Communities of practice can be examined as a theory to analyze health care organizations and also as a practical tool to enable collaborative learning and knowledge translation (Kislov, Harvey, & Walshe, 2011). They can build identity; a group forms by identifying attributes, values, and beliefs and by establishing a learning trajectory (Kislov et al., 2011). The group finds shared concerns that cross boundaries and coalesces around issues (Cashman et al., 2014). Through community building, a “uni-professional culture” through “social interaction” develops, which offers “interaction, trust, and motivation” (Canadian Institutes of Health Research, 2004, p. 24).

Communities of practice can be an effective strategy for knowledge brokering, providing many short- and long-term benefits to participating organizations and community members (Wenger, McDermott, & Snyder, 2002). Short-term benefits to organizations include improving business outcomes by providing quick answers to questions (Wenger et al., 2002). Long-term benefits include developing organizational capabilities such as increasing knowledge-based alliances (Wenger et al., 2002). Short-term benefits to community members include improving work experiences such as being better able to contribute to the team (Wenger et al., 2002). Long-term benefits include fostering professional development such as cultivating a stronger sense of identity (Wenger et al., 2002).

Pediatric workgroups

Community of practice is a type of participative leadership; the pediatric workgroups develop their own action plans reflective of their knowledge. Through conversations, workgroup members identify common needs and strategies to support pediatric practice. Through workgroup collaboration, members have created 43 AOTA pediatric documents such as trifolds for school administrators on the role of occupational therapy and tip sheets for parents on promoting play.

AOTA has the following seven volunteer pediatric workgroups that operate using the community of practice approach:

1. Early Childhood
2. School Mental Health
3. Autism
4. Childhood Obesity Prevention and Health Promotion
5. Response to Intervention
6. State Leaders in Department of Education
7. Transitions.

In total, 138 pediatric content experts who represent a diverse cross section of states and roles such as educator, clinician, and researcher meet every 6 weeks to discuss topics of mutual concern or interest. Through these regularly scheduled teleconferences, the workgroups discuss topics and then conduct shared work.

The AOTA Transitions workgroup helped to develop the fact sheet and FAQ focused on occupational therapy's role in transitions within an educational system (AOTA, 2008a) and an *OT Practice* article that focused on a cross-system approach, "The Role of Occupational Therapy in Transitions Throughout the Lifespan" (Gibson et al., 2010). The workgroup is currently drafting the completion of a slide presentation as a professional training tool that includes hyperlinks to case studies in systems such as education, mental health, military, productive aging, and work.

The IDEA Partnership

The **IDEA Partnership**, a coalition sponsored by the ED's Office of Special Education Programs and housed in the National Association of State Directors of Special Education, brings together national organizations, state agencies and teams, technical assistance centers, family and local groups, and individuals through shared work, activity, and learning. The partnership supports participation and collaboration at the national, state, and local levels and promotes interdisciplinary dialogue and consensus building by focusing on identifying common beliefs and shared work. The partnership's overarching goal is to improve outcomes for students with disabilities, generated through community building.

The IDEA Partnership uses a participatory framework, grounded in the belief that knowledge, skills,

and engagement create and sustain change when distributed equally across groups, roles, settings, and levels. The partnership aims to unite its members by using existing networks to translate relevant information through tool use and relationship building and seeks to learn how deeper understanding and consensus-driven work influence behavior change.

The IDEA Partnership has built communities of practice, which are topic-specific interdisciplinary groups coalesced to work collectively on a shared interest. These groups conduct free national community calls to share information and to network. They also help develop and present at conferences to build understanding and resources on issues such as autism, school mental health, creating agreement, and transitions. Membership in the IDEA Partnership is free and open to all. The IDEA Partnership has become a trusted source of information including topic-specific, evidence-based collections and dialogue guides. IDEA Partnership's websites are www.ideapartnership.org and www.sharedwork.org.

The IDEA Partnership holds a yearly National Community Meeting on Transitions in North Carolina. Additionally, the Secondary Transition Collection of the IDEA Partnership can be accessed through the partnership's websites. The collection includes guiding principles, fact sheets, essential elements, grounding assumptions, needs of the field, a glossary, resource guide, and evidence-based practices.

The IDEA Partnership Transition Community calls have led to several collaborative projects that included some AOTA involvement. One was a participatory action research study, led by Doris Pierce and Karen Summers (2011) at Eastern Kentucky University, that examined professional development opportunities and how they affect occupational therapy's role in transitions within an Arizona school district.

Summary

This chapter challenges readers to recognize the leadership role of occupational therapy in transition services. This role is evident when serving across the lifespan for different populations and within a variety of settings, environments, and conditions. Clients experience occupational transitions when navigating within and between systems such as health, education, and rehabilitation. Occupational therapy approaches the client holistically, promoting participation in all contexts.

Occupational therapy practitioners have a rich background in mental and physical health and can use this expertise to support successful transitions toward independence. Practitioners should advocate for their role in promoting smooth transitions and in reaching positive outcomes. This advocacy heightens accountability and adds value to service, thereby securing the profession. Practitioners can model the work of content experts across the country and can network through existing or developing communities. They can reference a variety of AOTA transition resources and incorporate transition language and philosophy within their work scope.

Questions

- How can transition planning and services be translated to your service delivery?
- What AOTA tools can you access and utilize in your setting?
- What language can you adopt to indicate your skills in transition services?
- What discussions and activities should you consider?

References

- American Occupational Therapy Association. (2008a). *Occupational therapy's role in transition services and planning*. Retrieved from <http://www.aota.org/-/media/Corporate/Files/Secure/Practice/Children/transitions.pdf>
- American Occupational Therapy Association. (2008b). *Transitions for children and youth: How occupational therapy can help* [Fact Sheet]. Retrieved from <http://www.aota.org/-/media/Corporate/Files/AboutOT/Professionals/WhatIsOT/CY/Fact-Sheets/Transitions.pdf>
- American Occupational Therapy Association. (2010). Standards of practice for occupational therapy. *American Journal of Occupational Therapy*, 64, S106–S111. <http://dx.doi.org/10.5014/ajot.2010.64S106>
- American Occupational Therapy Association. (2013). *What is the role of occupational therapy in supporting employment of young adults with disabilities?* Retrieved from <http://www.aota.org/-/media/corporate/files/secure/faq-employment-young-adults.pdf>
- American Occupational Therapy Association. (2014). Occupational therapy practice framework: Domain and process (3rd ed.). *American Journal of Occupational Therapy*, 68(Suppl. 1), S1–S48. <http://dx.doi.org/10.5014/ajot.2014.682006>
- Canadian Institutes of Health Research. (2004). *Knowledge translation strategy 2004–2009: Innovation in action*. Ottawa: Canadian Institutes of Health Research. Retrieved from <http://www.cihr.ca>
- Cashman, J., Linehan, P., Purcell, P., Rosser, M., Schultz, S., & Skalski, S. (2014). *Leading by convening: A blueprint for authentic engagement*. Alexandria: VA. Retrieved from <http://www.ideapartnership.org/documents/NovUploads/Blueprint%20USB/NASDSE%20Leading%20by%20Convening%20Book.pdf>
- Centers for Disease Control and Prevention. (2011). *Healthy People 2020*. Retrieved from http://www.cdc.gov/nchs/healthy_people/hp2020.htm
- Centers for Disease Control and Prevention. (2012). Prevalence of autism spectrum disorders: Autism and developmental disabilities monitoring network, 14 sites, United States, 2008. *Morbidity and Mortality Weekly Report*, 61(3), 1–19.
- Crabtree, L., & Demchick, B. B. (2015). Young adults on the autism spectrum: Perceived effects of participation in a university-based challenge course program in the community. *Occupational Therapy in Mental Health* 31, 1–13.
- Crabtree, L., & Sherwin, A. (2011). Begin with the end in mind: Promoting mental health, social participation, and self-determination in the transition from school to adult life. In S. Bazik (Ed.), *Mental health promotion, prevention, and intervention with children and youth* (pp. 267–286). Bethesda, MD: AOTA Press.
- Federal Partners in Transition Workgroup. (2015). *The 2020 Federal Youth Transition Plan: A federal interagency strategy*. Retrieved from <http://www.dol.gov/odep/pdf/20150302-FPT.pdf>
- Forum for Youth Investment. (2010a). *Ready by 21: Insulating the education pipeline to increase postsecondary success*. Retrieved from http://forumfyi.org/files/RB21_Credentialed-by-26_Brief-1%5B1%5D.pdf
- Forum for Youth Investment. (2010b). *Toolkits*. Retrieved from <http://www.readyby21.org/toolkits>
- Frolek Clark, G., & Chandler, B. (Eds.). (2013). *Best practices for occupational therapy in schools*. Bethesda, MD: AOTA Press.
- Gibson, R., Nochajski, S., Scheffkind, S., Myers, C., Sage, J., & Marshall, A. (2010, June 28). The role of occupational therapy in transitions throughout the lifespan. *OT Practice*, 15, 11–14.
- Individuals With Disabilities Education Improvement Act of 2004, Pub. L. 108–446, 20 U.S.C. §§ 1400–1482.
- Jackson, L. (Ed.). (2007). *Occupational therapy services for children and youth under IDEA* (3rd ed.). Bethesda, MD: AOTA Press.
- Kardos, M., & White, B. P. (2005). The role of the school-based occupational therapist in secondary education transition planning: A pilot survey study. *American Journal of Occupational Therapy*, 59, 173–180. <http://dx.doi.org/10.5014/ajot.59.2.173>
- Kislov, R., Harvey, G., & Walshe, K. (2011). Collaborations for leadership in applied health research and care: Lessons

- from the theory of communities of practice. *Implementation Science*, 6, 1–10.
- Koh, H. (2010). A 2020 vision for healthy people. *New England Journal of Medicine*, 362, 1653–1656.
- Kuhanek, H. M., & Watling, R. (Eds.). (2010). *Autism: A comprehensive occupational therapy approach* (3rd ed.). Bethesda, MD: AOTA Press.
- Law, M., Cooper, B., Strong, S., Stewart, D., Rigby, P., & Letts, L. (1996). The Person–Environment–Occupation Model: A transactive approach to occupational performance. *Canadian Journal of Occupational Therapy*, 63, 9–23.
- Mankey, T. (2011a). Occupational therapists' beliefs and involvement with secondary transition planning. *Physical and Occupational Therapy in Pediatrics*, 31, 345–358.
- Mankey, T. (2011b, April). *Outcome analysis of ready, set, go! An occupational therapy model to community transition*. Paper presented at the 2011 AOTA Annual Conference & Expo, Philadelphia.
- Mankey, T. (2012a, April). *Building evidence in school-based practice: Exploring educators' perceptions of occupational therapy in transition services*. Paper presented at the 2012 American AOTA Annual Conference & Expo, Indianapolis.
- Mankey, T. (2012b). Educator's perceived role of occupational therapy in secondary transition, *Journal of Occupational Therapy, Schools, and Early Intervention*, 5, 105–113.
- Mankey, T. (2014). Exploring funding for occupational therapy in transition services, *Journal of Occupational Therapy, Schools, and Early Intervention*, 7, 3–4, 194–203.
- Mankey, T., & Acre, C. (2010, April). *Ready, set, go! An application of occupational therapy model to community transition*. Paper presented at the 2010 AOTA Annual Conference & Expo, Orlando, FL.
- Mankey, T., Canizares, L., Krehel, C., & Warner, S. (2014, April). *Building evidence in transition services: Qualitative inquiry of transition teams regarding occupational therapy services*. Paper presented at the 2014 AOTA Annual Conference & Expo, Baltimore.
- Monahan, M., & Patten, K. (2009). *Creating successful transitions to community mobility independence for adolescents: Addressing the needs of students with cognitive, social, and behavioral limitations* [CE on CD]. Bethesda, MD: AOTA Continuing Education.
- Myers, C. T., & Podvey, M. C. (2013). Best practices in transition planning for preschoolers. In G. Frolek Clark & B. Chandler (Eds.), *Best practices for occupational therapy in schools* (pp. 235–244). Bethesda, MD: AOTA Press.
- Myers, C. T., & Podvey, M. C. (2014). *Best practices in transition planning for preschoolers*. Bethesda, MD: AOTA Continuing Education.
- Olson, L., & Orentlicher, M. L. (2012). *Occupational therapy service provision in an educational context: Topic 4, Transition from school to adult life for youth with ASD* [CE on CD]. Bethesda, MD: AOTA Continuing Education.
- Orentlicher, M. L. (2007). Transition from school to adult life. In L. Jackson (Ed.), *Occupational therapy services for children and youth under IDEA* (3rd ed., pp. 143–167). Bethesda, MD: AOTA Press.
- Orentlicher, M. L. (2013). Best practices in postsecondary transition planning with students. In G. Frolek Clark & B. Chandler (Eds.), *Best practices for occupational therapy in schools* (pp. 245–260). Bethesda, MD: AOTA Press.
- Orentlicher, M. L., & Dougan, C. (2011). Person-centered planning: An innovative approach for transition planning. *OT Practice*, 16, 1–8.
- Orentlicher, M. L., & Olson, L. (2010). Transition from school to adult life for students with an autism spectrum disorder. In H. Miller Kuhanek & R. Watling (Eds.), *Autism: A comprehensive occupational therapy approach* (3rd ed., pp. 665–700). Bethesda, MD: AOTA Press.
- Orentlicher, M. L., Schefkind, S., Pierce, D., & Mankey, T. (2011, April). *Are you ready to provide secondary transition services?* Paper presented at the 2011 AOTA Annual Conference & Expo, Philadelphia.
- Persch, A. C., Cleary, D. S., Rutkowski, S., Malone, H. C., Darragh, A. R., & Case-Smith, J. D. (in press). Current practices in job matching for individuals with intellectual and developmental disabilities. *Journal of Vocational Rehabilitation*.
- Pierce, D., Summers, K., & Mankey, T. (2011). *Developing occupational therapy secondary transition services: Research in three states*. Paper presented at the 5th Annual Secondary Transition State Planning Institute, National Secondary Transition Technical Assistance Center, Charlotte, NC.
- Persch, A. C. (2014). *The Model of Systematic Job Matching* (Unpublished dissertation). Columbus: The Ohio State University.
- U.S. Department of Education. Office of Special Education Programs. (n.d.a). *National Longitudinal Transition Study-2*. Retrieved from <http://www.nlts2.org/index.html>
- U.S. Department of Education. Office of Special Education Programs. (n.d.b). *Results-driven accountability core principles*. Retrieved from <http://www2.ed.gov/about/offices/list/osers/osep/rda/rda-core-principles.pdf>
- U.S. Department of Education. (2015). *Office of Special Education Programs' results driven accountability home page*. Retrieved from <http://www2.ed.gov/about/offices/list/osers/osep/rda/index.html#account>
- Wenger, E., McDermott, R., & Snyder, W. M. (2002). *Cultivating communities of practice: A guide to managing knowledge*. Boston: Harvard Business School Press.
- Wisconsin Community of Practice on Transition Practice Group on Health. (2014). *Transition health care checklist: Preparing for life as an adult*. Retrieved from <https://www.waisman.wisc.edu/cedd/pdfs/products/health/THCL.pdf>

Appendix 2.A. Transition Resources

AOTA Resources

Available to consumers

- **Driving and Community Mobility:** <http://www.aota.org/-/media/Corporate/Files/AboutAOTA/OfficialDocs/Statements/Driving%20and%20Community%20Mobility.PDF>
Article on role of occupational therapy in driving and community mobility.
- **Driving and Community Mobility Across the Lifespan:** <http://www.aota.org/-/media/Corporate/Files/AboutOT/Professionals/WhatIsOT/CY/Fact-Sheets/Driving.pdf>
Fact sheet aimed at anticipating community mobility needs throughout life's trajectory for people with and without disabilities.
- **Facilitating Employment of Individuals With Developmental Disabilities:** <http://www.aota.org/-/media/Corporate/Files/AboutOT/Professionals/WhatIsOT/WI/Facts/Workers%20with%20DD%20fact%20sheet.pdf>
Fact sheet on occupational therapy's role in facilitating work opportunities.
- **Occupational Therapy's Role in Early Childhood Transitions:** https://tadnet.adobeconnect.com/_a984157034/p60z90nn5nl/?launcher=false&fcsContent=true&cpbMode=normal
Webinar sponsored by the IDEA Partnership.
- **Occupational Therapy's Role in Transition:** <http://www.aota.org/Practice/Children-Youth/Transitions.aspx>
Area of the AOTA website devoted to all transition resources.
- **Recovering From Stroke:** <http://www.aota.org/-/media/Corporate/Files/AboutOT/consumers/Adults/Stroke/Stroke%20Tip%20Sheet.pdf>
Tips for people recovering from stroke.
- **Returning to Work After an Injury:** <http://www.aota.org/About-Occupational-Therapy/Patients-Clients/Work/Job.aspx>
Tips on returning to work after injury.
- **Students With Disabilities in Postsecondary Education Settings:** <http://www.aota.org/-/media/Corporate/Files/AboutOT/Professionals/WhatIsOT/CY/Fact-Sheets/Postsecondary-Education.pdf>
Fact sheet articulates occupational therapy's contribution to transition pathway after high school.
- **Tips for Aging:** <http://www.aota.org/About-Occupational-Therapy/Patients-Clients/Adults.aspx>
A series of tip sheets on typical and atypical transitions.
- **Transitions for Children and Youth:** <http://www.aota.org/-/media/Corporate/Files/AboutOT/Professionals/WhatIsOT/CY/Fact-Sheets/Transitions.pdf>
Fact sheet on occupational therapy's role in transitions.
- **Work Transitions for the Newly Unemployed:** <http://www.aota.org/About-Occupational-Therapy/Patients-Clients/MentalHealth/Unemployed.aspx>
Tips on dealing with job loss.

Available to members

- **FAQ: Occupational Therapy's Role in Supporting Employment of Young Adults With Disabilities:** <http://www.aota.org/-/media/Corporate/Files/Secure/FAQ-Employment-Young-Adults.PDF>
Synopsis on the role of occupational therapy for practitioners.
- **FAQ: Occupational Therapy's Role in Transition Services and Planning:** <http://www.aota.org/-/media/Corporate/Files/Secure/Practice/Children/transitions.pdf>
Synopsis on the role of occupational therapy for practitioners.
- **OT Practice Article: Physical Rehabilitation for the Homeless:** <http://www.aota.org/-/media/Corporate/Files/Secure/Publications/OTP/2004/OTP%2013%20Jul%202004.pdf>
Silver, M. (2004, July 26). Physical rehabilitation for people who are homeless, *OT Practice*, 9, 17–21.
Role of the occupational therapy in transitioning from homelessness.

- **OT Practice Article: Transitions Throughout the Lifespan:**

Gibson, R., Nocajski, S., Schefkind, S., Myers, C., Sage, J., & Marshall, A. (2010, June 28). The role of transitions throughout the lifespan. *OT Practice*, 15, 11–14.

Article with a broad view of occupational therapy's role in transitions in multiple systems, populations, and settings.

- **OT Practice Article: Transitions With Developmental Disabilities:**

Winkle, M. Y., & Cobb, A. L. (2010, November 29). Plotting next steps: Transitions for adults with developmental disabilities. *OT Practice*, 21, 13–16.

Case studies of young adults with developmental disabilities.

- **Standards of Practice for Occupational Therapy:**

American Occupational Therapy Association. (2010). Standards of practice for occupational therapy. *American Journal of Occupational Therapy*, 64, S106–S111. <http://dx.doi.org/10.5014/ajot.2010.64S106>

AOTA official document.

- **Transitions Across Contexts:** <http://www.aota.org/-/media/Corporate/Files/Secure/Practice/Children/Transitions-Checklist.pdf>

Series of questions to support transition practices.

Available for purchase

- **CE on CD: Creating Successful Transitions to Community Mobility Independence for Adolescents:** Available at http://www1.aota.org/shop_aota/prodview.aspx?TYPE=D&PID=825&SKU=4833

Review of adolescent transitions toward independence in driving and other community mobility issues.

Under development

- **Slides on the Role of Occupational Therapy in Transitions:** <http://www.aota.org/Practice/Children-Youth/Transitions/powerpoint.aspx>

Modules geared for occupational therapy practitioners to assist in building capacity in offering transition services.

Other Resources

- **IDEA Partnership Transition Collection:** <http://www.ideapartnership.org/using-tools/learning-together/collections.html?id=1485:1485-secondary-transition-collection-tools&catid=305:secondary-transition-collection>

Transition tools to begin conversations and understanding about secondary transition.

- **I'm Determined:** <http://www.imdetermined.org>

Tools to assist the student with disabilities to assume leadership in directing his or her own life.

- **Early Childhood Technical Assistance Center:** <http://ectacenter.org/>

Toolkits and resources on early childhood transition.

- **National Secondary Transition Technical Assistance Center:** <http://www.nsttac.org/>

Toolkits and resources on secondary transition.

- **Ready by 21:** <http://readyby21.org>

Partnership of national organizations offering meetings, toolkits, and other resources to support transition outcomes.

- **Think College:** <http://www.thinkcollege.net>

College options for people with intellectual disabilities.

- **National Rehabilitation Information Center:** http://search.naric.com/research/redesign_results.cfm?search=2&type=all&phrase=no&criteria=transitions

Transition resources offered through the library of the National Institute on Disability, Independent Living, and Rehabilitation Research.

Part II.

TRANSITION ACROSS THE LIFESPAN

CHAPTER 3.

EARLY CHILDHOOD TRANSITIONS

Mara C. Podvey, PhD, OTR, and Christine Teeters Myers, PhD, OTR/L

Chapter Objectives

After reading this chapter, readers will be able to

- ❖ Describe early childhood transitions for those with and without disabilities,
- ❖ Describe laws governing early childhood transitions,
- ❖ Explain theories and tenets related to best practices in early childhood transitions,
- ❖ Describe specific considerations for early childhood transitions,
- ❖ Describe the role of occupational therapy practitioners in early childhood transitions, and
- ❖ Explain how occupational therapy practitioners can support families throughout the early childhood transition process.

Key Terms and Concepts

- ❖ Bioecological systems theory
- ❖ Building family capacity
- ❖ Child factors
- ❖ Chronosystem
- ❖ Coaching
- ❖ Community
- ❖ Community participation
- ❖ Co-occupations
- ❖ Critical interagency variables
- ❖ Developmental care
- ❖ Early intervention
- ❖ Ecology of Human Performance framework
- ❖ Environment
- ❖ Evaluation team
- ❖ Exosystem
- ❖ Family centeredness
- ❖ Family-centered practice
- ❖ Family factors
- ❖ Family rituals
- ❖ Improving Head Start for School Readiness Act of 2007
- ❖ Individuals With Disabilities Education Improvement Act of 2004
- ❖ Macrosystem
- ❖ Mesosystem
- ❖ Microsystem
- ❖ Natural environments
- ❖ No Child Left Behind Act of 2001
- ❖ Occupational engagement
- ❖ Play
- ❖ Pretransition school visit
- ❖ Tasks

From the earliest days of life, children and their families participate in transitions and the subsequent complexities associated with transition processes. The transitions of young children among child care settings and education programs during the first 5 years of life is the norm for most families. However, research suggests that the transition experience is often more challenging for families of children with disabilities than for other families (Hanson et al., 2000; Podvey, Hinojosa, & Koenig, 2010).

Occupational therapy practitioners have the potential to make a significant, positive contribution to the transition process in early childhood because their specialized knowledge of participation in occupations and co-occupations can support quality of life for children with disabilities and their families. Practitioners have a unique view of children and families, which includes a deep understanding of the personal, social, environmental, and contextual factors that foster participation.

This chapter describes common early childhood transitions, with an emphasis on transitions specific to children with disabilities and their families; explains the theoretical and practical aspects of early childhood transitions; reviews how early intervention (EI) and occupational therapy practice in early childhood relate to transition; and clarifies the many roles and intervention strategies available to occupational therapy practitioners working with children and families during these transitions.

TJ's Story

TJ is an attractive but shy 3-year-old boy who loves being around other children; reading books with his mother, Meg; and roughhousing with his dad, Tom. They live in a well-to-do suburban community on the East Coast. Meg works an office job 45 minutes from home, and Tom is currently unemployed but used to commute to a nearby city and worked in the finance industry. Early on, TJ was a happy, babbling, typically developing child. At age 16 months, Meg began to notice that he was not communicating with her or responding to her any more. Despite reassurances from the pediatrician that everything

was fine, a hearing assessment revealed a build-up of fluid in TJ's ears that caused a temporary hearing loss. After tympanostomy tubes were inserted into his ears, TJ's doctor reported that he should begin to talk again in a few weeks. When a month went by without any change, the otolaryngologist suggested an evaluation for *EI*, a federally funded grant program that helps states provide services for infants and toddlers with disabilities and their families.

The evaluation revealed a communication delay, and speech-language services were offered. Tom's recent job loss made the family's financial contribution toward EI costs (a requirement in their state) prohibitive. Meg and Tom chose to pursue private outpatient services through Meg's employer-sponsored medical insurance, where their copay would be more affordable. Almost immediately, and stepping beyond her role,¹ the speech-language pathologist pulled Meg aside to tell her that she suspected that TJ had pervasive developmental disorder. "Do you know what that is?" she asked Meg. "It's autism." After this conversation, testing with a pediatric neurologist confirmed this diagnosis.

Before the diagnosis, despite numerous interactions with various medical and EI professionals, Meg and Tom never knew that something more than a language delay was affecting their son. Meg reached out to the EI service coordinator, Elizabeth, who had previously arranged for TJ's evaluation. Elizabeth was initially reluctant to arrange new services because Meg did not accept services previously offered. Elizabeth never told Meg that the team noticed other problems with TJ, but she did say that the EI professionals were not responsible for mentioning that something more severe than a speech delay might be at hand. It took until TJ's second birthday to agree on an appropriate balance of services.

Meg found a day care located within a special education school that could provide both day care and EI services, and because it was located near her office, she was able to attend sessions regularly. Meg and Elizabeth remained at odds to the point where Meg reported feeling physically ill whenever she had to attend a meeting with Elizabeth. In addition, the EI service providers frequently disagreed with Elizabeth regarding changes in services after the initial individualized family service plan (IFSP) was developed,

¹Similar to occupational therapy practice, the speech-language pathologist may identify early warning signs but not diagnose a condition.

but they were not allowed to make any changes to his program without her approval. Meg and TJ developed strong bonds with the occupational therapist, developmental interventionist (who was also a certified teacher), and speech-language pathologist throughout their time in EI.

As TJ's third birthday drew near, the process to transition TJ to preschool was initiated with the local school district. After her negative experience with Elizabeth, Meg was afraid of dealing with the case manager from her school district. When she described the kind of services she thought TJ might need, the case manager replied, "Maybe you should move." The case manager refused to look at the reports provided by the therapists who worked with TJ in EI, saying that "those people don't know anything about what it takes to make it in school." After conducting its own evaluation, the district found that it could not offer an appropriate placement in TJ's home district but offered no ideas on appropriate placements elsewhere, so Meg was left to find one on her own.

TJ was accepted to and enrolled in a program near his former day care. Quickly, Meg found the school to be lax in ensuring that TJ's educational program and related services were implemented in a timely manner. Communication was also a problem. A daily note about therapy would come from his teacher, typically saying something like "TJ had occupational therapy today—he walked there without any trouble." Despite repeated requests, Meg did not meet TJ's occupational therapists until he had been in school for more than 6 weeks, and although they established communication methods, including regular telephone calls and emails, they were difficult to pin down much of the time.

During the first 3 years of his life, TJ's family experienced several transitions, including the transitions into and out of private services, into and out of EI, into and out of day care, and into preschool. In addition, they experienced the transition into the world of families of children with disabilities. Although TJ's transition experiences were particularly challenging, many families have similar difficulties with various aspects of the transition process. TJ's story, which is a real-life story, identifies several current issues within early childhood transitions, including

- Treatment of the family as a barrier, rather than a partner, in the transition process
- Information withheld from the family

- Family unsure of their roles and rights relative to the transition process
- Infrequent or ineffective communication with the family by the program, the service providers, or both
- Intra-agency and interagency teams not cohesive in their approach to transition.

TJ's story can also help us consider more effective ways of supporting children with disabilities and their families and helping them navigate the transition process. Throughout the chapter, we highlight interventions and strategies that occupational therapy practitioners can use to facilitate a more positive experience for families.

Questions

- When was the family's expertise regarding TJ supported by the EI and school-based professionals?
- Why do you think the family perceived that they were treated as a barrier, not a partner, in the transition process?
- In what ways did communication affect the transition experience for TJ and his family?
- How could occupational therapy practitioners address the needs of TJ and his family throughout the transition process?

Transitions for Typical Children and Children With Disabilities

In the United States, all children—typical and those with disabilities—experience multiple transitions during early childhood. Some of these transitions are elective, and others are mandatory.

Typical Transitions

The first typical transition that occurs for most children is their transition home from the hospital where they are born. Although newborns are cared for by their parents and hospital staff immediately after birth, families typically prepare for the imminent birth of their child and his or her arrival home. This experience is exciting yet daunting for families and is universally viewed as a positive transition.

Most American children regularly receive child care outside their homes or from people outside their family (U.S. Census Bureau, 2013). Whether

by necessity or choice, this situation represents another transition for children and families. Spending time in nonparental care for some time each week is common among most children (Child Trends Data Bank, 2007). Approximately 52% of eligible children ages 3–4 years attend preschool in some form (U.S. Census Bureau, 2011). They might attend “school” within day care; attend a separate, private school that does not include a day care component; or attend a public preschool.

After preschool, most American children begin kindergarten at age 5 years. Forty-three states specifically require a kindergarten program in which children begin at this age (Education Commission of the States, 2011). Although some children may begin kindergarten slightly earlier or slightly later, most children transition to school at about this age. This transition is usually another positive milestone for many children and their families because it represents the growth and maturity that comes with the student role.

Transitions for Children With Disabilities

Children with disabilities frequently experience additional challenges during typical transition and may also experience additional transitions. During early childhood, children with disabilities frequently participate in programs designed to meet the needs of typical young children and in programs and services designed to meet their specific needs. Entering a system that provides special services can require an adjustment period while children and families get used to new rules, regulations, policies, and procedures.

Leaving a structured system either for another system (e.g., transitioning from EI services to preschool special education) or to a situation without additional supports (e.g., no longer qualifying for services) may require a new way of thinking or a new schedule to follow. For example, children with disabilities and their families may require transitions to and from medically based services, such as a neonatal intensive care unit (NICU) at birth or a pediatric intensive care unit in the early years of life.

Children and families often transition from one service provider to another while receiving services through a single agency. Although payment sources, guiding program philosophies, and service delivery schedules may not change with this type of transition, a change in personnel, specific service provider

training, or treatment approach may occur. For example, if a family has a change in their overall weekly schedule, the occupational therapist working with the family may not be able to accommodate that schedule change (e.g., the therapist works part-time and is not able to come at the times the family is now available). In this situation, a new service provider will have to join the case.

EI services are frequently funded by third-party medical insurance. Some children younger than age 3 years, along with their families, may receive home-based services to improve child and family outcomes. In some states, these services are funded entirely by the state and private insurance, whereas other states (e.g., New Jersey) require families to contribute financially (on a sliding scale based on family income) for many services provided through EI. Other children may receive preschool special education services through their local education agency (LEA) to provide necessary educational services before kindergarten entry. These services are provided by the school district at no cost to the family.

Theories and Tenets

Occupational therapy practitioners and others in the early childhood field have conceptualized the process of early childhood transitions as complex and multifaceted with myriad factors contributing to the overall success of the transition. The work of developmental psychologist Urie Bronfenbrenner (1979; Bronfenbrenner & Morris, 2006) strongly influenced ideas about early childhood transition.

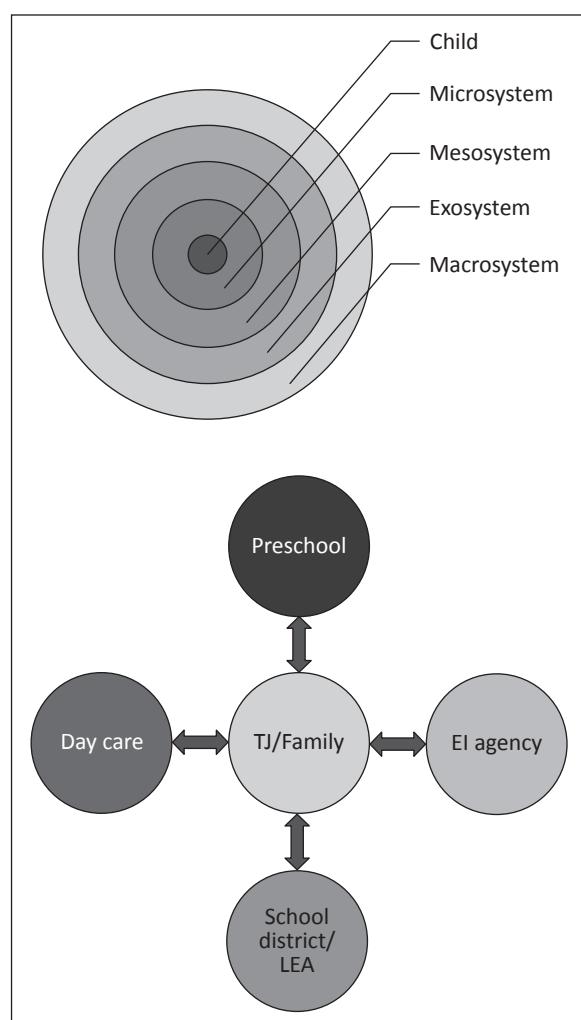
Bioecological Systems Theory

The *bioecological systems theory* views child development as influenced by the interaction of elements from within the child and from the child's environment. Bronfenbrenner identified the *environment* as comprised of several interacting layers, each having an effect on the child's development. The layers are the child's biological system; the family and community environments, such as child care settings (the *microsystem*); the connections among the various elements within the microsystem, such as the relationship between the child's teacher and his or her parents (the *); external influences on the microsystem, such as affordable child care*

centers within the child's community (the **exosystem**); societal influences, such as cultural values and laws (the **macrosystem**); and environmental events and transitions (the **chronosystem**). The child's caregivers are considered to be the closest influence on the child; therefore, interventions involving the child must also involve the family.

In the case of TJ, the microsystem is TJ's day care in a special education school, his parents, and his service providers (e.g., service coordinator, developmental interventionist, occupational therapist). The relationships among each of the Microsystems makes up a different mesosystem (Figure 3.1).

Figure 3.1. Bioecological systems theory and the Microsystems that make up the mesosystem in TJ's story.



Note. EI = early intervention; LEA = local education agency.

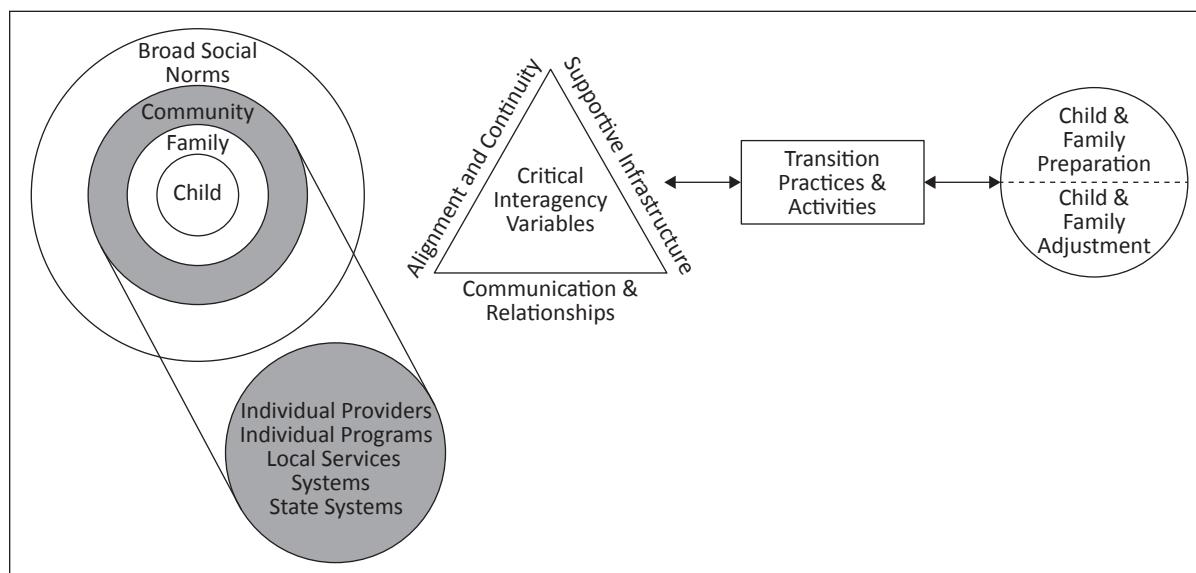
External influences such as the state-funded EI program and reimbursement for services are part of TJ's exosystem, whereas the laws guaranteeing him an appropriate public education and the societal norms and cultural values surrounding people with disabilities are part of the macrosystem. TJ's daily transitions to day care, his regular routine, and the long-term process of transitioning to a public preschool form his chronosystem.

Conceptual Framework of Transition for Young Children With Disabilities

Rous and colleagues (2007) developed the Conceptual Framework of Transition for Young Children With Disabilities based in part on the bioecological systems theory's focus on the centrality of the child who is transitioning and his or her systems of family, community, and society (Figure 3.2). In this framework, **child factors** such as type of disability, temperament, and age form the basis for transition planning. **Family factors**, such as resources and diversity, influence the child and the transition process while the child and family are situated within a **community** of providers, programs, local systems, and state systems.

Providers influence the transition process through their level of experience, training, and beliefs about transition. In addition, individual program philosophy and management may affect child and family involvement in transition. In turn, as one of many agencies forming the local services system, the program may be influenced by the prevailing local beliefs about the transition needs of children and families. In the Conceptual Framework of Transition for Young Children With Disabilities, state agencies influence the transition process through varying levels of supervision and leadership, thus shaping policies at the local level and indirectly affecting the quality of service delivery throughout the transition process.

Communication and relationships among the child, family, and community; a supportive interagency structure; and alignment and continuity of programs, curricula, and personnel expectations are identified as **critical interagency variables** in the model. Over time, these variables directly and indirectly influence transition practices and activities, the child and family preparation for and adjustment to the transition, and child outcomes after the transition.

Figure 3.2. Conceptual framework of early childhood transitions.

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Family-Centered Practice

Podvey and Hinojosa (2009) applied the bioecological systems theory to **family-centered practice** in occupational therapy during the transition from EI to preschool. Dunst (2000) described family-centered practices as those that treat families with respect and dignity, respond to families' individualized needs, provide sharing of information with families to support decision making, give families choices about programs and interventions, bring families and practitioners together for strong collaboration, and obtain resources for families so that they may raise their children in ways that support optimal child and family outcomes.

Podvey and Hinojosa (2009) stressed the importance of family-centered practice for occupational therapy practitioners working in traditional family-centered EI and child-centered preschool special education services. They described a strong link between the bioecological systems theory and occupational therapy because occupational therapy practitioners consider the interplay among the individual client, his or her valued occupations, the environment, and contextual influences, just as interactions between these elements are fundamental to the theory. Through the lens of the practitioner working within the transition process, family is considered the “core microsystem” surrounding the child, with a mesosystem consisting of the connection between

the microsystems of family and the school. Podvey and Hinojosa posited that relationships between families and school personnel may be strengthened by occupational therapy practitioners who have a direct connection to both systems.

For example, an occupational therapy practitioner who works in EI might anticipate that a child will have self-regulation difficulties in preschool. Therefore, the practitioner could

- Guide the family on how to advocate for their child's needs in preschool
- Encourage collaboration with school personnel to implement strategies that support self-regulation in the classroom
- Participate in the child and family's **pretransition school visit**, where an assessment of the environment takes place and further recommendations are made to both the family and school personnel.

Communication early in the transition process would alert the school-based occupational therapy practitioner to issues that may interfere with preschool participation and engagement in school-related academic tasks at home. This practitioner would then collaborate with both the teacher and family to further refine the use of strategies in the classroom and determine additional strategies to address the child's difficulty with self-regulation in both settings.

Ecology of Human Performance

Another direct application of an ecological model to occupational therapy in early childhood transitions is provided by Myers (2006), who used the *Ecology of Human Performance (EHP) framework* (Dunn, Brown, & McGuigan, 1994) to exemplify the role of occupational therapy practitioners in early childhood transitions. Ecological theories in the social sciences, including Bronfenbrenner's bioecological systems theory, contributed to the development of the EHP framework, which focuses primarily on the influence of context (i.e., temporal, physical, social, cultural) on performance.

The EHP framework centralizes the person and his or her context. The person is surrounded and affected by his or her context, and he or she cannot be viewed without considering the context. A plethora of possible **tasks**, defined as "objective sets of behaviors to accomplish a goal" (Dunn et al., 1994, p. 599), are conceptualized as being available to the person at any given moment, but the features inherent in the context provide the main support for engaging in those tasks. Therefore, applying the EHP framework to early childhood transitions involves understanding and supporting the child and his or her occupational performance through engagement in tasks in the context of the sending environment (e.g., EI setting) and the receiving environment (e.g., preschool).

Because intervention primarily focuses on context, Myers (2006) suggested that practitioners consider how to support families and children through EHP intervention strategies such as establishing or restoring a child's abilities to perform tasks within contexts and creating circumstances that promote task performance, or participation, in context. For example, a child with a physical disability who is starting preschool may spend his or her first day sitting quietly in the corner, interacting minimally with peers, and not participating independently in classroom activities. If the practitioner addresses this child's needs for assistive technology on the first day of school, or even before the first day, an opportunity for the child to participate in preschool occupations will be created and the first day may be spent playing and learning just like his or her typical peers. The interaction among the child, contexts, and tasks related to transitioning is crucial because the contexts may or may not support performance and the child's engagement in tasks may, in turn, change the context.

Policy Influencing Early Childhood Transitions

Although many transitions occur in early childhood, only a handful are governed by federal, state, or local laws. Most transitions are guided by personal choice (e.g., transition from home to day care) or third-party medical insurance (e.g., transition after birth from hospital to home).

The three federal laws that influence early childhood transitions include the *Individuals With Disabilities Education Improvement Act of 2004 (IDEA; Pub. L. 108–446)*, the *Improving Head Start for School Readiness Act of 2007* (Head Start Act [HSA]; Pub. L. 110–134), and the *No Child Left Behind Act of 2001 (NCLB; Pub. L. 107–110)*. IDEA and HSA have specific provisions for the transition from EI to preschool special education. HSA also provides guidance for any transition into or out of a Head Start program. NCLB does not govern transitions specifically, but it has implications for early childhood transitions relative to public school education.

Individual state laws, which flesh out the skeleton of these federal laws, may provide differing definitions and procedures resulting in differences in service delivery from state to state. Any discussion of the implementation of federal laws in a state must also encompass a thorough review of the state's current laws.

Laws that mandate formal transition points can also address informal transitions, which are transitions between microsystems. For example, IDEA includes transportation services for informal transitions, such as from home to school and from school back to home, as a related service. However, other informal transitions, such as movement between a Head Start program and a center-based therapy program, may not be covered by the law. For a detailed description of the laws, see Appendix 3.A.

Specific Considerations in Early Childhood

A discussion of early childhood transitions would not be complete without an acknowledgment of how the complexity of human development in the early years contributes to the overall success of a transition for both children and families. Leading researchers and policymakers agree that a child's

development is inextricably linked to biology, experience, and culture inherent in the daily life of the child and his or her family (Shonkoff & Phillips, 2000). Through continuous interplay of multiple contextual and biological factors, young children learn the skills they need for self-regulation, coping, and social interaction that are necessary for the development of competence in relationships, academics, and eventual participation in adult roles.

Family-Centered Practice in Natural Environments

Family-centered service delivery (i.e., practice) is truly the cornerstone of early childhood practice. As such, it is rooted firmly in Part C of IDEA and woven into the IFSP for EI.

Building family capacity

Linked to practices that promote family centeredness in early childhood programs, and also articulated as a purpose of EI services within IDEA's Part C (which covers EI services), is the idea of ***building family capacity***. Rather than the occupational therapy practitioner doing intervention *to* the child, the practitioner establishes a strong relationship with the family and works to help the family obtain confidence and competence in supporting their child's developmental needs and in preparation for transition.

Because the transition out of EI services is a necessary goal for all children and families, the use of a family-centered approach with a focus on building family capacity plays an important role in the transition process. For example, an occupational therapy practitioner working in EI could assist with building family capacity by helping a caregiver learn how to advocate for his or her child with a disability, a skill that will enhance family involvement throughout the transition process. In addition, the practitioner can anticipate the new skills that a child will need in a new environment and coach caregivers on how to teach the child skills that support school readiness before the transition, such as the child feeding him- or herself or washing his or her hands.

Natural environments

Another component of the family-centered approach is the Part C mandate that EI be provided in ***natural***

environments, that is, "settings that are natural or normal for the child's age peers who have no disabilities" (IDEA, 34 CFR § 303.18). Home and community settings where children without disabilities participate are examples of natural environments. Providing EI in natural environments gives families opportunities to participate in service delivery within familiar contexts, but implementing therapy services in natural environments is much more than simply service delivery in a home, child care, or community setting (Hanft & Pilkington, 2000).

During delivery of therapy services in the natural environment, occupational therapy practitioners will ideally coach caregivers to support a child's occupational performance within that environment rather than doing therapy with the child while the caregiver observes. ***Coaching*** is a form of collaboration between the practitioner and caregiver in which the caregiver "develops competence and confidence to implement strategies to increase the child's learning opportunities and participation in daily life" (Rush, Shelden, & Hanft, 2003, p. 34). This collaboration with families is another key aspect of building family capacity within EI.

Family centeredness

Given the multitude of contextual factors that influence transitions in early childhood, natural environment interventions are particularly useful in addressing pre- and posttransition needs of children and families. In occupational therapy literature, the role of ***family centeredness*** within natural environments has been illustrated in different ways that may be applied to early childhood transitions. DeGrace (2003) offered a view of family centeredness that focuses on the importance of family engagement and understanding how families derive meaning from their occupations, particularly those involving ***family rituals***.

Within the realm of early childhood, the transition from one environment to another for early child care or education constitutes a ritual for most families. The "first-day-of-school" ritual is often initiated as a child begins preschool or kindergarten and will continue as a family ritual through that child's years of schooling. The unique ritual of the first school day then gradually becomes the morning routine, with perhaps smaller rituals encompassing it, such as walking a child to his or her classroom and giving a good-bye kiss.

According to DeGrace (2003), occupational therapy practitioners using a family-centered approach “will provide interventions that influence how these families live and meaningfully occupy their time as a family unit” (p. 349). During daily transitions, for example, practitioners should strive not only to focus on the child’s performance of skills such as dressing, toileting, and feeding but also to address school-specific family rituals and routines that occur in natural environments. Interventions can include helping families manage a chaotic morning routine when getting children ready for school, providing strategies for children to safely board and ride the bus, and assisting parents on how to handle end-of-the-day meltdowns after their child is picked up from school. When transition-related rituals and routines that are important to families occur without incident, families may enjoy their time together more, and the stress of the transition process is potentially lessened.

In describing her model of occupational therapy developmental processes, Humphry (2002) highlighted *occupational engagement*, stating,

Some completely new occupations appear when the combined readiness of intrinsic capacities and a caregiver’s expectations for new occupations converge, thus participation in family life and sharing activities with significant others are crucial developmental mechanisms. (p. 177)

Occupational engagement of the child in the new setting, posttransition, may be developed when the child has an opportunity to practice new occupations beforehand within a familiar environment and with a caregiver. For example, in most preschool classrooms, children participate in eating a snack with their class. If a child is being fed by his or her caregiver at home but demonstrates signs of readiness to self-feed, the child’s engagement in the occupation of feeding with caregiver support could become part of the pretransition routine. Both family capacity and preparation for the transition are enhanced through this approach.

Early Childhood Occupations and Co-Occupations

Early childhood professionals emphasize initial and ongoing assessment and intervention aimed at addressing

child and family needs in the developmental domains of physical and motor, cognition, communication, adaptive and self-care, and social-emotional (Noonan, 2006). Occupational therapy practitioners consider these developmental domains in relationship to a child and family’s ability to engage in meaningful occupations and *co-occupations*, defined by Pierce (2003) as “as synchronous dance back and forth between the occupational experiences of the individuals involved, the action of one closely shaping the action of the other” (pp. 199–200).

The practitioner’s occupation-based focus within such areas as community participation, play, and activities of daily living (ADLs) supports the development of occupations, prepares a child and family for transition out of the sending environment, and may help ease the child into the new environment.

Community participation

Providing EI services in the natural environments where families and children spend their time each day promotes *community participation*. Too often, young children with disabilities are left out of community activities because of a lack of adaptations and modifications to support participation; caregivers’ or others’ beliefs that a child will perform better in a special, segregated program rather than an inclusive community program; and a lack of acceptance from the community at large (Law, Petrenchik, King, & Hurley, 2007; Nelson, Zoellick, & Dillon, 2000).

An important aspect of early childhood intervention by occupational therapy practitioners is the integration of community-based occupations into the family life, which may include assisting families to find community resources, such as quality child care, play groups, or story time at the local library. Practitioners may then work directly with the family, child, and community program to ensure that necessary supports are in place for the child’s full participation.

Young children with disabilities or who are at risk for disabilities, and who have opportunities to spend time in community settings with their typical peers in new settings, may have an easier adjustment to preschool (Eggum-Wilkens et al., 2014). Additionally, by initiating involvement in the community, caregivers learn valuable advocacy skills useful throughout the course of their child’s development and transition to adulthood.

Play

Occupational therapy practitioners and others in early childhood intervention have long agreed that **play** provides an invaluable contribution to child development, especially in the early years. According to Lane and Mistrett (2008),

The language of play is at the heart of development. Young children play with their food long before they learn the skill of eating, playing with their fingers becomes a pastime in and of itself, exploration of body parts and playing with feet and toes can keep them engaged for long minutes, and language evolves as they play with the production of sound. Play is the primary occupation in these early years. It is not balanced with the other occupations of self-care and “work” but instead forms the core for development of these other occupations. (p. 413)

Play may be an intervention or a goal of occupational therapy in early childhood. Caregivers receive coaching on how to incorporate play into the daily routine of the family (Pretti-Frontczak & Bricker, 2004) and how to make the most of unplanned opportunities for play in natural environments (Dunst, Trivette, Humphries, Raab, & Roper, 2001).

Although play is often incorporated into intervention as a therapeutic strategy or even as a reward, young children who are transitioning to preschool or kindergarten receive immeasurable benefit from engaging in play with caregivers and peers. Through play, children learn and practice physical, cognitive, communication, social-emotional, and adaptive skills necessary for the classroom environment. While engaged in play, they learn to build and negotiate relationships with others (Lane & Mistrett, 2008), transition-related skills that support social participation in school and beyond.

As the child transitions into the new setting, occupational therapy practitioners can share their knowledge of a child's play patterns and interests with receiving personnel to provide continuity from one environment to the other. For instance, in EI, the practitioner may coach the caregiver on how to use play activities to develop needed skills for preschool (American Occupational Therapy Association [AOTA], 2011a) and assist the caregiver in choosing appropriate toys to develop skills needed before the

transition to preschool (AOTA, 2011b). A toddler may engage in play with toys that facilitate the development of fine motor skills needed for ADLs he or she will eventually perform in preschool.

When a parent begins to play with the child, the play scenario becomes a co-occupation and an opportunity for the parent to encourage different types of manipulation with the toy, thus enhancing social, physical, and cognitive development. If the child plays with the toy in a community group with peers, another aspect of social development is introduced, further preparing the child for the transition to preschool, where he or she will encounter many group interactions and have opportunities to practice social skills such as sharing and turn-taking. As the child transitions to preschool, the practitioner can communicate with school personnel about the child's play preferences. Incorporating familiar toys and play routines into the new environment may lessen the child's anxiety, resulting in a more positive transition experience.

Activities of daily living

Children engage in many ADLs in the school setting (e.g., dressing, eating and feeding, functional mobility, personal hygiene, toilet hygiene, and bowel and bladder management). The degree of assistance needed to complete these activities will vary from child to child as a result of many individual factors such as age, presence and type of disability, and previous experience. Children who have assisted with the performance of their ADLs before starting school may have an easier time participating in these same activities in preschool (Chiarello et al., 2014).

In preparation for the transition, interventions that support participation and increasing independence in ADLs may be integrated into daily routines or used spontaneously as the opportunity arises in the course of caregiver-child interaction. For instance, if a family would like to work on dressing in preparation for their child to put on and take off his or her coat at school, the occupational therapist practitioner may coach the family by teaching them strategies for positioning and cueing the child during a dressing task. Once the caregivers feel comfortable using these strategies, they may incorporate them spontaneously into the child's task of putting on his or her coat before leaving the house and taking off his or her coat after coming inside.

Some ADLs may require adaptations or modifications, such as the use of a commode chair for toileting or adapted utensils for self-feeding. In this case, the sending practitioner could communicate with the receiving school personnel either in writing or verbally about the necessary adaptations and modifications before the child arrives. Working with the family, the school team could address the child's needs in the individualized education program (IEP) meeting so that the child could participate to the fullest extent starting on the first day in the new environment.

Occupational Therapy Roles in Early Childhood Transitions

Occupational therapy practitioners have many potential roles in early childhood transitions because of the diverse needs of young children and their families (AOTA, 2008; Myers, 2006, 2007, 2008). Many different agencies deliver services to children with disabilities and their families, and many options are available for families and children to consider when services from one of these agencies are terminated.

When children experience difficulties at birth, they may spend additional time in the hospital in the NICU and encounter practitioners in that environment. Once they leave the hospital, children with additional health and developmental needs up to age 3 years receive EI services through state agencies. Practitioners are often a part of the EI team.

Upon their exit from EI services, children may transition to typical early childhood settings such as day care or preschool or they may transition to a preschool program specifically designed to meet their special needs. Occupational therapy services may also be provided in these settings.

Transition From the NICU to Home

Many children enter the world requiring a greater level of care. These children receive care in specialized intensive care units designed specifically to meet the needs of newborns. The staffing-to-child ratio in these units is low because of the specific needs of the population. Many children in the NICU need life-saving medical care. The medical community acknowledges the need for ***developmental care*** within the NICU

setting (Symington, 2008), including developmentally supportive practices such as controlling environmental stimuli, positioning and swaddling, and clustering care activities for the benefit of the preterm infant. Occupational therapy professionals are beginning to provide this service in NICUs across the country.

NICU care is typically covered by medical insurance, so transition services provided by practitioners are incorporated into the medical expenses of the NICU stay. In this environment, practitioners typically address the transition to home in multiple ways (AOTA, 2006; see also Appendix A, "Specialized Knowledge and Skills for Occupational Therapy Practice in the Neonatal Intensive Care Unit").

First, practitioners work directly or indirectly with infants to promote developmental care within the NICU setting. This therapy is done in concert with the rest of the NICU team that is caring for the infant, but occupational therapy practitioners, who have a unique perspective on development, consider children's physical, cognitive, social, and environmental factors necessary for optimal growth and development, rather than focusing only on their health.

Second, practitioners adopt a family-centered perspective to collaborate with the infant's family to provide the information and training necessary to ensure a successful transition from the hospital to the family's home. This collaboration includes adapting the social and physical environments of the NICU to support bonding between the infant and the family, the overall development of the infant during the hospital stay, and fostering these bonds once the child leaves the NICU to go home. It also includes identifying and addressing the stressors that families and infants may have in leaving the hospital environment for home.

Third, practitioners can also provide families with information about adapting their home environment to meet the developmental needs of their child and about community-based services that can support them once they leave the hospital.

Finally, practitioners who work in NICUs are frequently involved with follow-up clinics to further support families and children in their development once they go home.

Transition to Early Intervention

Children with identified developmental issues or suspected delays who have left the hospital setting

can be evaluated for EI services. Children may leave the hospital with a referral to EI, or they may receive a referral from a pediatrician or other health care professional at any time before children turn age 3 years. In addition, any parents who suspect their children may have a developmental delay, or in some states be at risk for a developmental delay, may request an evaluation by an EI team. The referral process is developed by each state, but all states have lead agencies that provide EI service coordination for families until they exit the program.

Unlike NICU services, which are paid for exclusively by medical insurance, EI funding comes from multiple sources depending on the state, including personal insurance, Medicaid funds, specific grants for children with particular conditions, and out-of-pocket expenses for the families. The role of occupational therapy practitioners in the transition to EI services typically involves being a part of the ***evaluation team***, which may include a school psychologist, education specialist, social worker, general education teacher, special education teacher, physical therapist, speech-language pathologist, or other professional relevant to the needs of the child and family. As a member of the evaluation team, occupational therapy practitioners are responsible for

- Providing direct and indirect services to families and children
- Making referrals for other disciplines as necessary
- Helping families become acclimated to the EI system and services.

Because the underlying philosophy of EI is family-centered care, all contact with the family should support the family's needs, including during the transition to receiving services. During this transition, practitioners play an important role in early identification of potential developmental concerns that may contribute to a medical diagnosis (e.g., autism and related disorders) and concerns about infant and child mental health, which includes addressing the development of healthy social-emotional skills and treatment of existing mental health issues within the context of the family (Holloway & Chandler, 2010).

Recall that TJ's family was unaware that he might have an autism spectrum disorder (ASD) until it was mentioned by a private practitioner he began seeing after his EI evaluation. A practitioner working with TJ and his family during the evaluation and the first

few months of EI would have been in an ideal position to recognize, identify, and provide support for the family during this time.

Transition From Early Intervention Settings to Early Childhood Settings

Some children who begin EI services may not remain eligible for services until they turn age 3 years, or they may not be found eligible for Part B (which covers children from their third birthday until adulthood services) once they turn age 3 years. These children and their families may terminate their EI services at the appropriate time and enter various early childhood settings with their typically developing peers.

For example, a child might begin to attend a neighborhood preschool program three mornings a week once he or she is no longer receiving EI services. A family may also decide to start their child in a new day care or other early childhood setting at any time while still receiving EI services; in this case, the occupational therapy practitioner may continue to support the family before, during, and after the transition to this new setting. For example, the practitioner may visit the child at the new site or provide training to new caregivers.

When the child leaves EI services without entering a center-based program offered through their LEA or a Head Start program, which are federally funded, the child's family is responsible for the costs of the new program. The family may make arrangements to receive reimbursement from private insurance or other sources if it is possible, but there are no general legal provisions for families whose children have disabilities to receive financial support outside of these two programs. If a child enters a new early childhood program while still receiving EI services, but the program is not a part of the IFSP, the family will bear the responsibility for any costs.

Occupational therapy practitioners have multiple roles when children transition to early childhood settings. First, practitioners can help prepare the child for the demands of a new setting, such as facilitating participation in routines such as hanging up his or her coat in a cubby upon arrival or sitting on the floor while listening to a story being read, in social opportunities such as interacting with other children, or in formal school-related tasks such as negotiating the hierarchy of the school system and the special education department. Participation in

occupations with varying contexts such as toileting in the school restroom, eating lunch in the cafeteria, and walking through the halls in a line with other students may be less stressful for children who have already practiced. Readers are encouraged to think of other occupations or activities that practitioners can help with in preparation for transition.

Second, practitioners can help prepare families for the cessation of services, possibly providing information about community resources or programs that might benefit the family and child. Third, practitioners can prepare the new program for the special needs of the child by suggesting appropriate accommodations, such as extra seating support during snack time in a new day care setting so the child can access and consume food. It is helpful for practitioners to visit the new programs so that they can get a clear picture of the physical and social environment and what is expected of the child.

Finally, practitioners can educate the staff at new program about the child and any special considerations that might need to be made in that setting. For example, the practitioner can train classroom staff on transfers and positioning needs of a child with a physical disability or inform them about a particular reward system that has been successful in motivating the child.

Transition From Early Intervention Settings to Part B

The majority of children who exit EI upon turning 3 years of age transition directly into Part B services from their LEA (U.S. Department of Education, 2007). LEAs offer four main types of programs for preschool children with disabilities:

1. Early childhood special education programs (attended by more than half of children eligible for Part B services) and early childhood programs for typically developing children
2. Programs that combine early childhood special education and typical early childhood settings
3. Programs in separate schools for children with disabilities (about one-third of children in Part B services attend these three types of programs). (Because children with disabilities are eligible for free appropriate public education, the LEA covers the costs of all educationally related services, including transportation to and from the Part B program; Office of Special Education

and Rehabilitative Services, U.S. Department of Education, 2014.)

4. Part B services, for children who are attending other types of programs, such as home schooling.

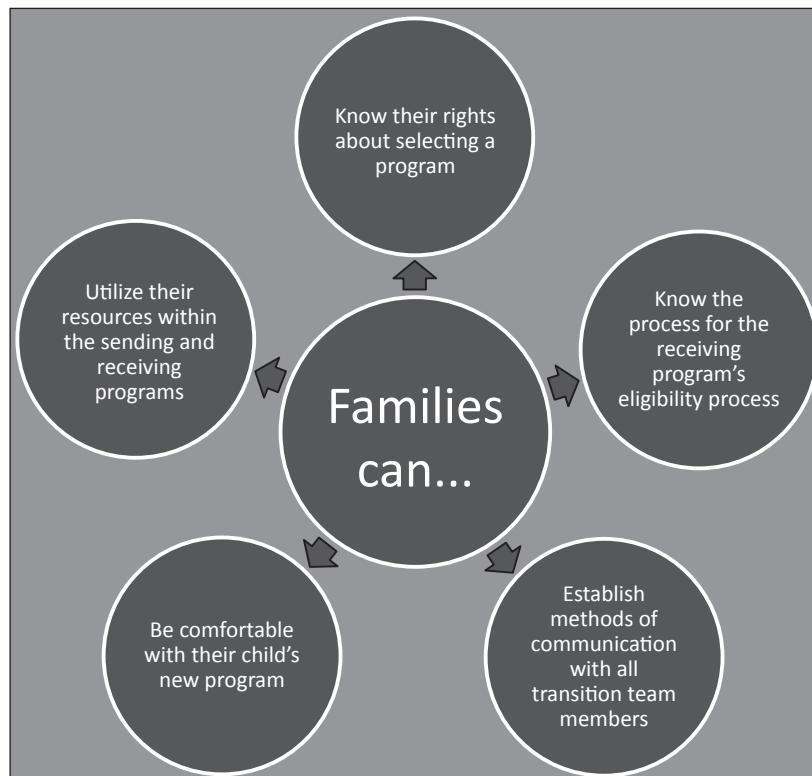
Role of early intervention practitioner

The role of EI occupational therapy practitioners when children transition to Part B settings is similar to the role when children transition to other early childhood settings. However, because the child will have a practitioner or other special education or related services in the new program, practitioners have an opportunity to work directly with the professionals in the receiving program. In TJ's case, his family had a very good relationship with the EI occupational therapists, but those therapists did not communicate with the therapists in the receiving program. Further, the occupational therapists in the receiving program did not solicit information from the sending program. The discipline-specific knowledge and insight gained by the EI therapists was lost and had to be rediscovered by the school-based therapists.

Role of school-based practitioner

School-based occupational therapy practitioners' role during the transition process is similar to that of practitioners in the EI setting when families begin those services. School-based practitioners can be a part of the evaluation team, provide direct and indirect services to children, make referrals for other disciplines as necessary, and help the child and family become acclimated to the preschool environment.

School-based practitioners should also collaborate with EI personnel whenever possible throughout the transition period. This collaboration can help practitioners learn pertinent information about the child and family to decrease the learning curve once the child begins school. In addition, school-based practitioners should collaborate with members of the team (e.g., teachers, paraprofessionals, case managers) to share information and establish a cohesive program for the child. For example, if a child has a visual impairment, the practitioner can provide specific resources and suggestions for the classroom environment, identify possible barriers to safe mobility within the school building, and train

Figure 3.3. Suggestions for families during early childhood transitions.

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others on the modification of written work to meet the child's needs.

Remember that TJ's mother felt there was little communication between individual service providers and other members of the team, including herself. This experience was frustrating and stressful for the family.

Transition to Part B Without Early Intervention

Children with delays may not always be identified in time to receive EI services. Some children's delays may not become apparent until after their third birthday. In that case, children may enter Part B services without having received any previous services. This situation can occur in the preschool years and any time from kindergarten through high school graduation. The role of occupational therapy practitioners during this transition is similar to their role when children transition from EI to preschool. Because there is no other agency with which to collaborate, and families are not likely to have had professionals guiding them

into the transition, practitioners may find that they have a greater role in educating and supporting families and children about the school environment. For suggestions for families, practitioners, and EI programs on how to support early childhood transitions, see Figures 3.3, 3.4, and 3.5.

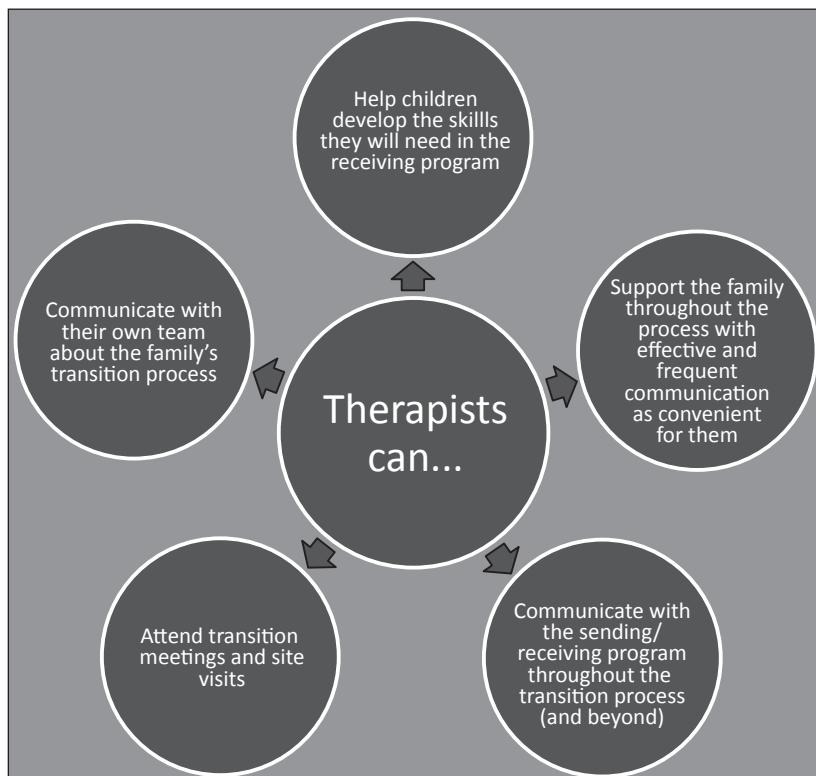
Research on Occupational Therapy's Current Role in Early Childhood Transitions

Over the past decade, researchers have examined the role of occupational therapy in early childhood transitions. Some of this research is summarized here.

Validated practices

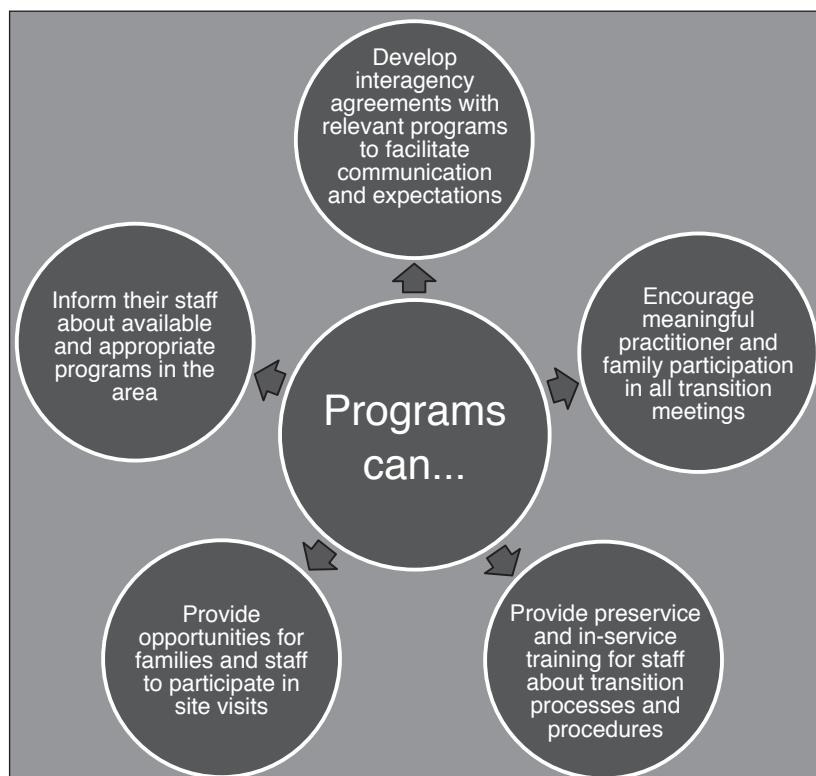
Rous (2008) conducted a study to validate recommended transition practices for professionals working in early childhood. Twenty of 21 practices were validated by more than 90% of the early childhood professionals completing the survey ($N = 419$).

Figure 3.4. Suggestions for occupational therapy practitioners during early childhood transitions.



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Figure 3.5. Suggestions for programs during early childhood transitions.



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Exhibit 3.1. 21 Recommended Validated Transition Practices

1. A primary contact person for transition is identified within each program or agency.
2. Referral processes and timelines are clearly specified.
3. Enrollment processes and timelines are clearly specified.
4. Program eligibility processes and timelines are clearly delineated.
5. Staff and family members are actively involved in the design of transition processes and systems.
6. Families meaningfully participate as partners with staff in program- and community-wide transition planning efforts.
7. Agencies develop formal mechanisms to minimize disruptions in services before, during, and after the transition of the child and family.
8. Community- and program-wide transition activities and timelines are identified.
9. Conscious and transparent connections are made between curricula and child expectations across programs and environments.
10. Transition plans are developed that include individual activities for each child and family.
11. Children have opportunities to develop and practice skills they need to be successful in the next environment.
12. Methods are in place to support staff-to-staff communication both within and across programs.
13. Staff roles and responsibilities for transition activities are clearly delineated.
14. Staff follow up on children after the transition to support their adjustment.
15. Staff know key information about a broad array of agencies and services available within the community.
16. Individual child and family transition meetings are conducted.
17. Transition team members share appropriate information about each child making a transition.
18. Families are aware of the importance of transition planning and have information they need to actively participate in transition planning with their child.
19. Families' needs related to transition are assessed and addressed.
20. Families have information about and are linked with resources and services to help them meet their specific child and family needs.
21. Families actively participate in gathering information about their child's growth and development.

Source. From "Recommended Transition Practices for Young Children and Families: Results from a National Validation Survey," by B. Rous, 2008. Lexington: University of Kentucky, Human Development Institute, National Early Childhood Transition Center. Used with permission.

Although all 21 practices (Exhibit 3.1) were validated by at least 75% of the participants, staff follow-up on children after the transition to support their adjustment was not validated by at least 90%

of participants. These practices were separated into two categories: (1) practices involving the inter-agency services system and (2) practices supporting child and family preparation and adjustment.

Occupational therapy practitioners have roles in the development and implementation of many of the validated practices. Roles that involve family members, such as making sure they participate as partners in the design of transition processes and systems, directly relate to family-centered approaches in occupational therapy. Several validated practices linked to child and family preparation and adjustment also incorporate family centeredness (i.e., transition plans are developed that include individual activities for each child and family, families are aware of the importance of transition planning) and support occupation-based practice (i.e., children have opportunities to develop and practice the skills they need to be successful in the next environment).

Extent of transition participation

A study by Myers (2008) shed light on the extent to which occupational therapy practitioners participate in early childhood transitions. The study surveyed practitioners working with children and families transitioning to preschool ($n = 144$) and kindergarten ($n = 164$). The majority of participants working in preschool settings reported full participation in the transition process from EI to preschool (66.0%) and from preschool to kindergarten (77.9%). More than half (53.8%) of participants working in EI perceived that they participated fully, and 65.7% of participants working in kindergarten classrooms reported full participation.

Participants identified strategies they used as a part of their intervention related to transitions. The most commonly identified strategy was evaluation and assessment of the child pretransition for those working in EI and posttransition for those working in preschools. Occupational therapy practitioners working in EI also identified working with families as a frequently used strategy, not surprising given the family-centered approach inherent in EI services. Other occupational therapy roles in these transitions included conferring with the sending and receiving occupational therapy practitioners about the child, attending meetings (i.e., placement, IFSP, IEP), and helping develop the IEP. Less frequently, study participants identified evaluating the preschool site for accommodations and going to the preschool site with the family before the transition.

In the same study (Myers, 2008), 41% of participants working in EI and 40% of those working in preschools perceived that they were not fully involved in transition planning. This finding suggests that although recommended practices for the involvement of early childhood professionals, including occupational therapy practitioners, in transition planning have been identified (Rous, 2008), the role of practitioners in early childhood transitions remains somewhat variable across states, districts, agencies, and schools. Participants identified the following as barriers to involvement in preschool transitions:

- Lacking funds to participate
- Not understanding their role in transition
- Lacking communication between agencies
- Not receiving invitations to meetings related to transition
- Perception that other professionals were more important to the child and family during the transition process.

Supporting factors for transitions

A study by Myers, Schneck, Effgen, McCormick, and Shasby (2011) explored the relationship between factors identified as supportive to participation in early childhood transitions and occupational therapy practitioners' perceptions of their involvement in the transition process. A survey with practitioners ($N = 263$) working with children and families transitioning from EI to preschool found that perceived supports to participation do indeed influence practitioners' involvement in transitions.

Practitioners working for employers who encouraged participation in the transition process and collaboration with professionals from either the sending or receiving program, and who paid for practitioners to attend planning meetings, perceived themselves as more involved in preschool transition planning than those whose employers did not encourage participation and collaboration or provide payment. Additionally, practitioners identified understanding their role in transition planning, having staff at their program who valued their participation in transition planning, and having experience in transition planning as factors that facilitated their involvement.

Research implications

The studies discussed here (Myers, 2008; Myers et al., 2011; Rous, 2008) provide several implications for occupational therapy practitioners who are involved in early childhood transitions. Because understanding their role in transition is a factor for increased involvement in the transition process, practitioners should seek out opportunities for formal training and mentoring to gain a strong understanding of their role in the transition to preschool and kindergarten.

Communication should be a key component of the practitioner's role, including communication with families and with staff from both sending and receiving programs, regardless of the practitioner's affiliation. Frequent formal and informal communication with personnel who are typically team leaders in the transition (e.g., service coordinators in EI, transition coordinators in preschool) will assist in overcoming the barrier of not being invited to transition-related meetings and increase the visibility of practitioners as vital and important members of transition teams. If practitioners become indispensable team members, agencies may be more likely to reimburse them for their involvement in these meetings.

Supporting Families Throughout Early Childhood Transitions

A growing body of literature in education and health care identifies ways in which various personnel, including occupational therapy practitioners, can support families throughout early childhood transitions, potentially reducing the stress and anxiety the families might feel during that process (AOTA, 2008; Myers, 2008; Myers & Podvey, 2013; Podvey et al., 2010; Podvey & Hinojosa, 2009). Strategies to use during the transition process include

- Using a family-centered approach,
- Preparing the child for the transition,
- Fostering relationships with families,
- Providing relevant and understandable information,
- Collaborating and advocating in transition teams and activities, and
- Establishing guidelines about communication.

This section discusses each of these strategies in detail.

Using a Family-Centered Approach

To ensure that a family's needs and wants are addressed in the transition-planning and implementation processes, it is best to use a family-centered approach as described previously in this chapter. Renzo's story (described in the Prologue) illustrates how professionals must understand and respect the priorities of the family when working with children with disabilities. Because the transition period is typically one of stress and anxiety for all involved (Podvey et al., 2010), keeping the families' priorities at the forefront of one's professional thinking allows the greatest opportunity to ease the tension for all family members. TJ's experience also underscores the difficulties that can arise when the family's needs are not a priority to the professionals working with them.

Preparing the Child for the Transition

When young children transition to a new environment, they are frequently expected to be able to do new things that may have not been previously expected of them. For example, a child who is entering a day care environment might now be expected to share the attention of the teacher while he or she is used to being the center of attention with his or her parents and practitioner. A child who is entering preschool might be expected to stand in line or wait quietly while seated, expectations that did not exist in the previous environment.

It is important for practitioners in both sending and receiving programs to understand the skills expected of the child in the receiving program and to make sure expectations are addressed within therapy before the transition. It is also helpful for practitioners from sending and receiving agencies to share this information with each other and with the families.

Fostering Relationships With Families

Regardless of setting, practitioners should strive to foster positive relationships with families as early as possible. This process should begin with the initial evaluation. Although subject to agency policy, it can be helpful for practitioners involved in the initial evaluation of the child to also work with that child and his or her family once services have started. Best practice also includes maintaining the same practitioners over time to maintain the therapeutic

relationship over time. Continuity of service delivery is important in developing a high level of trust, which can support families as they prepare to leave an agency and provide consistency as they begin a relationship with a new program.

Children often receive EI services in day care settings, so families and practitioners do not get to interact face to face during a session. Every effort should be made to establish and maintain connections with the families beyond the formal documentation process (e.g., communicating through weekly phone calls or emails, arranging for a monthly session that takes place with family members present). When children receive services in the school setting that do not typically include family members, efforts for communication must be even more vigilant. Similar strategies used by EI practitioners can be implemented in school settings, but it is also important to meet with family members early in the therapeutic relationship to ask and answer questions that might arise.

A meeting with the family is particularly important when a transition is imminent, because many questions arise for the family during this time. Exchanging information about the transition, new environment, or therapy might be included in the conversation, but the meeting can also serve as a source of emotional support for family members. Although families may need less support once they feel comfortable with a transition, meetings should be offered frequently in the early weeks after a transition.

Recall that the school-based occupational therapist working with TJ did not meet his family until 6 weeks after TJ began his program. His mother specifically expressed her wish to meet the therapist and to understand her son's program better. By the time she had met the therapist, Meg was incredibly stressed about the program and felt uncomfortable with the program staff.

Providing Relevant and Understandable Information

Occupational therapy practitioners are aware of resources that can be helpful to families at various stages in the therapeutic process. However, when it comes to transitions, practitioners' knowledge may be underused. In addition to providing information about child development and therapy, practitioners can help families develop a better understanding of the transition process by, for example, describing

expectations of the receiving agency, providing information about community supports, and describing the changes in therapy programs across agencies (see Appendix 3.B for resources on supporting children and families during early childhood transitions).

Although communicating clearly, directly, and in a timely manner with families about reports, goals, and outcomes is best practice, it is particularly important during the transition process. For example, a practitioner has written a report for a transition meeting but will not be present at the meeting to talk about the findings, it is crucial to discuss these findings with the family (and the personnel who will be there) before the meeting to reduce the chance for misinterpretation.

Collaborating and Advocating in Transition Teams and Activities

Although occupational therapy practitioners report that they are not always included in transition-related activities, such as attending meetings, visiting new programs, and designing agency policy for transitions, they should make every effort to include themselves in them. Lack of financial resources and time often contribute to the exclusion of practitioners in these activities. However, practitioners should encourage other transition team members to understand the importance of their contribution to the transition process and to support policies that require attendance of all service providers. For example, in a transition-planning meeting, the practitioner can make valuable contributions by describing environmental modifications that allow the child to more fully participate in a new preschool classroom and by explaining the shift in therapeutic goals to a client-centered, educationally relevant focus.

Another important way that practitioners in both sending and receiving programs can participate in the transition process is to attend general transition events offered by their programs, such as site visits or open houses. For example, an EI practitioner who works in a day care environment can attend a preschool open house with a family whose child is getting ready to turn age 3 years. Similarly, a preschool practitioner can attend that same open house to meet and greet families and children who are preparing for transition to a particular preschool classroom.

Transition activities such as these serve multiple functions. First, they help the sending and receiving practitioners more meaningfully contribute to the

planning process by being aware of both the child and the specific environment into which the child will be transitioning. Second, for practitioners in a receiving program, visits provide a wonderful opportunity to establish a rapport with families and children before their arrival in the program. Third, practitioners' contributions can appropriately influence a parent's decisions about how a receiving program might fit his or her child. Fourth, visits allow the rest of the transition team to see the practitioner as a contributing member of the team whose presence can be invaluable to the overall transition. Finally, visits increase practitioners' visibility across agencies, encouraging their inclusion as partners during transition.

Establishing Guidelines About Communication

It is important for occupational therapy practitioners to establish expectations about communication with family members as early as possible (Podvey et al., 2010). This is particularly important for practitioners in receiving programs and those who will not be face to face with family members during every (or most) therapy sessions.

Method of communication

First, establish which methods of communication are best for the family. Email has become a very convenient method of communication for many practitioners. However, not all people have equal access to email or communicate effectively through electronic means. Telephone and face-to-face discussions may be preferred by some families.

Time of day

Second, determine the time of day that is most convenient to exchange information. For some people, taking personal phone calls during work hours is impossible. They may not be able to return a phone call during the practitioner's working hours no matter how important communication might be to them.

Frequency

Third, establish reasonable expectations about the frequency of communications upfront. Not doing so can result in misunderstandings between

practitioners and the family. For example, a school-based practitioner might believe that communication with the family on a biweekly basis is reasonable and therefore writes a note in the child's communication book every 2 weeks. However, the family may have communicated with the EI practitioner at every session and therefore believes that the school practitioner is being negligent about keeping them apprised of the child's progress.

Families may not retain all that practitioners may have said during meetings because they may be processing a large amount of new information, policies, and procedures. In addition, families may initially focus on procedural issues related to the transition or the program but, as time goes on, they may have more questions specific to the content and structure of therapeutic interventions. Remember that families find great comfort in communication, so consistent and meaningful communication can result in more positive, more comfortable transitions for families.

Developing the Occupational Therapy Role in Early Childhood Transitions

How do occupational therapy practitioners expand or even initiate their role in early childhood transitions? First, they should recognize the many opportunities they have to address transition-related needs of children and families. For example, within a typical day of providing EI services, a practitioner has countless opportunities to work with families on building capacity by helping them learn skills for advocacy and increase their child's engagement in a variety of occupations that will carry over from home and community to the preschool classroom. Figure 3.3 offers suggestions for families during early childhood transitions; many of these suggestions can be facilitated by the practitioner.

Second, on both the sending and receiving ends of the transition, practitioners should strive to build strong relationships with team members, bolstered by informal and formal methods of communication. Figure 3.4 includes several suggestions for practitioners to use to form good relationships with the team.

Third, practitioners may also review transition policies and procedures currently in place within their early childhood programs and determine where their skills as practitioners may be helpful.

If positive relationships between team members are already in place, it will be easier to address these potential areas of involvement.

Finally, practitioners should consider attending training on transition practices if it is offered by an LEA or EI program. Although many of these trainings are not specific to occupational therapy, they still provide an overview of general transition policies and procedures. Figure 3.5 summarizes ways in which practitioners can encourage their programs to use best practices in early childhood transitions.

Example of Occupational Therapy in an Interdisciplinary Transition Program

The Transition to Preschool Program (ToPS) at Eastern Kentucky University (EKU) is an example of occupational therapy's role in supporting preschool transitions and how higher education is working with community agencies to support these transitions. ToPS is a summer program designed for children ages 2 and 3 years who are transitioning to preschool or another environment, such as center-based child care, in the fall. EKU's Departments of Occupational Therapy, Psychology, and Special Education; the local EI program; Head Start; and the county preschool program collaborate on the program, which is staffed by EKU faculty and students.

Children with and without disabilities are recruited from a variety of sources such as EI service coordinators and other service providers, the county public health department, library story time, and county preschool screenings. Children and families attend the 2-hour program once per week for 5 weeks. While the children participate in preschool transition activities, their families participate in a parent group oriented toward support and transition-related training.

Childhood and classroom occupations addressed during the program include the ritual of saying goodbye (transitioning from caregiver to classroom); free play with a variety of objects and materials; play in centers and on the playground; participation in circle time, snack time, and structured sensorimotor activities; and transition between activities and back to the caregiver at the end. Relationships with peers and following classroom rules are also addressed.

Communication with caregivers about what the child did that day takes place at the end of each day, either verbally or in writing, or both. The unique contribution of occupational therapy includes classroom modifications and adapted equipment to address children's physical and sensory needs; contextual adaptations of occupations to promote performance; and collaboration with caregivers, faculty, and students from other disciplines to determine individualized outcomes for each child.

The EHP framework (Dunn et al., 1994) guides practitioners and students who participate in the program. In the EHP, the child is viewed as a complex individual who makes sense of the world in his or her unique way. The EHP is founded on the bioecological systems theory principle that performance of tasks should take place in the natural context. The majority of the children in ToPS have never been inside a classroom before. Most have little to no experience playing with their peers in a large-group setting. From that starting point, the practitioners and students spend the first day assessing the child's response to the novel contexts of preschool (e.g., large classroom with tables and chairs, wide variety of play options, social interactions with peers, culture of following rules and directions).

Modifications and adaptations are made to the classroom environment and tasks when necessary to support children's participation. For instance, a child who is overwhelmed by auditory and visual stimuli has the option to complete a craft activity in a quiet area just off the main classroom.

As the program continues, practitioners and students work with early childhood special educators and students to embed interventions into the program curriculum, further reinforcing the use of occupational therapy in the natural context. Opportunities for participating in tasks within the child's range of performance are created, such as craft activities and gross motor games, allowing new skills to be established and emerging skills to be refined. Through a continued focus on the contexts and occupations of preschool, the children in ToPS become increasingly better prepared for their eventual transition.

Mikala's Story

Five-year-old Mikala had been participating in Head Start preschool services for almost 2 years. Mikala had a diagnosis of cerebral palsy (CP) spastic hemiplegia

that affected her left side. Her mother, Diana, was a single parent who worked full-time. She appreciated the help she received from Head Start, including parenting support and extended-day child care.

Mikala also received occupational therapy and physical therapy from the local school district while at Head Start. However, Mikala would be leaving Head Start at the end of the school year and starting kindergarten at her neighborhood elementary school, which worried Diana. Diana was concerned about how the teacher would react to having a child with CP in her classroom. She was also unsure of who Mikala's new therapists would be and how much therapy she would receive. Most important, Diana would still be working full-time after the transition, and Mikala would need to attend the after-school program until early evening. Diana was anxious about leaving Mikala in the care of strangers for such a long time.

The transition coordinator at the local school district, Rita, became involved in Mikala's transition early in the process. In conjunction with the IEP meeting, Rita coordinated a meeting with Mikala's Head Start teacher, her current therapists, the resource teacher at the elementary school, and Diana. Mikala's therapists provided information to the team members from the elementary school to help them begin addressing Mikala's needs in the new environment. For instance, Mikala needed adapted seating and equipment to assist with writing, feeding, and eating. Additionally, many of Diana's questions were answered, and her concerns about the teacher's reaction to Mikala were diminished.

Diana and Mikala also had the opportunity to visit the new school in the spring. Her occupational therapist from Head Start, Jennifer, attended this visit as well. During this visit, Mikala's new occupational therapist, Sarah, was there to meet Diana, Mikala, and Jennifer. Sarah had already reviewed the paperwork sent over from Head Start, so she knew about Mikala's potential occupational therapy needs. She also was able to listen to Diana's concerns about Mikala's therapy and worked with Jennifer to begin identifying adaptations and modifications to support Mikala's participation in the classroom.

On the first day of kindergarten, Diana walked Mikala to her new classroom and kissed her good-bye, tears welling in her eyes. Diana felt good about Mikala's teacher and her classroom because all accommodations were in place, including Mikala's adapted seating and

devices. Mikala, always an outgoing child, walked over to a group of girls playing in the corner, and they instantly pulled her into their game.

However, Diana was still anxious about the after-school program. Just as she was leaving, Diana saw Sarah in the hallway. Hearing Diana's concerns, Sarah told her she would check in on Mikala at the after-school program that day and then email Diana to let her know how she was doing. Diana felt immediate relief as she got into her car to drive to work.

At 3:30 that afternoon, Diana received an email saying that Mikala was doing well. Sarah had made sure that Mikala had her adapted seating in place for snack time and arts-and-crafts activities, even providing instruction on positioning Mikala to the after-school staff. Because proper supports were in place in anticipation of Mikala's arrival at school, Diana's fears were gone and she felt confident that Mikala would do well in her new school.

Questions

- What aspects of Mikala's story demonstrate collaboration and communication between families and professionals and among the professionals from the different programs? How did this collaboration and communication support Mikala and Diana during the transition?
- How did Jennifer provide transition-specific interventions pretransition? How did Sarah provide transition-specific interventions posttransition?
- How did both occupational therapy practitioners address Mikala's needs in the physical and social contexts?
- How does this story contrast with the experiences of TJ and his family?

Summary

Although not every family goes through every transition, all transition experiences have certain similarities, including a fear of the unknown. Family-centered care and theoretical models supporting its use have been described and can be helpful in successfully implementing various early childhood transitions. Occupational therapy practitioners have potential roles within these transitions, separate from their roles in EI, preschool, Head Start, or other programs.

Questions

- The ease with which families transition may be mitigated by good communication. How do you communicate with families? How frequently and what type of information do you share? Do you share this information with the rest of the team?
- Identify one professional, program, or agency serving the same children and families as you. How collaborative is your relationship with each of them? How might you begin to strengthen your relationship with each of them for the benefit of the children and families you serve?
- What transitions do the children and families you serve commonly encounter? Describe your level of participation in the transition process. Can you participate more? What strategies can you identify that would help you become more involved immediately? What more can you do within your organization to improve your general overall involvement in the transition process?
- What strategies do you use to help families and children with disabilities during the transition process? What kinds of activities would you like to do that you are not currently doing or able to do? How can you implement more strategies into your agency or organization to assist families during the transition process?

References

- American Occupational Therapy Association. (2006). Specialized knowledge and skills for occupational therapy practice in the neonatal intensive care unit. *American Journal of Occupational Therapy*, 60, 659–668. <http://dx.doi.org/10.5014/ajot.60.6.659>
- American Occupational Therapy Association. (2008). *Transitions for children and youth: How occupational therapy can help*. Retrieved from www.aota.org/-/media/Corporate/Files/AboutOT/Professionals/WhatBOT/cy/fact-sheets/transitions.pdf
- American Occupational Therapy Association. (2011a). *Building play skills for healthy children and families*. Retrieved from <http://www.aota.org/-/media/Corporate/Files/Practice/Children/Browse/Play/Building%20Play%20Skills%20Tip%20Sheet%20Final.pdf>
- American Occupational Therapy Association. (2011b). *How to pick a toy: Checklist for toy shopping*. Retrieved from <http://www.aota.org/-/media/Corporate/Files/AboutOT/consumers>Youth/Play/Toys%20tip%20sheet.pdf>
- Bronfenbrenner, U. (1979). *Ecology of human development*. Cambridge, MA: Harvard University Press.
- Bronfenbrenner, U., & Morris, P. A. (2006). The bioecological model of human development. In W. Damon & R. M. Lerner (Eds.). *Handbook of child psychology* (6th ed., pp. 793–828). Hoboken, NJ: John Wiley & Sons.
- Chiarello, L. A., Palisano, R. J., McCoy, S. W., Bartlett, D. J., Wood, A., Chang, H.,...Avery, L. (2014). Child engagement in daily life: A measure of participation for young children with cerebral palsy. *Disability and Rehabilitation*, 36, 1804–1816.
- Child Trends Data Bank. (2007). *Child care*. Retrieved from <http://childtrendsdb.org/archivepgs/21.htm>
- DeGrace, B. W. (2003). Occupation-based and family-centered care: A challenge for current practice. *American Journal of Occupational Therapy*, 57, 347–350. <http://dx.doi.org/10.5014/ajot.57.3.347>
- Dunn, W., Brown, C., & McGuigan, A. (1994). The ecology of human performance: A framework for considering the effect of context. *American Journal of Occupational Therapy*, 48, 595–607. <http://dx.doi.org/10.5014/ajot.48.7.595>
- Dunst, C. (2000). Revisiting “rethinking early intervention.” *Topics in Early Childhood Special Education*, 20, 95–104.
- Dunst, C. J., Trivette, C. M., Humphries, T., Raab, M., & Roper, N. (2001). Contrasting approaches to natural learning environment interventions. *Infants and Young Children*, 14, 48–63.
- Education Commission of the States. (2011). *State kindergarten statutes: State comparisons*. Retrieved from <http://mb2.ecs.org/reports/Report.aspx?id=14>
- Eggum-Wilkens, N. D., Fabes, R. A., Castle, S., Zhang, L., Hanish, L. D., & Martin, C. L. (2014). Playing with others: Head Start children’s peer play and relations with kindergarten school competence. *Early Childhood Research Quarterly*, 29, 345–356.
- Hanft, B. E., & Pilkington, K. O. (2000). Therapy in natural environments: The means of end goal for early intervention. *Infants and Young Children*, 12(4), 1–13.
- Hanson, M. J., Beckman, P. J., Horn, E., Marquart, J., Sandall, S. R., Greig, D., & Brennan, E. (2000). Entering preschool: Family and professional experiences in this transition process. *Journal of Early Intervention*, 23, 279–293.
- Holloway, E., & Chandler, B. E. (2010). Family-centered practice: It’s all about relationships. In B. E. Chandler (Ed.), *Early childhood: Occupational therapy services for children birth to five* (pp. 77–107). Bethesda, MD: AOTA Press.
- Humphry, R. (2002). Young children’s occupations: Explaining the dynamics of developmental processes. *American*

- Journal of Occupational Therapy*, 56, 171–179. <http://dx.doi.org/10.5014/ajot.56.2.171>
- Individuals With Disabilities Education Improvement Act of 2004, Pub. L. 108–446, 20 U.S.C. §§ 1400–1482.
- Improving Head Start for School Readiness Act of 2007, Pub. L. No. 110–134, 42 U.S.C. § 9801 *et seq.* (2007).
- Lane, S. J., & Mistrett, S. (2008). Facilitating play in early intervention. In L. D. Parham & L. S. Fazio (Eds.), *Play in occupational therapy for children* (2nd ed.). St. Louis: Mosby.
- Law, M., Petrenchik, T., King, G., & Hurley, P. (2007). Perceived environmental barriers to recreational, community, and school participation for children and youth with physical disabilities. *Archives of Physical Medicine and Rehabilitation*, 88, 1636–1642.
- Myers, C. T. (2006). Exploring occupational therapy and transitions for young children with special needs. *Physical and Occupational Therapy in Pediatrics*, 26, 73–88.
- Myers, C. T. (2007). The role of independent therapy providers in the transition to preschool. *Journal of Early Intervention*, 29, 173–185.
- Myers, C. T. (2008). Descriptive study of occupational therapists' participation in early childhood transitions. *American Journal of Occupational Therapy*, 62, 212–220. <http://dx.doi.org/10.5014/ajot.62.2.212>
- Myers, C. T., & Podvey, M. C. (2013). Best practices in transition planning for preschoolers. In G. F. Clark & B. E. Chandler (Eds.), *Best practices for occupational therapy in schools* (pp. 235–243). Bethesda, MD: AOTA Press.
- Myers, C. T., Schneck, C. M., Effgen, S. K., McCormick, K. M., & Shasby, S. B. (2011). Factors associated with therapists' involvement in children's transition to preschool. *American Journal of Occupational Therapy*, 65, 1–9. <http://dx.doi.org/10.5014/ajot.2011.09060>
- Nelson, D., Zoellick, L. R., & Dillon, A. (2000). Catching the wind, changing the rules: Enhancing community options for families of young children. In J. Nisbet & D. Hagner (Eds.), *Part of the community: Strategies for including everyone* (pp. 43–83). Baltimore: Paul H. Brookes.
- No Child Left Behind Act of 2001, Pub. L. 107–110, 20 U.S.C. § 6319 *et seq.* (2008).
- Noonan, M. J. (2006). Naturalistic curriculum model. In M. J. Noonan & L. McCormick (Eds.), *Young children with disabilities in natural environments* (pp. 75–98). Baltimore: Paul H. Brookes.
- Office of Special Education and Rehabilitative Services, U.S. Department of Education. (2014). *36th annual report to Congress on the implementation of the Individuals With Disabilities Education Act, 2014*. Retrieved from <http://www2.ed.gov/about/reports/annual/osep/2014/parts-b-c/36th-idea-arc.pdf>
- Pierce, D. E. (2003). *Occupation by design: Building therapeutic power*. Philadelphia: F. A. Davis.
- Podvey, M. C., & Hinojosa, J. (2009). Transition from early intervention to preschool special education services: Family-centered practice that promotes positive outcomes. *Journal of Occupational Therapy, Schools and Early Intervention*, 2, 73–83.
- Podvey, M. C., Hinojosa, J., & Koenig, K. (2010). The transition experience to preschool for six families with children with disabilities. *Occupational Therapy International*, 17, 177–187.
- Pretti-Frontczak, K., & Bricker, D. (2004). *An activity-based approach to early intervention* (3rd ed.). Baltimore: Paul H. Brookes.
- Rous, B. (2008). *Recommended transition practices for young children and families: Results from a national validation survey*. Lexington: University of Kentucky, Human Development Institute, National Early Childhood Transition Center. Retrieved from http://www.hdi.uky.edu/nectc/Libraries/NECTC_Papers_and_Reports/Technical_Report_3.sflb.ashx
- Rous, B., Hallam, R., Harbin, G., McCormick, K., & Jung, L. A. (2007). The transition process for young children with disabilities: A conceptual framework. *Infants and Young Children*, 20(2), 135–148.
- Rush, D., Shelden, M. L., & Hanft, B. E. (2003). Coaching families and colleagues: A process for collaboration in natural settings. *Infants and Young Children*, 16, 33–47.
- Shonkoff, J., & Phillips, D. (Eds.) (2000). *National Research Council and Institute of Medicine: From neurons to neighborhoods: The science of early childhood development*. Washington, DC: National Academy Press.
- Symington, A. J. (2008). Developmental care for promoting development and preventing morbidity in preterm infants. *Cochrane Database of Systematic Reviews*, 4, CD001814. <http://dx.doi.org/10.1002/14651858.CD001814.pub2>
- U.S. Census Bureau. (2011). *Current population survey data on school enrollment*. Retrieved from <http://www.census.gov/hhes/school/data/cps/2011/tables.html>
- U.S. Census Bureau. (2013). *Who's minding the kids? Child care arrangements: Spring 2011*. Retrieved from <https://www.census.gov/prod/2013pubs/p70-135.pdf>
- U.S. Department of Education. (2007). *27th annual report to Congress on the implementation of the Individuals With Disabilities Education Act*. Washington, DC: Author.

Appendix 3.A. Laws Influencing Early Childhood Transitions

Individuals With Disabilities Education Improvement Act

Educational services for children identified with a disability provided by early intervention providers or administered by LEAs or school districts are regulated by IDEA (2004, Pub. L. 108–446). This federal law requires that the services cover all children from birth to age 21 years, but some states extend that coverage longer. For example, California covers children under IDEA until they are age 22 years, and Michigan covers children under IDEA until they are age 26 years.

Two main parts of this law, Part C and Part B, apply to early childhood transitions, specifically, the transition from early intervention to preschool special education. Part C of IDEA covers early intervention services. Nationally, these services are provided for children from birth until the day before the child's third birthday, although a few states, such as Maryland, may opt to extend coverage for families through age 5 years. Part B of IDEA covers children from their third birthday until they receive a regular high school diploma or until they age out of the system, whichever comes first.

This discussion will be limited to Part B services to preschool, which serves children from their third birthday until they enter kindergarten. (Transitions related to older children are discussed in Chapter 5, "Transition From School to Adult Life," and Chapter 6, "Transition and Work.") Occupational therapy practitioners are considered to be primary service providers in early intervention. They are also qualified to be service coordinators.

Under Part C, children with disabilities and their families are provided with educational services to help the child function within the family unit. The services provided, and the outcomes to be achieved through these services, are outlined in an IFSP. The IFSP is written by members of the treatment team, which includes the family. When a child turns age 30 months, a section of the IFSP must include a transition plan, although this plan could be placed in the IFSP when the child is as young as age 24 months. This plan directly addresses the steps that must be taken, the time in which the steps must be taken, and services that must be provided to support the child and family as they exit Part C

services before the child's third birthday. The transition plan can be developed at an IFSP meeting or at a transition planning conference (TPC).

More than two-thirds of children who exit Part C services are eligible for Part B services (U.S. Department of Education, 2007), and under those circumstances, a representative from the LEA, who provides Part B services, may also take part in the transition planning process. Other children that transition out of Part C when they turn age 3 years may no longer be eligible for or may no longer need educational services under IDEA. These children may receive referrals to other programs (e.g., Head Start, private service providers), attend non-LEA-sponsored preschool programs or day care, or remain at home with their families. When a child turns 3 years of age and his or her eligibility for Part B services has not yet been determined, the eligibility process continues, but the Part C services are terminated in accordance with state law.

The lead agency that administers IDEA services may be different in each state (National Early Childhood Technical Assistance Center [NECTAC], 2012). For example, in Florida, Part C services are administered by the Department of Health, whereas Alabama's lead agency is the Department of Rehabilitation Services. Some states, such as Iowa and Maine, use their Department of Education or Special Education to administer Part C services.

Part B services are typically administered by a state's Department of Education. The transition from early intervention to preschool special education frequently includes a change in which state agency administers IDEA services. This change can lead to communication barriers that affect the transition process because the policies and procedures at one agency may not match those of the other agency. Despite interagency agreements, which may be established to facilitate communication, the experience of many families during the transition relative to interagency communication is not always optimal (Podvey, Hinojosa, & Koenig, 2010).

Service coordination for all children eligible for Part C services is the responsibility of the lead agency, which is designated by each state. The lead agency is responsible for notifying a child's LEA no fewer than 90 days before the child's third birthday when it is believed that the child may potentially be eligible for Part B services. When children are found to be eligible for early intervention 45 and

90 days before their third birthday, notification must be made as soon as possible after determining the child's eligibility.¹

Notification to the LEA is an important step in the timely determination of the child's eligibility for Part B services, and the subsequent development of the IEP if the child qualifies, before the child's third birthday. The notification process is mandated as a part of Child Find, which is a federally mandated service provided by LEAs to identify and provide essential services to children with disabilities. On the child's third birthday (or later if the state chooses to extend Part C services), the lead agency no longer provides services and the IFSP is terminated, and the LEA now assumes responsibility for services and the IEP is implemented. If a child turns 3 years of age over the summer when school is not in session, the team determines when Part B services will begin.

The transition from Part C to Part B services also represents a paradigm shift from family-centered services in early intervention to educationally based services in preschool. For example, occupational therapy practitioners are no longer primary service providers under Part B. Rather, education becomes the primary service, and practitioners provide related services. Children may only receive occupational therapy services through IDEA if they are necessary for the child to benefit from the special education program. As a result, children with disabilities and their families must accommodate to a new orientation to service delivery. This change may result in a change in the child's goals and objectives because the focus of the child's function is now on academic participation rather than function within the family microsystem. Instead of following a family-training model, which addresses how a child functions within the family, services are now provided to help the child function within the school environment.

Although many areas are addressed in both early intervention and preschool special education environments, such as motor and communication skills, the ways in which services are delivered may change. For example, in early intervention, parents may be trained by an occupational therapy practitioner in their home to facilitate their child's engage-

ment in play with age-appropriate toys. In Part B, the parents would not be present for most sessions, which would occur at the preschool program, unless they were specifically invited to attend. Instead, the practitioner might work with the child and a classroom paraprofessional within the classroom to appropriately select and engage with toys during independent play time. Family involvement in their child's education typically decreases with this transition, frequently leaving out family members who were previously an integral part of the process (Podvey, Hinojosa, & Koenig, 2013).

IDEA stipulates that children who receive services through Part C should have a smooth and effective transition to Part B; beyond the process outlined previously, this responsibility lies with individual states. Interagency agreements may outline procedures at state and local levels to facilitate these transitions. Part B services provide for a free appropriate public education at public expense for eligible children with disabilities. These services are individualized to meet the needs of each child and are documented in the form of the IEP. This legal document outlines the services and outcomes necessary to help the child achieve educational goals. No part of the IEP specifically addresses the transition of a child into the LEA program. Rather, the IEP outlines the services that will be provided as of the time the child begins the program.

According to the law, occupational therapy practitioners are considered team members and therefore may participate in the transition process, but they do not have a specific, mandated role in the transition from Part C to Part B. Practitioners who work in early intervention can, and do, participate in the development of the IFSP and are eligible to attend transition-related meetings such as the TPC. However, their attendance is not required. Similarly, practitioners in preschool special education may participate in the initial evaluation process and the development of the IEP and can attend TPCs; however, their participation is not required. Families can request the attendance of the practitioner at any meeting, but other considerations, such as scheduling conflicts (including part-time employment), may be a

¹It is considered a special circumstance when children are referred to Part C services less than 135 days from their third birthday. Guidelines have been developed to address the transition to Part B for children and families under these circumstances (Diefendorf & Lucas, 2010).

barrier to participation (Myers, Schneck, Effgen, McCormick, & Shasby, 2011).

Improving Head Start for School Readiness Act

In the 1960s, President Lyndon B. Johnson began a legislative War on Poverty in America with the primary objective of eliminating poverty in the cities. The Economic Opportunity Act of 1964 (Pub. L. 88–452) funded many programs, including Head Start, to achieve this objective (Zigler & Muenchow, 1992).

The Head Start program was originally conceived as a way of fighting poverty while benefiting some of the youngest victims and their families. Head Start addresses risks associated with poverty, both directly and indirectly, through child-centered programs and parent education. The philosophies on which Head Start was founded were influenced in large part by the ecological theory promoted by one of its earliest contributors, Uri Bronfenbrenner.

Since its inception, Head Start has grown to include not only children ages 3 and 4 years but also children in a variety of other categories who are also considered economically disadvantaged, including children under the age of 3 years (in a program known as Early Head Start), children with disabilities, children of migrant and seasonal workers, children of American Indian and Alaskan native descent, and homeless children. Today, the Head Start program provides educational, health, and social services to families in poverty with the goal of preparing children for kindergarten.

The Improving Head Start for School Readiness Act of 2007 (HSA; Pub. L. 110–134), requires grantee and designee agencies to establish and maintain policies to support families during smooth transitions into and out of the various Head Start programs. This support includes assisting with the physical transition, such as the coordination with schools or other sending and receiving agencies to transfer relevant records for children entering and exiting their program. The law also provides for open lines of communication between programs to share expectations for the child's learning and development, outreach to parents and staff of receiving programs to discuss educational and other (e.g., psychosocial) needs of children, and continuity of parents' involvement in their child's education

program. This provision of the HSA can help families by providing support for the emotional part of the transition, which extends beyond the technical transfer of information.

Staff of all Head Start programs must participate in outreach activities that allow for communication with their counterparts in other programs to facilitate continuity for children between these programs. In addition, the staff of these programs is required to initiate meetings with parents of children served by their program, along with educators in the sending and receiving programs, to discuss the progress and abilities of children served by their programs. Finally, Head Start programs are required to initiate joint transition-related training for all staff.

In line with the requirements of Part C of IDEA, the HSA requires transition planning to begin at least 6 months before children age out of Early Head Start to ensure appropriate placements and services are secured once the children turn 3 years of age. However if an appropriate placement is not secured by that time, provisions allow for children to remain in their current program until they can transition to another program.

As a part of the transition process, HSA also gives grantee and designee agencies the responsibility of preparing parents to become advocates for their children. This preparation is necessary whether children exit to a Head Start or district preschool program or transition to a child care setting. As their children leave a Head Start program, parents are educated about their children's progress during their enrollment. To prepare for entering a new program, parents are also provided with education and training regarding exercising their rights and understanding their responsibilities in the school setting. In addition, Head Start staff must facilitate communication between parents and school personnel so that parents can participate in decisions relating to their child's education.

Similar to IDEA, HSA does not mandate any specific roles for occupational therapy practitioners beyond the general staff responsibilities already described. However, the HSA specifically states that children with disabilities must comprise at least 10% of children served by the program; therefore, practitioners may have the opportunity to provide IDEA services in Head Start environments for those children identified as requiring such services in their IEP.

No Child Left Behind

In the United States, public education has been governed by the legislation known as the Elementary and Secondary Education Act of 1965 (ESEA; Pub. L. 89–313). This law covers the educational needs of all American children and therefore influences all children within elementary and secondary schools, including children with disabilities. In 2001, ESEA was reauthorized by Congress as the NCLB (Pub. L. 107–110). It does not directly address early childhood transitions, but it added new provisions for the educational system beyond what had been seen in previous ESEA legislation. First, it increased the accountability of state and local governments, and individual schools, for students' academic performance. Second, it allowed for school choice, particularly for children attending low-performing schools. Third, it provided for more flexible spending of federal education money by state and local education agencies. Finally, it added a stronger emphasis on literacy for all children, particularly for children below fourth grade.

NCLB addresses children with disabilities in several ways. It includes most children with disabilities in the assessment of student progress, which focuses attention on the academic achievement of children with disabilities (Cole, 2006). It also encourages providing students with disabilities with access to a general education curriculum. In addition, NCLB sets the standard for highly qualified personnel in all classrooms.

Finally, NCLB sets the standard of using scientifically proven methods in the classroom. Title I preschool programs (in low-income areas) are addressed by NCLB in terms of their funding and efforts toward high-quality preschool programming. Although not specifically mentioned in the law, it is conceivable that NCLB may allow families to have greater choice in finding a high-quality preschool placement when their child's LEA is a Title I school.

There are no mandated roles for occupational therapy practitioners stated within NCLB. Practitioners may provide services and supports for students with disabilities in general education classrooms and may help provide recommendations for testing accommodations (e.g., for standardized testing) for students who need them.

At the time of publication, NCLB reauthorization was pending vote in Congress. Readers are encouraged to follow the status of reauthorization and its implications for practice.

State Laws

Although federal laws provide the outline for service delivery for children, individual state laws may differ in terms of definitions and procedures. For example, the cost of Part C services to families differs across states (Mackey Andrews & Taylor, 2007). In some states, such as New Jersey, families are expected to pay a portion of many Part C services. Other states, such as New York, may use funds from other sources, such as Medicaid or private insurance, to pay for these services.

Another way in which states have the ability to tailor the federal law is in defining the standards by which they identify young children in need of Part B special education and related services (NECTAC, 2011). For example, New Hampshire broadly defines a child as having a developmental delay if he or she has a delay in one of the five developmental areas (i.e., physical, cognitive, communication, adaptive, social-emotional) and needs special education and related services. Young children in Michigan must meet a stricter standard; they must demonstrate a 50% delay in one or more areas to be considered eligible. Therefore, in addition to being well-versed in federal law, it is critical for practitioners to be aware of the laws in the state in which they practice.

References

- Cole, C. (2006). *Education Policy Brief—Closing the achievement gap series: Part III. What is the impact of NCLB on the inclusion of students with disabilities?* Bloomington, IN: Center for Evaluation and Education Policy. Retrieved from http://www.ceep.indiana.edu/projects/PDF/PB_V4N11_Fall_2006_NCLB_dis.pdf
- Diefendorf, M., & Lucas, A. (2010). *Federal IDEA Part C and Part B transition requirements for late referrals to part C (>135 days of child's 3rd birthday)*. Chapel Hill, NC: National Early Childhood Technical Assistance Center and Regional Resource Center Program. Retrieved from http://www.nectac.org/~pdfs/topics/transition/timeline_late_referral_final9-7-2010.pdf
- Economic Opportunity Act of 1964, Pub. L. 88–452, 78 Stat. 2642.
- Elementary and Secondary Education Act of 1965, Pub. L. 89–313, 20 U.S.C. §§ 2701–3386.
- Individuals With Disabilities Education Improvement Act of 2004, Pub. L. 108–446, 20 U.S.C. §§ 1400–1482.
- Improving Head Start for School Readiness Act of 2007, Pub. L. 110–134, 42 USC § 9801 *et seq.* (2007).

- Mackey Andrews, S. D., & Taylor, A. (2007). To fee or not to fee: That is the question! *NECTAC Notes*, 22, 1–16. Retrieved from <http://www.nectac.org/~pdfs/pubs/nnotes22.pdf>
- Myers, C. T., Schneck, C. M., Effgen, S. K., McCormick, K. M., & Shasby, S. B. (2011). Factors associated with therapists' involvement in children's transition to preschool. *American Journal of Occupational Therapy*, 65, 1–9. <http://dx.doi.org/10.5014/ajot.2011.09060>
- National Early Childhood Technical Assistance Center. (2011). *NECTAC notes no. 27: Eligibility policies and practices for young children under Part B of IDEA*. Retrieved from <http://www.nectac.org/~pdfs/pubs/nnotes27.pdf>
- National Early Childhood Technical Assistance Center. (2012). *NECTAC list of Part C lead agencies as of September 2011*. Retrieved from <http://www.nectac.org/partc/ptclead.asp>
- No Child Left Behind Act of 2001, Pub. L. 107–110, 20 U.S.C. § 6319 *et seq.*
- Podvey, M. C., Hinojosa, J., & Koenig, K. (2010). The transition experience to pre-school for six families with children with disabilities. *Occupational Therapy International*, 17, 177–187.
- Podvey, M. C., Hinojosa, J., & Koenig, K. (2013). Reconsidering insider status for families during the transition from early intervention to preschool special education. *Journal of Special Education*, 46, 211–222. <http://dx.doi.org/10.1177/0022466911407074>
- U.S. Department of Education. (2007). *27th annual report to Congress on the implementation of the Individuals With Disabilities Education Act*. Washington, DC: Author.
- Zigler, E., & Muenchow, S. (1992). *Head Start: The inside story of America's most successful educational experiment*. New York: Basic Books.

Appendix 3.B. **Resources for Supporting Children and Families During Early Childhood Transitions**

- **American Occupational Therapy Association:** <http://www.aota.org>
Provides up-to-date resources for child and youth practice areas
- **AOTA Fact Sheet on Transitions for Children and Youth:** <http://www.aota.org/-/media/Corporate/Files/AboutOT/Professionals/WhatIsOT/CY/Fact-Sheets/Transitions.pdf>
Fact sheet that can be provided to teachers, other school personnel, and parents for more information about early childhood transitions
- **AOTA FAQ on Transitions:** <http://www.aota.org/-/media/corporate/files/secure/practice/children/transitions.pdf>
Provides information on occupational therapy's role in transition services and planning
- **AOTA Tip Sheet:** <http://www.aota.org/-/media/Corporate/Files/AboutOT/consumers/Youth/Autism/Living-With-an-ASD-Tip-Sheet.pdf>
Tip sheet on supporting a smooth transition to preschool for families living with an ASD
- **CONNECT:** <http://community.fpg.unc.edu/connect-modules/learners/module-2>
The Center to Mobilize Early Childhood Knowledge's Module 2: Transition outlines practices

to help support children and families as they transition among programs in the early care and education system

- **Early Childhood Technical Assistance Center:** <http://ectacenter.org/topics/transition/transition.asp> and <http://ectacenter.org/topics/transstoK/transstoK.asp>
Center to improve state early intervention and early childhood special education services systems, increase the implementation of effective practices, and enhance the outcomes of these programs for young children and their families
- **IDEA Partnership:** <http://www.ideapartnership.org/>
Federally funded project bringing together members of national and state associations for collaborative work in early childhood and school practice
- **National Early Childhood Transition Center:** <http://www.hdi.uky.edu/nectc/NECTC/home.aspx>
Federally funded center with the mission to examine factors that promote successful transitions between infant/toddler programs, preschool programs, and public school programs for young children with disabilities and their families
- **Shared Work:** <http://www.sharedwork.org>
National community on practice issues, including early childhood and school transitions

CHAPTER 4.

TRANSITION WITHIN SCHOOL

Donna J. Case, PhD, OT/L

Chapter Objectives

At the completion of this chapter, readers will be able to

- ❖ Describe typical transitions students face as they progress throughout K–12 schooling,
- ❖ Identify additional challenges that may affect students with disabilities' successful transition throughout their school career,
- ❖ Explain occupational therapy's role in all students' school transitions, and
- ❖ Recommend resources to facilitate school transitions.

Key Terms and Concepts

- | | |
|---|---|
| <ul style="list-style-type: none">❖ Adjustment❖ Adult life services❖ Common Core State Standards❖ Elementary schools❖ Encounter❖ Executive functioning❖ High school❖ Individualized education program❖ Individuals With Disabilities Education Improvement Act of 2004❖ Kindergarten | <ul style="list-style-type: none">❖ Middle school❖ No Child Left Behind Act of 2001❖ Preparation❖ Preschool services❖ School culture❖ Section 504 of the Rehabilitation Act of 1973❖ Self-determination❖ Social expectations❖ Stabilization❖ Transitions |
|---|---|

As children progress through public schools, they experience many changes and transitions that can hold great promise, with possibilities for personal growth, additional learning, and greater independence and responsibility (Neild, 2009). Such transitions can also be times of great stress and frustration. **Transitions** are times when students and their families need to add new skills or adaptations to existing skills to master new environments and expectations (Gibson et al., 2010). Transitions from one educational level to another can be difficult for any student, but if unsuccessful, they can be detrimental to the life-long success of students with disabilities.

Successful transition from one grade level to another within an educational environment requires forethought and deliberate planning to support students' motivation, ability, love of learning, participation in leisure occupations, and social participation. As typically developing students progress throughout their educational careers, they are expected to demonstrate greater skill mastery and independence. Students with disabilities face even greater demands caused by their cognitive or physical disabilities such as remembering rules and maneuvering through crowded areas, thereby requiring careful planning and preparation (Brandes, Ormsbee, & Haring, 2007).

Because of their expertise in activity and participation, occupational therapy practitioners play an important role in supporting students and their families in successful transitions. They offer valuable service leading to development of life skills, further education, employment, and community integration. They are essential contributors and key partners within the school team.

This chapter describes the theoretical and practical aspects of typical school transitions that students face throughout their school careers, the challenges associated within each transition, the additional demands placed on students with disabilities, and occupational therapy's role in addressing these areas. Appendix 4.A provides additional resources to support successful transitions in schools.

James's Story

James's greatest difficulty in fourth grade was wide fluctuations in his affect. He moved quickly from calmly reporting, "I don't like it when people get

mad and loud" to loud explosive behavior such as screaming at or hitting others. This explosive behavior often occurred at home or away from school. James's teacher reported his behaviors as disruptive, but "typical . . . maybe a bit more extreme." Academically, he had difficulty staying on task to complete homework assignments. Socially, he often got into trouble, as indicated by numerous trips to the principal's office.

His concerned parents took him to a psychiatrist, and he was diagnosed with attention deficit hyperactivity disorder (ADHD) at 9 years of age. James was placed on Ritalin and continued to see his psychiatrist on a monthly basis for therapy. At the beginning of fifth grade, behaviors such as extreme fluctuations in affect, from calm one moment to aggression the next, were noted. He was further diagnosed with bipolar disorder.

In school, James was reluctant to read either silently or aloud, having difficulty focusing on the words, and continued to have problems completing assignments. The teacher also identified "clowning" behavior such as talking out of turn, making jokes, and mimicking the teacher's actions. At home, his parents provided substantial support such as sitting next to him each evening to complete homework. James's parents also insisted that he read out loud at home to them for 20 minutes each night. He continued to make adequate academic progress with his parents' support. James reported having friends at school, but all friendships outside of school were with friends of his siblings.

In middle school, James's school performance declined in several ways. He often could not remember what classwork assignments to complete at home, and when he did complete them, he had difficulty remembering to turn in his homework assignments the next day. His explosive behaviors such as verbal outbursts; hitting out at others; or moving in a very fast, jerky manner continued. Although James received passing grades on exams, he began receiving poor grades because of failure to turn in homework assignments and was in danger of failing his courses for the semester.

James's parents, in cooperation with the school, required James to write his assignments in a notebook at the end of every class period. They continued to assist James with his homework on a nightly basis. His parents also requested that the teachers ask James for his homework every day to cue James

to turn in assignments. James's teachers refused to honor this request because they felt it was inappropriate given his age and grade level, saying that they did not do that for anyone else. James's parents requested he be given accommodations under Section 504 of the Rehabilitation Act, but the school district refused.

His parents then requested a special education evaluation so James could receive accommodations for his disabilities and an ***individualized education program (IEP)***. James's special education evaluation identified him as a student with emotional and learning impairments, thus qualifying him for an IEP. His IEP included a statement of his current functioning level, barriers that prevent him from progressing in his education, supports and accommodations to remove those barriers, and annual goals that provide a roadmap for him to progress in his educational program.

At James's parents' request, an occupational therapist joined the IEP team to assess his areas of occupational performance in academic achievement and social participation. The goal of occupational intervention was to increase his level of independence and function throughout the school day. Specifically, the focus was on increasing his organizational skills, assisting him in completing assignments, and helping him manage his emotions and behaviors in more socially acceptable ways.

Several strategies were recommended to support James's ability to independently complete homework assignments. The team suggested that James check in with the resource room teacher at the end of each day to make sure he had his assignments written in his homework notebook and to help him finish incomplete school assignments. When James refused to use a personal digital assistant device to remind him to turn in assignments, the occupational therapist recommended a watch with an auditory timer, which activated when it was time for James to turn in an assignment. James preferred to use a watch because it was similar to watches worn by other students. Using the watch, he began to have greater success turning in homework assignments.

He was able to maintain his relationships with his peers because his accommodations did not differentiate him from his fellow students and allowed him to be successful. The number of explosive episodes at home decreased as James began to complete school assignments in school and turn in assignments on

time. The IEP team also recommended that James continue to receive assistance for his mental health needs through his private psychiatrist. Although the occupational therapist recommended that James receive ongoing consultative services, his district IEP team declined occupational therapy services, stating the need was not part of his educational program.

When James transitioned to high school, he had trouble navigating to his classes, which were housed in separate buildings on a large campus. He was often late to class. He had different teams of teachers in each building and had trouble adjusting to their varying styles and cultural backgrounds. Because students were in different buildings for classes, he had difficulty developing new friendships or maintaining existing ones. In addition, his siblings were graduating from high school and their friends were moving away to their postsecondary schooling.

The occupational therapist emphasized James's need for organization and structure to be able to attend and stay focused, especially within such a large campus. James transferred the watch alarm function to a cell phone, which allowed him to fit in even more with the other students and receive additional information aside from auditory prompts. James's classroom schedule was adjusted to minimize his movement between campus buildings.

Because James reported feeling most comfortable and successful when playing sports, he was encouraged to participate in recreational football and soccer leagues. These activities offered social participation and helped stabilize his mood. James did not receive transition services beyond those offered by the guidance counselor. He remained reluctant to think about making plans for after high school graduation. As a result, he struggled to prepare for his postsecondary life. He took few college preparation courses but decided at the end of his senior year that he would pursue college through a local community college.

Questions

- What are areas of transition that James experienced throughout his school years?
- What are James's strengths and challenges that affect his movement toward future education, community integration, and life skills independence?
- How much support did James's family provide, and did it help or hinder his transitions?

- How could more continuous or earlier occupational therapy service support James's academics and social participation and prepare him for future transitions?
- What additional strategies might have helped James prepare for his transition from middle school to a large high school campus?
- What technology could James use that will assist him in being able to keep track of assignments and other appointments throughout his day?
- Think about the students you serve in your school. If you do not work in a school, think about your own K–12 school experience. What transitions have you or your students experienced? What might have made these transitions easier?

Educational Laws That Relate to School Transitions

Although school transitions are expected for all students, federal educational laws mandate careful and coordinated services to support students with disabilities as they embark on these transitions. These laws mandate transition services for students moving from early intervention to preschool and kindergarten and from secondary to postsecondary environments. They do not address transitions from one grade level to another.

Individuals With Disabilities Education Improvement Act

The *Individuals With Disabilities Education Improvement Act of 2004 (IDEA; Pub. L. 108–446)* ensures that all children in the United States are entitled to a free, appropriate public education. Services for students with disabilities help prepare them for future education, independent living, and employment (National Dissemination Center for Children With Disabilities, 2009). IDEA's intent is that schools, educators, students, and their families work in partnership to provide the best possible education for eligible students regardless of whether they have a diagnosed disability (Kinney, 2006). Some at-risk students who have not been identified with a disability are entitled to receive early intervening services, such as response to intervention within general education if they are experiencing academic

challenges, rather than having to wait for a referral through special education.

Although IDEA requires formal transition planning for toddlers transitioning from early intervention to preschool (see Chapter 3, "Early Childhood Transitions") and for adolescents transitioning to adult life (see Chapter 5, "Transition From School to Adult Life"), it does not address the need for transitioning students from one educational level to another. However, even without legal mandates, a great need exists for transition planning beginning when children enter the school system and continues throughout their K–12 school experiences.

No Child Left Behind

No Child Left Behind Act of 2001 (NCLB; Pub. L. 107–110) was signed into law in January 2002 and substantially changed the Elementary and Secondary Education Act of 1965 (ESEA; Pub. L. 89–313). It expanded the federal role in education and has become the driving force for education reform and policy. It covers all states, school districts, and schools that receive Title I federal grants. Schools that receive Title I funds provide remedial education programs for poor or disadvantaged children. NCLB is designed to hold states more accountable for the educational growth of all students, including those with disabilities, and to improve students' academic achievement. It specifically focuses on reading literacy and math and requires states to establish high expectations for learning and achievement for all students.

NCLB requires annual testing of students in third through eighth grades in math, reading, and science. Students are tested to determine their level of proficiency or grade-level performance and adequate yearly progress toward achieving state standards. Scores are disaggregated by poverty, race, ethnicity, disability, and limited English proficiency to ensure that all groups are making progress (Education Week, 2004; Jackson, 2007).

On July 8, 2015 the U.S. House of Representative passed a reauthorization of the ESEA, the Student Success Act. The bill represents a dramatic departure from NCLB. In addition to eliminating the current accountability system, the measure would allow states to set their own academic standards. The U.S. Senate is currently debating its own version of the ESEA reauthorization, the Every Child Achieves Act. Should the Senate pass

its bill, the two chambers, along with the White House, would need to reconcile the two bills. Practitioners are encouraged to follow the progress of these reauthorizations, as the new law will affect occupational therapy practice in schools and school transitions.

Common Core State Standards

Forty-five states, the District of Columbia, four territories, and the Department of Defense Education Activity voluntarily adopted the **Common Core State Standards (CCSS)**, which are learning standards in English language arts and mathematics. The CCSS were developed by state leaders to provide a framework for preparing children for college and the workforce in a manner that ensures consistency and quality across states (Common Core State Standards Initiative [CCSSI], n.d.a). They clearly identify what is expected from students at each grade level, from kindergarten to twelfth grade and apply to all students, including those with disabilities who access the general curriculum with supports and accommodations (CCSSI, n.d.b).

Although the NCLB and the CCSS do not implicitly address transitions, they affect students' schedules by focusing more on academics and less on other life skills, including those related to transition. Occupational therapy practitioners work collaboratively to facilitate access to the CCSS and general education curriculum for all students through the use of universal design for learning techniques and the design of individualized student supports and accommodations such as differentiated instruction and assistive technology (Handley-More, Hollenbeck, Orentlicher, & Wall, 2013). When students are able to achieve academic success, they are better prepared for the transition from one grade level to the next.

Section 504 of the Rehabilitation Act

Section 504 of the Rehabilitation Act of 1973 (Pub. L. 93–112) is a civil rights statute that prohibits any program receiving federal funding from excluding people from the program on the basis of a disability. It requires that students with special health care needs and other disabilities receive appropriate education services, which can include accommodations and supports to allow them to meet their individual educational needs in the same way as those of students without disabilities are met

(McKinley & Stormont, 2008). This regulation requires schools to provide needed accommodations and services for students who have a physical or mental impairment that substantially limits one or more major life activity, which includes education.

Students who receive services under Section 504 do not have an IEP or an individual family service plan (IFSP). As noted in James's story, James's parents originally requested that he receive accommodations under Section 504, which the school district denied. Students who receive services under Section 504 are also at risk for difficulty transitioning and should be evaluated for the necessary supports to facilitate successful transitions.

Occupational Therapy Roles in School Transitions

Occupational therapy has important roles in students' school transitions. Occupational therapy practitioners support students through four stages, as described by Schartzman, Atler, Borg, and Schwarzman (2006):

1. Preparation
2. Encounter
3. Adjustment
4. Stabilization.

Preparation is something done to get ready for the transition before it occurs and is crucial to students' success as they move from one stage of schooling to another. **Encounter** occurs when students move from one stage of schooling to another. **Adjustment** is how students deal with the transition, including modifications they may need. **Stabilization** is when students adjust to the new school environment. After evaluating children's and their environment's readiness for the transition, occupational therapists make recommendations for student training, adaptations, and environmental and task modifications to promote adjustment and stabilization.

Assessment

School occupational therapists routinely assess students; the many environments within the educational program; and how well the demands of specific educational tasks, including moving from one class to another, completing homework, taking tests, and dealing with others, are supported within the

environment as part of students' daily routines. Occupational therapists are uniquely qualified to assess how well students are progressing within a specific transition, such as identifying a student's strengths and weaknesses in relation to the demands of the transition and determining which resources and expectations the environment provides. For example, if a student is required to store books in a locker in the new environment, the occupational therapist should evaluate the student's ability to manipulate the lock, reach for books in the locker, organize books and materials, and manage time.

Occupational therapy practitioners know that the context of environment is critical when evaluating a person's ability to function at a specified level (Mancini & Coster, 2004). They understand how crucial it is to bridge the gap between students' and their families' strengths and weaknesses and the demands that each new environment will place on them. Because practitioners use a holistic approach, they can help prepare students for the transition and proactively and systematically address issues that may affect students' successful transition to a new level of schooling.

Promoting Participation Through Occupation

Occupational therapy practitioners help strengthen students' ability to participate and do what is most meaningful to them by analyzing and then modifying both activities and environments (American Occupational Therapy Association [AOTA], 2014). These skills make practitioners crucial members of transition-planning teams for students with disabilities. Although practitioners may not lead the transition-planning group, their contributions to the group can ensure a more thorough and successful transitions for students with disabilities.

Occupational therapy practitioners can bring together students and their families as well as school personnel to help prepare for all students' successful transitions throughout their school career. They may be the only educational personnel who move with students as they progress through the levels of K–12 public education. Therefore, they have extended opportunities to develop rapport and relationships with students and their parents and to prepare proactively for various transitions over the years. As students and their parents experience the tumult that change brings, it can be comforting to

have an educational professional with whom they are familiar and can ask questions of freely.

Providing and Adapting Technology

Occupational therapy practitioners assist in providing and adapting technology to facilitate students' access to their curriculum and environment. Accessibility, usability, and flexibility are considered when practitioners are part of the transition process (see Chapter 10, "Supportive Environments for Transition"). After introducing or adapting technology, practitioners can address issues of executive function such as organization and task initiation by breaking down technology use and tasks into manageable chunks, facilitating academic success for students with disabilities.

Addressing Social–Emotional Health

Occupational therapy practitioners are skilled in addressing mental health, social participation, behavior, and social skills, which sometimes are most important for keeping students with disabilities in school and engaged. Practitioners might help students with disabilities develop social and acceptable behaviors and prepare educators and peers to manage and understand specific behaviors demonstrated by the students. For example, understanding why a student with a disability might engage in stereotypic behaviors such as rocking or hand flapping can lead to greater social acceptance (Nevill & White, 2011). When appropriate, practitioners can help students develop self-advocacy skills to inform others about their disability and associated needs.

Facilitating Self-Determination

Occupational therapy practitioners can facilitate students' self-determination skills by preparing them for the issues that may arise as they grow and move through various life stages. **Self-determination** is defined as a person acting with autonomous action, self-regulated behavior, self-initiation, and self-realizing action (Wehmeyer, 1998; also see Chapter 1 in this text, "Foundations of Transition"). It can be accomplished through the development of specific independent living skills (e.g., through role playing) and the use of scaffolding techniques to allow students with disabilities to

function at the highest level possible. In addition, practitioners can inform students and their families about helpful community resources, including community mental health agency services, adult health care support, and equipment and assistive technology sources (AOTA, 2008).

Whole-School Initiatives

Occupational therapy practitioners can have a wide impact on students who are transitioning within the K–12 environment by addressing transitions of all students, including those who are typically developing. They can help create a positive school climate for all students by developing classroom and schoolwide routines that have clear expectations, beginnings, and endings. In addition, students should be made aware of consequences for not following the routines. If a school develops routines that are consistent between classrooms and areas within the school, all children will be better able to transition throughout their school career.

These routines may include using common words or phrases to signal transitions between subjects and areas. Routines for each area—such as hallways; the cafeteria; the playground; and spaces used for music, foreign language, and physical education instruction—should be clearly stated and visible within the environment. Practitioners can assist school personnel in developing clear and consistent verbal and visual cues to use when students transition between activities and areas in the school. Visual cues allow students to know when activities are beginning and ending and prepare them for the next activity.

In addition to routines, practitioners can contribute to anti-bullying initiatives and recess promotion programs by developing peer-to-peer support programs and including students in schoolwide diversity programs to address both physical and mental health. These prevention and promotion strategies can help all students develop habits associated with healthy lifestyles and character building needed for successful transition to community integration and employment.

Sam's Story

Sam, age 5 years, has been diagnosed with severe physical limitations and cognitive impairments. He has a trachea tube and uses an external oxygen source

on a continuous basis. Sam also has a feeding tube and is currently working toward taking one spoonful of pureed food while at preschool each day. He has received occupational therapy services since age 3 years in an early childhood preschool program. Sam's mother has requested that Sam be mainstreamed in his regular elementary school for kindergarten.

Sam's team, which includes his occupational therapist, parents, classroom teacher, speech-language pathologist, reading consultant, and physical therapist, met with the kindergarten teacher and support staff at his local elementary school to begin to discuss his transition from preschool to kindergarten. A plan was made for Sam to transition to kindergarten by first splitting his time between his preschool and the new kindergarten, gradually increasing the amount of time he spent in kindergarten until he was full-time.

To prepare Sam for this transition, during his final year of preschool, his educational program emphasized preparing him for his district kindergarten entrance requirements. His occupational therapist focused on developing prewriting skills, including holding a writing utensil and tracing lines and shapes; scissor skills; and increasing his ability to bring food to his mouth, chew, and swallow.

Sam's occupational therapist also observed his proposed kindergarten classroom environment to determine supports and barriers to Sam's success. Sam and his parents toured the classroom and other school spaces and Sam made visits to the new classroom with a member of his preschool staff. These activities allowed Sam to become familiar with his new environment and gave his preschool staff the background they needed to determine what supports Sam required, including how to integrate Sam's wheelchair, other adaptive equipment, and technologies into the kindergarten classroom. Staff at Sam's new school were trained in medical procedures, such as techniques for feeding using his feeding tube, and methods for written and spoken communication, all of which were necessary to facilitate Sam's successful transition.

Once Sam actively began transitioning from preschool to kindergarten in the fall, a member of his preschool staff accompanied him to the kindergarten classroom several times. The team met monthly to address problems and issues that arose from these scheduled visits. As the fall semester progressed, Sam's team planned for him to attend kindergarten for 50% of the school week and to transition from using preschool staff support in the classroom to relying solely on the kindergarten team. Sam's

transition team continued to meet monthly until he transitioned full-time to kindergarten.

Questions

- How does the kindergarten environment differ from the preschool environment both physically and socially?
- What were the elements of occupational therapy intervention that contributed to Sam's successful transition to kindergarten?

Transition From Preschool to Kindergarten

Students with disabilities receive *preschool services* in a variety of locations and settings, such as an area preschool with itinerant support provided by special education personnel, an integrated preschool where children with and without disabilities are taught together, or a preschool program with children grouped by disabilities. Occupational therapy practitioners provide consultation and collaborative support to the child's family and preschool teacher and direct occupational therapy intervention. Areas of emphasis include play, social participation, self-care, and education (Pape & Ryba, 2004). Students may attend preschool half-days or fewer than 5 days per week. As students move from preschool to *kindergarten* at about 5 years of age, they begin their journey through the K–12 educational program, facing changes in the physical and social environments and in task demands and routines.

Physical Environment

When children transition to kindergarten, they usually encounter a physical environment that is much larger than what they have experienced thus far. In addition, kindergarten classrooms, learning stations, hallways, and cafeterias are often highly decorated with brightly colored pictures, artwork, and samples of class work. Both features may overstimulate children with cognitive, emotional, and sensory processing impairments, causing them to shut down. They also may increase children's distractibility, decreasing their ability to learn. Other students in the classroom may also be a distraction. Moreover, teachers may set up desks and work areas within the classroom that provide barriers to children with disabilities from fully participating in their educational programs.

Social Environment

The social environment of kindergarten usually varies greatly from that of preschool. Kindergarten class size is generally larger than that of preschools, often with 20 to 26 students who may have varying backgrounds. As children enter kindergarten, they leave behind familiar teachers and staff for those unknown to them. Kindergarten may be a more formal environment than preschool or home, with less unstructured time and more time spent in teacher-directed activities. Projects are more frequently done in groups and less individually, which require children to learn to work collaboratively. Classroom and schoolwide rules are enforced (Michigan Department of Education, n.d.).

Children without disabilities begin to demonstrate independent skills, such as tying their shoes, pulling their clothing up and down for toileting, and using a pencil to write, that may not be possible for children with disabilities without intervention and support from the transition team. In addition, children in kindergarten need to be able to communicate with peers and adults as their expressive language skills grow exponentially.

Daily Routines and Required Tasks

The daily routines and required tasks in kindergarten become more rigorous. Many kindergarten programs are now 5 full days per week, a big change for children used to being home for at least part of the day. Kindergarteners move with their class from their homeroom to specials areas, including music, art, physical education, the library, the cafeteria, and recess. Students with mobility issues may experience difficulty moving from one environment to another. Those who are highly distractible may find it very difficult to move from one environment and adjust to a new one several times a day.

Currently, kindergarten focuses more on academics than in the years before the mid-1990s (Gershon, 2015). There is a greater demand for learning math and reading skills. More time is spent writing numbers and letters than is spent in learning social skills, problem solving, and exploring gross and fine motor skills (Michigan Department of Education, n.d.).

Preschool staff may be more apt to recognize that students need assistance and prompt them to ask for help because asking for help is a developing skill for most preschool children. Because kindergarten class sizes are larger, teachers may not have time

to notice whether a child is waiting to be asked whether he or she needs something.

Kindergartners are expected to come to school and be able to take care of themselves (Calvin, 2010), independently putting on and taking off their shoes, coats, hats, and mittens. Although some preschool children may not be independent in toileting, it is expected that children in kindergarten are more able to care for their toileting needs. Having specialized physical areas to change a diaper or help a children on and off the toilet may be difficult in the kindergarten environment. Children who require such assistance in kindergarten risk drawing attention to themselves, which may further isolate them from their peers. Preserving children's privacy and dignity sets the stage for their K–12 career and is essential.

Occupational Therapy's Role in Transitioning From Preschool to Kindergarten

Occupational therapy practitioners can facilitate the transition from preschool to kindergarten by determining students' strengths and barriers to success in all kindergarten environments and contexts, including the playground, hallways, the classroom, lunchroom, the school bus, and so forth. The process should bring together preschool and kindergarten staff and parents or caregivers. Practitioners involved in the transition from preschool to kindergarten should consider the following questions:

- What barriers to participation may need to be discussed and prepared for before the student moves from preschool to kindergarten?
- How will transition preparation affect the student with a disability in moving from preschool to kindergarten?

The very layout of the school may be a physical barrier to the student with disabilities. For example, the gym, music room, cafeteria, and recess area may be far from the classroom and be difficult for students to maneuver when many others are moving in them. In addition, students with cognitive impairments may need support from others to locate these areas. Therefore, practitioners must ensure transition planning includes allowing students to move throughout the school and find the best pathways to particular locations before beginning kindergarten.

Practitioners can obtain a baseline time for different routes, and encourage students to improve on that time as they become more familiar with the new environment. Once school begins, practitioners can implement techniques such as allowing students to leave class earlier than others or providing peers to assist students when moving from one school area to another.

Best practices in early school transition include promoting communication and collaboration across disciplines, involving the families, and preparing children and their families (Myers, 2013). For example, having the kindergarten teacher visit the student in preschool will help the teacher become more comfortable with the student and help the student begin to develop a relationship with his or her new teacher. It can also be helpful for the student to visit the kindergarten classroom accompanied by familiar preschool staff, such as the preschool teacher, occupational therapy practitioner, or paraeducator, before beginning kindergarten. The classroom teams and support staff should clearly state the expectations for kindergarten, and the practitioner should explain the modifications or adaptations that have been used in preschool and provide new methods that address the stated expectations. For more specific transition strategies for occupational therapy practitioners, see Exhibit 4.1.

Exhibit 4.1. Strategies During the Transition From Preschool to Kindergarten and From Kindergarten to First Grade

- Promote strengths-based approaches, and identify students' preferences and abilities so staff are prepared to facilitate student participation.
 - Provide low- and high-technology equipment for students with disabilities, and provide staff education as needed to support access, progress, and participation.
 - Provide environmental and task analysis and modifications to increase participation.
 - Assign buddies to promote peer interaction or assign first-grade mentors to work with kindergartners (buddies can ease anxiety when students transition to a new environment and model appropriate behavior).
 - Offer additional supports such as sensory or social stories to help students assume independence during classroom routines.
-

Transition From Kindergarten to First Grade

As students move from kindergarten to first grade, additional changes occur. Even though the students usually remain within the same school building, they will experience a change to a more structured, rule-based environment with greater expectations and demands (Sink, Edward, & Weir, 2007). Students may feel a loss of control in the first-grade classroom (Gregory, 2000). This feeling may lead to students acting out or shutting down in the classroom. First grade is critical for students' social and academic development and can be the time some at-risk children begin to fall through the cracks (Sink et al., 2007).

In many instances, kindergarten and first-grade teachers do not collaborate for the transition of students moving from one grade to the next, leading to difficulty for students with and without disabilities. Expectations for behavior and academics are not always communicated to students and their families, leading to confusion and what may be perceived as a lack of follow-through.

assigned homework, including increased demands for written output. Students are expected to improve their handwriting skills and read longer books with increased vocabularies, with sentences closer together. Test taking begins, which can add stress to the student and family. Students are expected to be able to tie their own shoes, keep track of their belongings, and be independent in toileting.

Occupational Therapy's Role in Transitioning From Kindergarten to First Grade

Occupational therapy practitioners can facilitate students' transition from kindergarten to first grade by discussing with students and their families, along with the kindergarten and first-grade teachers, the differences in expectations of each class and the proximity of the new classroom to other areas within the school. Practitioners can share with the incoming teacher and staff the strategies that have and have not worked for a student, demonstrate how the student's assistive equipment and technology work, and offer problem-solving suggestions.

Physical Environment

First grade is often the beginning of more formal learning in many schools, and the physical environment may be considerably different compared with kindergarten. Play time may be eliminated completely, and classroom size can be larger than that of kindergarten. Many kindergarten classes have a bathroom inside the classroom, which is not the case in first grade. In addition, first-graders may move more frequently throughout the building, they may use lockers for the first time, and their schedules are more aligned with the rest of the school. Therefore, first-graders may be more exposed to students in other grades in the hallways, recess yard, and restrooms.

Daily Routines and Required Tasks

Daily routines and required tasks in first grade are more demanding than in kindergarten. First grade involves a full day without a rest period, unlike kindergarten. Learning often requires more time in a chair and less time to play or move. Students are exposed to more academic subjects and have more

Transition Between Elementary School Grades

Traditionally, *elementary schools* span kindergarten to fifth grade, or ages 5–11 years. Some elementary schools now comprise two or three grades only, so students with disabilities may change schools every 2–3 years. In such cases, students again must traverse between the culture of the familiar school and that of the new one.

Few educational professionals address the issues of students with disabilities moving within a school between grades. Many assume that the successful strategies used in a previous year will automatically translate to the new school year. However, success with the same strategies is not a guarantee and does not always happen.

Occupational Therapy's Role in Transition Between Elementary School Grades

Because occupational therapy practitioners often continue with the students throughout their elementary

school career, they are invaluable in supporting students' successful transitions throughout elementary grades. Consider the following questions:

- What barriers can be eliminated by careful planning for students' progress from one elementary grade to another?
- What are the skills, habits, and roles that need to be prepared for, planned, and anticipated to promote participation?
- How does implementing school and classroom strategies for all student transitions affect the successful transition of students with disabilities?
- What skills that may be needed for transitioning to middle school should be addressed while students are still in elementary school?
- What strategies should have been used to facilitate James's successful transition from elementary to middle school?

School Culture Expectations

School culture encompasses procedures for safety, channels of communication, problem solving, organizational structure, and values and beliefs. At some schools, teachers are the case managers for other staff, including teachers of special content and occupational therapy practitioners, with all communication between home and school going through the teacher. At other schools, families are encouraged to speak directly with any staff person. Some schools address their procedures and expectations through student handbooks or older students acting as mentors to incoming students. Other school culture-related issues include familiar classmates and friends spread out among unfamiliar students coming from different schools.

In some schools, time limitations may lead to fewer opportunities for educators to communicate with each other regarding the strengths and weaknesses as well as the accommodations and assistive technology required for students with disabilities. For these students who are in a general education placement, their teachers may not have received their IEPs or even know what issues may arise when students have a specific disability. The school culture determines the type of communication

that may occur between professionals. If it is assumed that teachers of incoming students have been given information regarding a student's accommodations and needs, but in reality there is no mechanism to ensure that this occurs, the student may move into a new classroom without proven strategies in place.

Because occupational therapy practitioners may be the only people who stay with students as they move from one school to another, they may be point persons for communication among staff members. Practitioners can facilitate students' transition between elementary-level schools by proactively training the education staff and other students regarding the needs of a student and sharing past successes and challenges. Practitioners provide expertise in barrier removal, adaptations for greater independence, and teacher and staff training within a specific classroom and school (D. Ritchie, personal communication, January 18, 2011).

To facilitate successful transition, practitioners inform students and families about and prepare them for the different expectations and culture of a particular school and how they might differ from the current one. From school building to school building, students may have little awareness of how things are done, including procedures and expectations. In James's elementary school, his teachers asked him about his homework and reminded him to turn it in when he forgot. When James transitioned to middle school, his teachers expected all students to turn in homework without reminders and were unwilling to accommodate James. In many districts, practitioners may provide intervention in many schools, thus they may be the only person in the new environment who understands how new requirements may affect the student's transition.

The practitioners may provide role-playing opportunities for students to practice acceptable methods for navigating expectations regarding homework, bathroom privileges, lunchtime routines, and participation in available special and extracurricular activities. Practitioners should maintain records of all the accommodations that have been provided to students thus far, including those that have not worked. This information can be added to students' portfolio so that they can use it to advocate for themselves in the future.

Social Expectations

Social expectations such as how or when students may visit the bathroom, ask a question, or access educational supplies fluctuate from classroom to classroom. Children who receive their education in a self-contained classroom, part-time in a resource room, or with a full-time assistant when in a general education classroom may experience a sense of social isolation. If a student has an aide, the presence of the aide may keep other children from approaching him or her. In addition, other students and classroom staff may refer comments and questions to the assistant rather than the child. The aide may attempt to “help” the child by taking over his or her work and interactions with peers (Frolek Clark & Chandler, 2013).

Practitioners can prepare other classmates, teachers, and school personnel to see students with disabilities as individuals first; explain how to communicate with them; provide guidance about how much help the children require; and suggest modifications to the classroom setup to facilitate interactions between students and their typically developing peers.

Students' equipment and adaptations may place them physically at a different level or place than classmates. For example, when elementary students are doing a group floor activity, the child with a disability may be required to stay in a wheelchair or away from the group because of the child's need for personal space. Therefore, practitioners can assist the child and educational staff in positioning the child (e.g., using a floor sitter) or modifying the activity (e.g., having everyone sit in a chair) to enable interaction with classmates. Practitioners can facilitate a discussion with students and their team about what equipment is required in the new environment (e.g., adapted keyboard) and how to place equipment for best access.

As part of facilitating students' social performance, practitioners can instruct students, their families, and the classroom staff on self-determination and help students begin the process of self-determination so they can advocate for themselves. Students who feel that they have some control in their life are better able to deal with the structure, demands, and requirements of elementary school, including the increased emphasis on literacy, math, science, and other subjects. Renzo's story in the

“Prologue” describes the importance of him developing the ability to determine for himself what his life will become.

Daily Routines and Task Demands

As students progress through the elementary school years, increases in daily routine activities and task demands create increased expectations for student independence. The volume of work expected to be produced increases exponentially as students move into fourth and fifth grade. Where children once could successfully produce desired products with some adaptations or accommodations, these techniques may no longer be sufficient.

Occupational therapy practitioners can prepare students with disabilities for the increased expectations of each new grade level to facilitate their successful progression. For example, providing assistive technology such as a laptop computer or notebook can accommodate the increased amount of work required. Homework assignments throughout the school year should increasingly resemble those given at the next level of schooling so students can begin to plan and prepare for more advanced work. As practitioners facilitate conversations about homework expectations, they have an opportunity to address the increased social and behavioral expectations students face as they progress through elementary school. Working on such issues during elementary school prepares students to transition to middle school.

Transition to Middle School

The transition from elementary to *middle school*, traditionally sixth through eighth grades and ages 11–13 years, is a major stepping-stone for students with disabilities and their families, and many challenges and barriers need to be navigated (Kinney, 2006). For many students, with and without disabilities, this transition is difficult (Detwiler, 2008; Theriot & Dupper, 2010). In most elementary schools, learning occurs in self-contained classrooms with one or two teachers and might require travel to other areas of the building for art, music, or physical education. Students generally know and are comfortable with their peers in their class (Lorain, 2015).

Expectations and practices change dramatically at the middle school level. Most middle or junior high students rotate from classroom to classroom with different teachers and possibly different classmates for each subject. Each classroom and teacher may have different norms or rules for restroom breaks, homework responsibilities, and behavioral expectations. Students must adjust to this new environment in social, developmental, and academic ways (Lorain, 2015).

Physical Environment

The physical environment may be greatly different between elementary and middle schools. Middle school buildings are usually more spread out than elementary school buildings. For some students, it might take longer than the allotted time to reach destinations and be difficult to determine accessible routes. Some students' schedules may require them to walk from one end of the school to another for consecutive classes. Students with disabilities may fatigue and need a rest area, which is often difficult to arrange in the middle school environment (Detwiler, 2008).

Powered wheelchair batteries may need to be recharged before the end of the school day. Students who used manual wheelchairs successfully in elementary school may have difficulty getting to classes in the middle school building, having to maneuver their wheelchairs through crowded hallways and classrooms filled with desks. Careful planning to address these issues is necessary during the transition process.

Crowded hallways and noisy classrooms can be very difficult for students with sensory impairments. Students who have difficulty understanding where their bodies end and the environment begins will crowd too close toward others, talk too loudly in a manner that may make others uncomfortable, or be unable to focus on the required tasks.

Lockers are often provided in middle school, and students are expected to manage a lock, keep belongings in the locker, and take out just what is needed for a specific period of time. Middle school students usually have at least one textbook per class and may have up to seven classes within a school day, which necessitates going to the locker several times throughout the day. Students must be able to

get easily to their lockers, which may not be near any of their classes or in their normal pathways.

Students need to be able to access the lock on their lockers. Students without disabilities can struggle with using a combination lock (the most common type of locks in a school setting). It may take students with disabilities longer and more tries to get their lockers open. Within the allotted time, students must be able to quickly select books and supplies needed from their locker, take them out, put away the books and supplies used for previous classes, close the locker, secure the lock, and head to their next class.

Students with health impairments may also need to visit the nurse's office, which may be physically far away from their classrooms, or the nurse may be at the school only for limited periods of time, thus affecting students' daily schedules of required tasks. Therefore, occupational therapy practitioners can assist students and their educational team in allotting the time needed to visit the nurse's office, asking the nurse whether students can be serviced in a room closer to the students' classrooms, or providing techniques and adaptations to allow the students to address their own health care need such as taking medication.

Lunch Period

Eating lunch in the cafeteria can be more difficult for students with disabilities because the number of teachers or educational staff in the room may be low (Theriot & Dupper, 2010). Lunch can be the most troublesome time of the school day for students with disabilities for social and practical reasons. Students in elementary school tend to eat lunch with their class, whereas in middle school, students may sit where they desire, and there are often multiple lunch periods. Middle schools typically include students from multiple elementary schools, so children's friends from elementary school may not be assigned to the same lunch period.

Having friends to sit with during lunch is important and can be difficult for students with disabilities. Some students with disabilities eat isolated from friendships and positive interactions with others. The crowded room and loud noise can be overwhelming to many students and may cause them to have increased difficulty in feeding or even swallowing. Students who use scoop

dishes or adaptive handled spoons may not wish to appear different from their peers and refuse to use the equipment that has provided independence in feeding in elementary school. Students who are stressed or refuse adaptive equipment may not eat enough to fully participate in their academic day (Schultz-Krohn, 2013).

Using Restrooms

In elementary school, students with disabilities may have used one specific restroom that accommodated their specific needs. The restroom was most likely near the elementary classroom, and because most learning occurred within that classroom, students were able to use it when needed. However, the middle school environment includes a multitude of restrooms (Detwiler, 2008), and the restroom used is determined by its proximity to the classroom that students are in when the need arises. Because not all restrooms within a building are required to be accessible, and not all accessible stalls are configured for students' specific disability, students with disabilities may need to plan for restroom breaks when they are close to the bathroom that accommodates their disability and not when the need arises.

If students need assistance when toileting, it must be planned, and a person specified to assist must be available when necessary. Some students with disabilities require an area for diapers to be changed, requiring an assistant to be in the stall with them. This situation can be physically challenging and socially difficult for students with disabilities.

Daily Routines and Required Tasks

Middle school daily routines and tasks are usually very different from those in elementary school. Academic demands such as note taking and types and frequency of tests greatly increase (Theriot & Dupper, 2010). Students learn more subjects and move from one subject room to another throughout the day. Students may receive homework from each subject teacher, and many middle school students have several hours of homework each evening. Student assignments are generally longer and require preparation and planning to complete within a timely manner.

Many assignments may be given as a group project that requires students to be able to work with others who may not know them or understand the specific issues that relate to their disability. Students' expected performance is increased as the school begins to prepare them for the world that will await them when they leave public education. Students are expected to demonstrate higher level academic skills, such as abstract thinking and organizing complex writing and projects. They begin to take classes that relate to future life plans. For example, some classes are more conducive for students going to college and some are related to a specific vocation.

Students with disabilities may rely on assistive technology that uses a rechargeable battery throughout the day, such as power wheelchairs, laptops, and communication devices. If students do not ensure that the power wheelchair charge will last through the day, they may become unable to move to the next class. Laptops and communication devices may need to be plugged in periodically for students to continue using them. Anticipating these difficulties and preparing for them is critical for students' ongoing academic success.

Social Environment

The social environment in middle schools can be difficult to navigate for students with and without a disability. Middle school students are adjusting to physical, hormonal, and emotional changes that fluctuate within their daily life. They vacillate between wanting to be an adult with adult privileges, or at least being treated like one, and acting like a child with less responsibility. Their sphere of influence moves from that of the family structure to a social peer support groups. A family's opinions become less important, and those of their peers increase greatly.

Because of these changes, middle school students struggle to accept themselves and, in turn, others. They may have a great fear of being ridiculed or embarrassed in front of their friends, which influences their decision making. What friends think becomes more important than the values instilled within their family. During this time, students are more likely to engage in at-risk behavior (Lorain, 2015) that could harm their academic career for some time to come.

As students transition to middle school, they become more aware of social relationships, are more conscious of their own differences from their peers, and attempt to remove themselves from their dependency on their parents (Theriot & Dupper, 2010). Girls often experience increased peer pressure and the prevalent development of cliques with ever-changing entrance criteria. Even girls without disabilities have difficulties navigating through this culture. A girl in a clique can suddenly find herself cast out of the group for reasons unknown or different from those that had been previously in place.

Boys also find peer relationships difficult in middle school. In addition to spikes in hormones that occur randomly but with frequency, boys may struggle with academics and conflicts with authority (Theriot & Dupper, 2010). Boys may also face increased expectations for athletic performance or abilities. They tend to mask their insecurities through physical shows of strength and ability that may be beyond the ability of students with disabilities.

The pressure on students with disabilities who may not understand the unspoken cultural rules of their peers can become immense and increase their feeling of isolation within the school and community. Students with disabilities, especially those with emotional, cognitive, or autism spectrum disorder (ASD), may have trouble understanding the changing nature of the social structure within their school. It is important to plan and prepare students and their families for these changes in the transition preparation process to prevent decreased academic performance, diminished motivation, and skewed self-perception. Intentional social skills training and preparation for the changes students will experience when transitioning to middle school should begin while they are still in elementary school.

During middle school, some students may develop strained relationships with their parents and family. Students may want to be seen as individuals outside of the family unit and begin to spend more time with peers, leading to less time with the family. Parents may struggle to deal with the complexity of hormonally driven emotions and decisions of their children at home. They may not be as aware of those same issues within the school environment and their implications on their children's academic performance both in middle school and beyond.

Puberty may also affect students' behavior. The noise of more students, the bigger physical area in which to engage in acting out behavior, and the need for peer acceptance during this time can cause students to engage in disruptive behaviors to impress their friends. These behaviors can interrupt classroom learning for other students and students with disabilities. Students with emotional impairments may become more volatile and erratic, and negative behaviors and limitations that are the result of a disability can appear to escalate. Sometimes, these behaviors can be more the result of hormones and peer pressure than of the disability itself. It is important that these distinctions be acknowledged and addressed for students' safety and the safety of those around them.

School Culture Expectations

The school culture in middle school may result in a change in how information is shared between the school and parents. In elementary school, students may have used a notebook in which the teacher wrote notes or placed information for the family, so parents could know how things progressed at school that day and what homework assignments their child needed to complete. Once in middle school, students are expected to keep track of their homework assignments, perhaps within a schedule notebook (Detwiler, 2008). Parents may not always know what homework students have, and with up to seven teachers assigning homework, it can be overwhelming to keep up with the amount of work (E. Gregory, personal communication, May 6, 2006).

Teachers prepare their students for adulthood by expecting them to take initiative and ownership of their education. For students without disabilities, this is a reasonable process, but it can be an overwhelming barrier for students with disabilities. This change was James's main difficulty when he began middle school. Students like James, with ADHD or bipolar disorder, may find it difficult to remember to turn in assignments even if they have completed them before class. Not turning in homework assignments can greatly affect students' grades and lead to having to retake a course. James was in danger of failing courses because he did not remember to turn in his completed homework in a timely manner.

Exhibit 4.2. Strategies for Preparing Middle School Students for Adult Life

- Develop or lead life skills classes.
 - Support development of student portfolios outlining vocational skills.
 - Teach students self-determination and self-advocacy skills.
 - Recommend leadership opportunities for students with disabilities.
 - Adapt or modify activities and environments to enable students' participation in volunteer opportunities, part-time jobs, clubs, or after-school activities.
 - Teach independence and safety when using school or public transportation.
 - Teach students coping and other strategies for dealing with bullying.
 - Promote health and wellness.
-

Planning for the Transition to Adult Life

Although IDEA mandates transition to *adult life services* (i.e., community experiences; development of employment and other postschool adult living objectives; and, when appropriate, acquisition of daily living skills and functional vocational evaluation) beginning at age 16 years, schools can begin teaching vocational and independent living skills in middle school. Occupational therapy practitioners working in middle schools can begin preparing students for the transition to adult life. Suggested strategies are listed in Exhibit 4.2.

Occupational Therapy's Role in the Transition to Middle School

Occupational therapy practitioners provide a holistic approach in facilitating students' transition into and within middle school by anticipating that difficulties will arise when moving from a smaller, more protected environment to a middle school. Practitioners can determine students' physical and psychosocial needs that occur in middle school and develop strategies for successful transition. For specific strategies, see Exhibit 4.3. As you review these strategies, consider the following questions:

- What barriers can be eliminated by careful planning for students' transition from elementary to middle school?

Exhibit 4.3. Strategies During the Transition to Middle School

- Facilitate independence by breaking down student tasks into manageable steps (e.g., if a student has difficulty carrying a heavy backpack, he or she could be coached to place only the books for morning classes into his or her backpack; he or she could then visit the locker at lunchtime to exchange the books for the afternoon schedule).
 - Color code book covers, notebooks, and supplies by classes.
 - Rehearse, by role playing, specific social scenarios that may occur when students are in the new environment.
 - Have students research what others have done in similar social situations, and view movies or videos that address social situations that may occur.
 - Introduce students to a mentor from the new school before transition (the mentor can help students begin to navigate the changes in middle school).
 - Facilitate discussion and participation in meaningful occupations that may help eliminate negative behavior changes.
 - Facilitate a plan of access so that students are able to charge their laptops or powered wheelchairs.
 - Prepare students for technology needs by recommending the purchase of an extended-life battery or possible use of an iPad, which has an extended battery.
 - Arrange lunch bunches or social groups to address issues of shared concern or plans.
 - Provide staff training on universal design for learning and on strategies to enhance differentiated instruction to maximize participation for all students.
 - Recommend that students visit their school before the transition.
 - Share digital videotapes and portfolio information with prospective teachers.
-

- What are the skills, habits, and roles that need to be prepared for, planned, and anticipated to diminish the effect of these barriers and to promote participation?
- How does implementing school and classroom strategies for all student transitions affect the successful transition of students with disabilities?

- What social and emotional factors may add to students' transition from elementary to middle school?
- What factors would have helped in James's transition from elementary to middle school?
- What strategies can be used to teach students to identify and begin preparing for their goals and plans for the future?

Transition to High School

In **high school**, generally ninth to twelfth grades and ages 14–19 years, students begin to move away from childhood and into more adult roles. Moving from middle school to high school is a transition to a new stage in life (Neild, 2009). Transitioning to high school can be filled with anxiety and confusion for students and parents. Because many students with disabilities become "stuck" and stop progressing toward graduation in ninth grade, the first year of high school, it is important for occupational therapy practitioners to provide students, parents, and high school personnel with proactive means for systematically checking in with all parties involved to identify early the student's difficulties with the transition to ninth grade (Neild, 2009; see Exhibit 4.4).

Consider the following questions:

- How should occupational therapy practitioners address the social and emotional aspects unique to teenagers transitioning from middle to high school?
- How can occupational therapy practitioners facilitate high school students' need for autonomy with their need for assistance from parents or guardians?
- What barriers to successful transition to high school can be removed with careful reflection and action by occupational therapy practitioners?
- How can occupational therapy support the academic achievement of students to meet standards for graduation?
- How can occupational therapy support the social and life skills goals necessary for community living?

A difficult transition can lead to a decrease in academic achievement, an increase in behavioral

Exhibit 4.4. Strategies During the Transition to High School

- Recommend accommodations and technology to allow students with disabilities to participate in curricular and extracurricular activities with their peers.
 - Provide in-service and training to educators and students without disabilities on disability awareness and tolerance.
 - Offer social skills training to facilitate peer interaction.
-

difficulties, and even to a student dropping out of school before achieving a diploma (Neild, 2009; Smith, Feldwisch, & Abell, 2006). The ninth grade can determine how well the remainder of students' high school years will go.

Time Management

High school schedules can change daily. Some high schools use a block schedule with A and B day classes (Clark, 2008). Part of the block schedule is longer length of class time. In traditional schedules, the classes may be 50 minutes long, but block scheduling classes may extend to 90 minutes. This increase in class time can benefit some students with disabilities by decreasing the amount of navigating through the school because fewer classes are taught each day and allowing for more in-depth learning and continuity. However, for students who have difficulty focusing and staying on task, additional class time can be difficult.

If students are involved in a class they find challenging or in a subject area in which they are not interested, students may shut down or act out. However, some middle schools offer block scheduling and then change to daily scheduling when transitioning to high school. Students who were used to block scheduling may not be prepared for the changes associated with regular scheduling. For example, they may have difficulty completing homework on a daily basis for all subjects.

Changes in routines can be difficult for people with cognitive or emotional disabilities. Students with ASD may find changes in routine and navigating an A and B block schedule particularly hard. Students who

require routine and a predictable schedule may need more planning and preparation to assist them in navigating a block schedule with as little stress as possible. Helping students with disabilities navigate through their class schedules and special activities that occur throughout the school year requires transition planning, not just as students move from middle to high school but throughout high school.

Time management and prioritization of work are skills that require executive functioning, an area in which many people with and without disabilities struggle. ***Executive functioning*** is high-level cognitive processing that is required for functions such as preparing assignments, organizing tasks, monitoring one's own performance, and managing resources to achieve a desired goal (Cooper-Kahn & Dietzel, 2008). For many high school students, the demand for performing executive functioning skills within time constraints begins. Previously, teachers may have broken down large tasks for the students and given them dates for each subcomponent's completion.

Many educators in high school begin to provide less structure for students, thus facilitating students to become more independent. However, many teenagers wait until the last minute to begin a project and do not allocate sufficient time for task completion. For many students with disabilities, doing things at the last minute without forethought and planning is a luxury they cannot afford.

the percentage of students graduating high school within a 4-year cycle. Low marks are given for adequate yearly progress for schools whose students need more years to complete high school. The expectation that students will graduate within 4 years, combined with increased state requirements for graduation, puts additional pressure on students with disabilities. Special educators are now required to be highly qualified to teach the courses their students with disabilities need for high school graduation. Many districts are requiring that these courses be taught at a rigorous level compatible to those taught to students in general education courses (U.S. Department of Education, 2014).

Although such requirements can benefit many students with disabilities, they can be detrimental to those who have limited cognitive abilities. Many educators question whether students with some disabilities will be able to receive a diploma within a specified time or at all under these guidelines (Johnson, Thurlow, & Stout, 2007). Students who do not receive a diploma may develop an alternative portfolio or receive a certificate of attendance instead, which may shock many students and parents who expected an academic diploma at the end of the K–12 career. Practitioners can introduce the reality of where a students' educational track will lead as a part of their transition process.

School Culture

School culture changes from elementary and middle school to high school. Elementary and middle school teachers generally teach academics and also nurture the whole child. High school teachers generally believe that their role is to teach students how to approach new content and learn academic subjects (Kennelly & Monrad, 2007). Because this difference in culture is unwritten, it is imperative that occupational therapy practitioners provide transition activities and approaches so that transitioning students and their families can better negotiate these changes.

New academic expectations in high school include the students earning credits toward their graduation. NCLB evaluates schools and states on

Daily Routines and Required Tasks

High school requires advanced ability in performing daily routines and required tasks such as managing time, staying on task, behaving appropriately, and developing social skills (Smith et al., 2006). Although these skill areas can be difficult for all students, they can completely derail the performance of students with disabilities. Occupational therapy practitioners can address performance in these areas by developing enrichment programs or seminars for students with and without disabilities to discuss expected transition difficulties. In addition to addressing these skills and other similar topics, these groups can negate the social isolation encountered by many students with disabilities.

Frequently, project-based learning becomes group based, with each member responsible for specific parts of the project. Group members may choose to meet outside of school, which can be problematic for students with disabilities who are unable to use public transportation or do not have their own vehicle or license. Add this issue to the larger geographic regions that are within a high school's catchment area, and meeting outside of school can be prohibitive. In group projects, members are expected to monitor each other and provide group pressure to keep individual members on track and on time. Students with disabilities must deal with the varying personalities of their group and the group dynamics as a whole, which can be extremely difficult for students with emotional impairment or ASD.

Social Environment

The high school social environment contains many challenges. The vast majority of high school students enter a new high school with approximately 60% of students unknown to them (Neild, 2009). Schools segregate students by curricular track (Kennelly & Monrad, 2007), and students themselves segregate into groups often by athletic ability, musical ability, and other common interests. Friendships move from those who live geographically near them to those who live in a larger geographic region.

High schools draw students from a wider geographic region and may involve specialized areas of study, perhaps specializing in science and technology, the arts, or future employment pathways, thus bringing different students together for the first time. Many students can independently take public transportation or drive themselves to school. Developing relationships is difficult for students with disabilities, and it can be made even more difficult because they cannot use public transportation on their own or drive. However, even if parents of students with disabilities are willing to provide transportation to social activities, students may not want to be seen with their parents. These difficulties may lead to social isolation.

During high school, the number of available extracurricular activities increases. Students may choose to become involved in athletics or the arts. These activities occur after school hours and

require a great level of independence to participate in them and use transportation to attend practices and competitions. Many relationships that develop within high school begin in one of these extracurricular activities. Students who participate in the same activities often sit together in classes and at lunch and do other activities together outside of the extracurricular activities. Students who are prevented from participating in extracurricular activities because of their disabilities will find it difficult to develop such relationships within high school. In addition, these relationships can be the factor that keeps a student in school.

Lack of meaningful relationships can lead to increased isolation and withdrawal from others (Palmer, Heyne, Motie, & Abery, 2011). Students who are at risk or have a lack of meaningful relationships may be more accepting of students with disabilities, or students with disabilities may become victims of students with risk-taking behaviors. Therefore, planning and preparation must be done for students with disabilities to develop and maintain social relationships both inside and outside of high school.

Because practitioners are aware of the many new demands associated with entering high school, they can work closely with the school staff to anticipate and address concerns before students arrive in the building. For example, during middle school, James should have been taught skills to develop a group of peers who could assist him in maneuvering successfully in high school.

Transitioning Beyond High School

Middle and high school students must not only address their transition from one academic environment to another but also begin planning for life after high school. They should begin to determine what their career and learning pathway will be while they are in middle school. For example, if students plan to attend college, they must take specific prerequisite classes. Students and their families must prepare for eligibility requirements for financial and insurance support, which may change when students turn age 18 years. It is also important to develop life and vocational skills that will prepare

students for employment and independent living. Students' transition from school to adult life is addressed in detail in Chapter 5, "Transition From School to Adult Life."

Summary

Thoughtful planning for students' transitions throughout their school career can help them succeed in school and build a foundation for a meaningful life. Although occupational therapy practitioners have been involved in transitions for students moving from high school to postsecondary life, they have been less involved in students' transitions throughout the K–12 experience. Practitioners have unique skills that can facilitate students' educational career and allow for successful transitions throughout the student's school years.

References

- American Occupational Therapy Association. (2008). *Occupational therapy's role in transition services and planning*. Retrieved from <https://www.aota.org/-/media/Corporate/Files/AboutOT/Professionals/WhatIsOT/CY/Fact-Sheets/Transitions.pdf>
- American Occupational Therapy Association. (2014). Occupational therapy practice framework: Domain and process (3rd ed.). *American Journal of Occupational Therapy*, 68(Suppl. 1), S1–S48. <http://dx.doi.org/10.5014/ajot.2014.682006>
- Blair, S. E. (2000). The centrality of occupation during life transitions. *British Journal of Occupational Therapy*, 63, 231–237.
- Brandes, J. A., Ormsbee, C. K., & Haring, K. A. (2007). From early intervention to early childhood programs: Timelines for early successful transitions. *Intervention in School and Clinic*, 42, 204–211.
- Calvin, M. B. (2010, February 3). *Expectations for kindergarten 2010*. Retrieved from <http://www.suite101.com/content/expectations-for-kindergarten-in-2010-a196473>
- Clark, G. F. (2008). Getting into a collaborative school routine. In B. Hanft & J. Shepherd (Eds.), *Collaborating for student success: A guide for school-based occupational therapy* (pp. 130–134). Bethesda, MD: AOTA Press.
- Common Core State Standards Initiative. (n.d.a). *Application to students with disabilities*. Retrieved from <http://www.corestandards.org/assets/application-to-students-with-disabilities.pdf>
- Common Core State Standards Initiative. (n.d.b). *Mission statement*. Retrieved from <http://www.corestandards.org>
- Cooper-Kahn, J., & Dietzel, L. (2008). *What is executive functioning?* Retrieved from http://www.ldonline.org/article/What_Is_Executive_Functioning%3F
- Detwiler, M. (2008, September). Transition to middle school for the child with special developmental needs. *Exceptional Parent Magazine*, 38(9), 22–23.
- Education Week. (2004). *No Child Left Behind*. Retrieved from <http://www.edweek.org/ew/issues/no-child-left-behind/>
- Elementary and Secondary Education Act of 1965, Pub. L. 89–313, 20 U.S.C. §§ 2701–3386.
- Every Child Achieves Act of 2015, S. 1177, 114th Cong. (2015).
- Frolek Clark, G., & Chandler, B. (2013). Best practices in supporting student access to school environments. In G. Frolek Clark & B. Chandler (Eds.), *Best practices for occupational therapy in schools* (pp. 69–79). Bethesda, MD: AOTA Press.
- Gershon, L. (2015, June 3). *Why did kindergarten become just another grade?* Retrieved from <http://daily.jstor.org/kindergarten-become-just-another-grade/>
- Gibson, R. W., Nochajski, S. M., Schefkind, S., Myers, C., Sage, J., & Marshall, A. (2010). The role of occupational therapy in transitions throughout the lifespan. *OT Practice*, 11, 11–15.
- Gregory, G. (2000). *Transitions in first grade*. Retrieved from <http://cehdclass.gmu.edu/cip/g/gc-c007.htm>
- Handley-More, D., Hollenbeck, J., Orentlicher, M. L., & Wall, E. (2013, September). Education reform initiatives and school-based practice. *Early Intervention and School Special Interest Section Quarterly*, 20(3), 1–4.
- Individuals With Disabilities Education Improvement Act of 2004, Pub. L. 108–446, 20 U.S.C. §§ 1400–1482.
- Jackson, L. L. (2007). Legislative context of occupational therapy practice in schools and early intervention settings. In L. L. Jackson (Ed.), *Occupational therapy services for children and youth under IDEA* (3rd ed., pp. 1–22). Bethesda, MD: AOTA Press.
- Johnson, D. R., Thurlow, M. L., & Stout, K. E. (2007). *Revisiting graduation requirements and diploma options for youth with disabilities: A national study*. Minneapolis: University of Minnesota, National Center on Educational Outcomes. Retrieved from <http://www.cehd.umn.edu/nceo/onlinePubs/Tech49/TechReport49.pdf>
- Kennelly, L., & Monrad, M. (2007). *Easing the transition to high school: Research and best practices designed to support high school learning*. Retrieved from http://www.betterhighschools.org/docs/NHSC_TransitionsReport.pdf

- Kinney, P. (2006). Meeting special challenges in transitions. *Principle Leadership*, 69, 28–30.
- Lorain, P. (2015, June 12). Retrieved from <http://www.nea.org/tools/16657.htm>
- Mancini, M. C., & Coster, W. J. (2004). Functional predictors of school participation by children with disabilities. *Occupational Therapy International*, 11, 12–25.
- McKinley, L. A., & Stormont, M. A. (2008). Identifying needs and barriers for children with ADHD. *Teaching Exceptional Children*, 41, 14–19.
- Michigan Department of Education. (n.d.). *Parent Guide 2: What if my child has a disability?* Retrieved from http://www.michigan.gov/documents/mde/Parent_Guide_5_174304_7.pdf
- Myers, C. T. (2013). Best practices in transition planning for preschoolers. In G. Frolek Clark & B. Chandler (Eds.), *Best practices for occupational therapy in schools* (pp. 235–243). Bethesda, MD: AOTA Press.
- National Dissemination Center for Children With Disabilities. (2009). *Questions and answers about IDEA: Purposes and key definitions*. Retrieved from <http://www.nichcy.org/InformationResources/Documents/NICHCY%20PUBS/QA1.pdf>
- Neild, R. C. (2009). Falling off track during the transition to high school: What we know and what can be done. *Future of Children*, 19, 53–76.
- Nevill, R. A., & White, S. W. (2011). College students' openness toward autism spectrum disorders: Improving peer acceptance. *Journal of Autism and Developmental Disorders*, 41, 1619–1628.
- No Child Left Behind Act of 2001, Pub. L. 107–110, 20 U.S.C. §§ 6301–8962.
- Palmer, S., Heyne, L., Montie, J., & Abery, B. (2011). Feature issue on supporting the social well-being of children and youth with disabilities. Minneapolis: Institute on Community Integration.
- Pape, L., & Ryba, K. (2004). *Practical considerations for school-based occupational therapy practitioners*. Bethesda, MD: AOTA Press.
- Rehabilitation Act of 1973, Pub. L. 93–112, 29 U.S.C. §§ 701–796l.
- Schartzman, A. J., Atler, K., Borg, B., & Schwarzman, R. (2006). Fueling the engines: A role for occupational therapy in promoting healthy life transitions. *Occupational Therapy in Health Care*, 20, 36–59.
- Schultz-Krohn, W. (2013). Best practices in eating, drinking, and swallowing skills to enhance participation. In G. Frolek Clark & B. Chandler (Eds.), *Best practices for occupational therapy in schools* (pp. 527–539). Bethesda, MD: AOTA Press.
- Sink, C. A., Edward, C. N., & Weir, S. J. (2007). Helping children transition from kindergarten to first grade. *Professional School Counseling*, 10, 233–237.
- Smith, J. S., Feldwisch, R., & Abell, A. (2006). Similarities and differences in students' and parents' perceptions of the transition from middle school to high school. *Research in Middle Level Education*, 29, 1–9.
- Student Success Act of 2015, H.R. 5, 114th Cong. (2015).
- Theriot, M. T., & Dupper, D. R. (2010). Student discipline problems and the transition from elementary to middle school. *Education and Urban Society*, 42, 205–222.
- U.S. Department of Education. (2014). *18 indicators identified by the Office of Special Education Programs (OSEP) at the U.S. Department of Education: SSIP FAQ Report 2014*. Washington, DC: Author.
- Wehmeyer, M. L. (1998). Self-determination and individuals with significant disabilities: Examining meanings and misinterpretations. *Research and Practice for Persons With Severe Disabilities*, 23, 5–16.

Appendix 4.A. Resources for Transition Within Schools

- **Transitions for Children and Youth Fact Sheet:** <https://www.aota.org/-/media/Corporate/Files/AboutOT/Professionals/WhatIsOT/CY/Fact-Sheets/Transitions.pdf>
This document defines transitions for children and youth and how occupational therapy practitioners can facilitate successful transitions for them.
- **PowerPoint Presentation: Occupational Therapy's Role in Transitions:** <http://www.aota.org/Practice/Children-Youth/Transitions/Resources.aspx#sthash.MjgWbxff.dpuf>
This document focuses on roles for occupational therapy practitioners in providing transition services across the lifespan and can be shared with administrators and parents.
- **Occupational Therapy's Role in Transition Services and Planning:** <http://conaboy.com/wp-content/uploads/2014/02/TransitionsFAQ.pdf>

This document identifies the role of occupational therapy practitioners in developing a transition plan and services for students with disabilities.

- **FAQ on Employment of Young Adults With Disabilities:** (members only) <http://www.aota.org/-/media/Corporate/Files/Secure/FAQ-Employment-Young-Adults.PDF>

This document identifies the importance of employment for youth with disabilities and occupational therapy practitioners' role in facilitating their employment.

- **Transitions Across Contexts: Checklist for Occupational Therapy Practitioners:** <http://www.aota.org/Practice/Children-Youth/Transitions/Resources.aspx#sthash.MjgWbxff.dpufpdf>

This document provides a checklist for occupational therapy practitioners across many transition areas to facilitate successful transitions.

CHAPTER 5.

TRANSITION FROM SCHOOL TO ADULT LIFE

Meira L. Orentlicher, PhD, OTR/L, FAOTA

Chapter Objectives

After reading this chapter, readers will be able to

- ❖ Describe the transition from school to adult life for people with and without disabilities;
- ❖ Describe laws and funding options governing the transition from school to adult life;
- ❖ Explain best practices and predictors of successful postschool transitions; and
- ❖ Describe the role of occupational therapy practitioners in the transition from school to adult life, including evaluation, intervention, and supporting families.

Key Terms and Concepts

- ❖ 2020 Federal Youth Transition Plan
- ❖ Age-appropriate transition assessment
- ❖ Areas of occupation
- ❖ Assess, Plan, Instruct, and Evaluate model
- ❖ Customized employment
- ❖ Discovery
- ❖ Federal Partners in Transition
- ❖ Formal measures
- ❖ Higher Education Opportunity Act of 2008
- ❖ Individual transition plan
- ❖ Individuals With Disabilities Education Improvement Act of 2004
- ❖ Informal measures
- ❖ Integrated jobs
- ❖ Occupational profile
- ❖ Person-centered planning
- ❖ Segregated day programs
- ❖ Self-determination
- ❖ Sheltered workshops
- ❖ Summary of performance
- ❖ Supported decision making
- ❖ Supported employment
- ❖ Transition planning
- ❖ Transition services
- ❖ Vocational training

Graduating from high school is an exciting, yet challenging, time for young adults as they prepare for new opportunities and experiences in attending college, starting work, living outside of their parents' home, and developing new relationships. Schools offer supports to typical young adults as they prepare for this transition by providing services such as guidance counseling. Students with disabilities, especially those who will leave high school without a high school diploma, face added challenges associated with their disabilities that may require additional supports. For example, a young man with physical disabilities needs to find employment and residence in settings fully accessible for his wheelchair. A young woman with special health care needs requires employment in a setting that will accommodate several breaks during the day to address her needs. A young man with an autism spectrum disorder (ASD) may find it challenging to participate in interviews or take a crowded bus to school or work.

Although all young adults must consider and plan for the financial implications of their adult choices (e.g., cost of college), transitioning from school-based to adult disability services requires additional planning, especially if the young adult is not expected to ever be fully employed or legally independent. This chapter describes the legal mandates for transition from school to adult life and provides evidence for best practice. It also outlines roles for occupational therapy in supporting students and families before, during, and immediately after the transition.

Adam's Story

Adam is age 21 years and was diagnosed with high-functioning autism when he was age 5 years. He is 1 of approximately 240 special education students in his high school. Along with about 50 other special education students, Adam attends a special program called SAIL, which stands for Strategies for Adult Independent Living. Students eligible for the program can attend it throughout their time in high school, from 4 to 7 years. It is a hybrid program, combining typical academic classes such as history and science with life skills and vocational classes, which are attended by the students with disabilities. It is expected that Adam

will receive a high school diploma from his local district, although he is not expected to receive the state's Regents diploma.

Although Adam's state requires transition services to begin at age 15 years, Adam and his mother Linda were not invited to attend a transition planning meeting at the school until Adam was age 19 years. School professionals in attendance included his teacher, social worker, psychologist, and special education administrator. At the meeting, it was decided that upon leaving school, Adam will attend a local day habilitation program. When Adam and his parents later attended an orientation meeting at the day habilitation program, they learned that the organization that manages the program, Career, Choice, and Freedom (CCF), offers other community-based programs in employment, residential services, and recreation. They also learned that CCF has a contract with Adam's school to provide transition planning services for students whom the school labels as difficult. Linda then requested to work with CCF and has been working with its transition consultant, Frank, ever since.

Person-Centered Planning

The first step in transition planning that Frank introduced to the family was conducting a person-centered planning meeting using the planning tool Promoting Alternative Tomorrows With Hope (PATH; O'Brien, Pearpoint, & Kahn, 2010). The meeting took place in their home and was attended by Adam, Linda, his father Jeffery, and his older brother Evan. At the meeting, the family decided that Adam would attend the community-based programs at CCF, not the day habilitation program. They also decided that Adam would begin attending CCF's vocational and recreational programs while still in school, which would allow him to get used to these new programs and meet some of the other young adults that attend them and the staff. Because Adam has a hard time getting used to new situations, this period of adjustment was beneficial.

For the past 2 years, since the initial meeting, Frank has met with Adam and his family several times for follow-up. Initially, Adam was more closed off, but as he got to know Frank better, he slowly opened up and began sharing his thoughts, interests, and dreams for the future. At age 19 years, Adam could picture himself only living with his parents, but later on, he agreed to

go to a sleepaway camp for teens with disabilities. After experiencing living away from home for the summer, he began visualizing himself living away from his parents. Adam also expressed interest in visiting a program for young adults with ASD at the local community college. Students in the program can take classes for credit or audit classes with typical students and take special life and social skills classes for students with ASD.

IEP Planning Meetings

Frank attended two individualized education program (IEP) and transition planning meetings at Adam's school, where he assisted the team in choosing the specific classes and experiences Adam would attend during the SAIL program. It was decided that 1 day per week Adam would attend the program at CCF, 1 day per week he would participate in the supported employment program at the school by going to a job site with a job coach and two other students, and 3 days per week he would attend academic classes and the life skills program.

Although Adam was not provided with individualized occupational therapy, one of the district's occupational therapists worked as a consultant to the life skills program. She assisted the team in brainstorming methods for training Adam to perform certain activities and recommended adaptations to tasks and tools when needed. For example, she recommended that Adam be provided with a visual schedule that included the activities of daily living (ADLs) that he needed to perform every morning before going to school or work.

Long-Term Planning

Frank encouraged Adam's parents to meet with a lawyer and create a disability trust that would secure Adam's financial future. Evan agreed to serve as the trustee to ensure the long-term care for Adam once their parents pass on. They also met with a Medicaid case manager and applied for Medicaid Home- and Community-Based Services Waiver benefits that would pay for the program at CCF once Adam leaves school, added Adam to several waitlists for residential programs, and met with the family's physician to begin the process of transitioning Adam from pediatric to adult care.

Exit Meeting and Future Plans

When Adam turned age 21 years and was getting ready to leave school, Frank held an exit meeting with the family and school professionals to finalize Adam's transition plan. It was decided that during the summer Adam would attend the sleepaway camp and then begin the program at CCF full-time in September. During the previous 2 years, Adam had expressed several times that he would like to work with cars. Unfortunately, this interest was not explored while Adam was still in school. Instead, he joined other students for work experience at a chain pizza restaurant. Frank promised that once Adam attended CCF full-time, the staff would explore developing employment opportunities in car-related businesses. Although CCF offers transportation to all of its programs, to attend the program at the local community college, Adam would need to take a public bus. Adam said that he did not feel ready to do that yet.

It was agreed that during his first year at CCF Adam would be provided with travel training and learn how to use local buses. Once he felt ready to take the bus on his own, the community college option would be explored again. Additionally, at this point Adam and his family felt that for now he should live at home. More independent living options would be explored again in the future. Adam would attend the recreation programs offered at CCF, which include weekly evening outings, several weekend trips per year, and parties. Evan agreed to take Adam periodically to swim at the local pool, which is another interest Adam expressed at his person-centered planning meeting.

Questions

- What specific areas of occupation were considered when planning Adam's transition?
- At the first transition meeting at the school, it was decided that upon leaving high school Adam would attend a day habilitation program full-time. However, the family decided to go in a different direction and chose instead a variety of community-based programs. What may have influenced this decision? What are the differences between the day habilitation program and the program planned by Frank and Adam's family?
- What aspects of Adam's story demonstrate collaboration and communication between families and professionals and between the professionals

from the different school and adult services programs? How did this collaboration and communication support Adam and his family during transition planning?

- Although individualized occupational therapy services were not provided during Adam's transition planning, how could an occupational therapy practitioner support Adam and his family before, during, and after the transition?
- Not all of Adam's aspirations and transition plans were addressed at this point. What are the additional anticipated transitions? How can occupational therapy support Adam in these anticipated transitions?

Evidence to Support Practice

This section provides an overview of current literature on the outcomes of young adults with disabilities once they leave high school, predictors for these outcomes, and support for best practices in transition.

Transition Outcomes

Approximately 375,000 students with disabilities graduated from or aged out of high school in 2012 (Institute on Disability, 2014). Compared with typically developing individuals, these students lag behind in employment, postsecondary education, and community living skills (Baer, Daviso, Flexor, McMahan, & Meindl, 2011; Powers et al., 2007). In 2013, only 33.9% of U.S. citizens with disabilities were employed, compared with 74.2% of people without disabilities (Rehabilitation Research and Training Center on Disability Demographics and Statistics [StatsRRTC], 2014). In addition, people with disabilities who were employed earned about two-thirds of the median earnings of people without disabilities, and 28.7% were living in poverty, compared with the national poverty rate of 13.6% (StatsRRTC, 2014).

People with disabilities also face health risks at higher rates than people without disabilities. For example, the smoking rate for people with disabilities in 2013 was 25.4% compared with 16.2% in people without disabilities (StatsRRTC, 2014). The obesity rate for people with disabilities was 40.1%, compared with 24.9% in the general population

(StatsRRTC, 2014). Moreover, young adults with disabilities report lack of social relationships, lack of financial control, and dependency on the Social Security system (Davies & Beamish, 2009; Hughes & Avoke, 2010; McDougall, Evans, & Baldwin, 2010; Nonnemacher & Bambara, 2011; Wehman & Brooke, 2013).

Predictors of Transition Outcomes

The severity and type of disability, race, socioeconomic status, and gender play a large role in predicting postschool outcomes for young adults with disabilities (Baer et al., 2011; Flexor, Daviso, Baer, Queen, & Meindl, 2011; Grigal, Hart, & Migliore, 2011; Lee & Carter, 2012). For example, a student with a mild disability may be more likely to travel independently. More jobs and educational opportunities are open to people with mild disabilities compared with those available for people with severe disabilities (Rowe, Mazzotti, & Sinclair, 2015). Education level, living situation, and supports and services provided also affect postschool outcomes.

Race and gender

According to the secondary analysis of the Second National Longitudinal Transition Study (Wagner, Cameto, & Newman, 2003), which collected data over a 10-year period, 67% of young adults with disabilities who had paid work were White, and only 40% of those never employed were White (Grigal et al., 2011). Magill-Evans, Galambos, Darrah, and Nickerson (2008) found that men are more likely to be employed even when their level of education and cognition is low compared with women. They are also more likely to attend postsecondary education (Baer et al., 2011; Flexor et al., 2011; Grigal et al., 2011). In contrast, women are more active participants in the community compared with men, who tend to be more isolated (Wagner et al., 2003).

Education level

Education level predicts employment, specifically, education beyond high school (Magill-Evans et al., 2008) equates with greater employment. According to Foley et al. (2013), in young adults

with Down syndrome, increased independence in ADLs and greater competence in self-care routines predict postschool employment or participation in employment training. After interviewing students 1 year after school, Baer et al. (2011) concluded that students with intellectual disabilities (ID) who completed 3 or more semesters of career and technical education were more likely to have full-time employment. However, young adults with increased behavioral problems were less likely to obtain **integrated jobs** (i.e., jobs held by people with disabilities in typical workplace settings alongside people without disabilities) or attend postsecondary education.

Type of schooling has a great effect on leisure participation (Badia, Orgaz, Verdugo, & Ullán, 2013). Specifically, young adults with developmental disabilities who attended regular education schools participate in more leisure activities than those who attended special education schools. Additionally, the type of disability is a predictor for preferred leisure activities. Young adults with ID expressed a preference for more frequent participation in social and physical activities than those with motor disabilities.

Living situation

Kim and Dymond (2012) conducted a survey to investigate whether the type of living situation predicts the level of assistance needed in independent living skills and the frequency of community participation in people with severe disabilities. They found that compared with people residing in group homes, those who live in supported apartments participate more in community activities, demonstrate higher levels of adaptive behavior, and have more opportunities to engage in meaningful, age-appropriate activities.

Similarly, Tichá et al. (2012) found that adults with intellectual and developmental disabilities (IDD) who lived alone or with three or fewer people reported greater everyday choice than adults with IDD living in larger group settings. A longitudinal study by Woodman, Mailick, Anderson, and Esbensen (2014) showed that adults living with relatives demonstrated advantages in health, whereas those living in a nursing home or hospital showed the highest rates of dementia.

Services and supports

One key factor that influences postschool outcomes is transition services and supports (Certo et al., 2008; Lee & Carter, 2012; Lindstrom, Doren, & Miesch, 2011). Transition services begin with an **individual transition plan (ITP)**, and the type of transition goals on the ITP predicts transition outcomes for youth with ID. For example, goals reflecting high expectations for students, such as attending a 2- or 4-year college, lead to better employment outcomes (Baer et al., 2011; Flexor et al., 2011; Grigal et al., 2011).

Describing the benefits of services and supports offered through high school, family members, teachers, rehabilitation counselors, and young adults with disabilities emphasized that having a transition specialist at school helped young adults in the transition process by providing assistance such as helping with résumés, interviews, job opportunities, and postsecondary education (Lindstrom et al., 2011). When comparing the transition outcomes between students who began the transition process at age 14 years and those who began at age 16 years, Cimera, Burgess, and Wiley (2013) found that students who began transition services at age 14 years had higher rates of employment and higher salaries, indicating the need for earlier transition services in high school.

Best Practices in Transition

Landmark, Ju, and Zhang (2010) conducted a literature review to examine which transition practices are most supported by research. The most-to least-substantiated practices were paid and unpaid work experiences, employment preparation emphasizing job searching skills and vocational training, family involvement, inclusion in regular education classrooms, social skills and independent living skills training, self-determination, and community and interagency collaboration.

In terms of student and family involvement, students with disabilities and their families expressed that being involved in their transition planning is empowering and leads to more positive outcomes (Carter, Swedeon, Walter, Moss, & Hsin, 2011; Davies & Beamish, 2009; Hagner et al., 2012; Nonnemacher & Bambara, 2011; Wehmeyer, Palmer, Soukup, Garner, & Lawrence, 2007).

For example, in a randomized controlled trial, 47 families of students with ASD were provided with resources and strategies for involvement and taking action in transition planning. The parents' and students' expectations for the future, and the students' ability to choose a vocational path, were significantly higher than those of the control group (Hagner et al., 2012).

Self-determination is a predictor of employment, independent living, and community access for students with disabilities (Shogren, Wehmeyer, Palmer, Rifenbark, & Little, 2015; Wehmeyer, 2015). **Self-determination** is defined as having the skills to make choices and decisions, problem solve, set and attain goals, advocate and be a leader, and self-regulate and control oneself (Carter et al., 2011; Landmark et al., 2010; Wehmeyer et al., 2007). It is an important factor contributing to feelings of personal development and self-fulfillment for youth and young adults with chronic disabilities (McDougall et al., 2010). Youth expressed that it was important for them to have the support of others, good medical care, know how to obtain accommodations, knowledge about their rights, reliable transportation, and involvement in community agencies (Nonnemacher & Bambara, 2011). In addition, people with disabilities stated that choosing what to do during free time, how to spend personal money, and where to live or work were important ways to express their independence (Carter et al., 2011; Nonnemacher & Bambara, 2011).

Laws and Initiatives That Shape Practice

The Individuals With Disabilities Education Improvement Act of 2004 (IDEA; Pub. L. 108–446) is the main law that governs transition services for students with disabilities who are transitioning to adult life. IDEA and the 2020 Federal Youth Transition Plan are discussed in this section. Additional laws and initiatives that pertain to student transition are discussed in other chapters; for example, the Rehabilitation Act Amendments of 1998 (Pub. L. 105–220), Americans With Disabilities Act Amendments Act of 2008 (Pub. L. 110–325), and other employment-related laws are discussed in Chapter 6, “Transition and Work.” The No Child Left Behind Act of 2001 (Pub. L. 107–110), Common Core State

Standards (Common Core State Standards Initiative, n.d.), and other school-based laws and initiatives are discussed in Chapter 4, “Transition Within School.” Education Pipeline (Forum for Youth Investment, 2010) and other general transition-related initiatives are discussed in Chapter 2, “Occupational Therapy and Transition.”

Additional current and pending federal regulations are summarized in Exhibit 5.1. Readers are encouraged to use the links provided to search the status of these regulations.

Exhibit 5.1. Current and Pending Federal Regulations Pertaining to Transition

Workforce Innovation and Opportunity Act (<http://www.dol.gov/WIOA>)

President Barack Obama signed the Workforce Innovation and Opportunity Act (WIOA; Pub. L. 113–128) into law on July 22, 2014. WIOA is designed to help job seekers access employment, education, training, and support services to succeed in the labor market and to match employers with the skilled workers they need to compete in the global economy. It supersedes the Workforce Investment Act of 1998 (Pub. L. 105–220) and amends the Adult Education and Family Literacy Act (or Title II of the Workforce Investment Act of 1998), and the Rehabilitation Act of 1998 (Pub. L. 105–220). The WIOA is scheduled to take effect on July 1, 2015, with full implementation within 1 year, unless otherwise noted. The U.S. Department of Labor will issue further guidance on the timeframes for implementation of the proposed regulations.

Under WIOA, state and local workforce boards are required to spend 15% of their vocational rehabilitation funds to provide transition services. The purpose of these funds is to make the transition from school to employment more coordinated between schools and adult vocational services.

Final Rule Amending Medicaid Regulations Section 1915(i) Home- and Community-Based Services (<http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Home-and-Community-Based-Services/Home-and-Community-Based-Services.html>)

(Continued)

Exhibit 5.1. Current and Pending Federal Regulations Pertaining to Transition (Cont.)

The final rule amends the Home- and Community-Based Services (HCBS) under the Patient Protection and Affordable Care Act (Pub. L. 111–148). This rule offers states new flexibilities in providing necessary and appropriate services to the elderly and people with disabilities. The rule, which became effective in March 2014, requires settings and programs funded under HCBS to provide opportunities for participants to engage in community life, have access to the community, control their personal resources, and seek employment and work in competitive settings. States were required to submit transition plans by March 17, 2015, showing how they plan to comply with the new requirements within 5 years.

Achieving a Better Life Experience Act, Division B
[\(<https://www.congress.gov/bill/113th-congress/house-bill/5771/text>\)](https://www.congress.gov/bill/113th-congress/house-bill/5771/text)

The Achieving a Better Life Experience (ABLE) Act (Pub. L. 113–295) was signed into law on December 19, 2014. It allows eligible people with disabilities the ability to establish “ABLE accounts” for qualified beneficiaries that resemble the qualified tuition programs, often called *529 accounts*. The new ABLE accounts will allow more individual choice and control over spending on qualified disability expenses and limited investment decisions while protecting eligibility for Medicaid, Supplemental Security Income, and other federal benefits for people with disabilities.

The Secretary of the Treasury is required to issue regulations and other necessary guidance within 6 months of enactment of the law, or mid-June 2015. Each state must then decide whether to offer a qualified ABLE program to its residents, and, if so, whether the program will be run by the state; by another entity, such as a financial services firm; or by another state under a special contract. On June 22, 2015, the Internal Revenue Service proposed rules for ABLE accounts, ([see <https://www.federalregister.gov/articles/2015/06/22/2015-15280/guidance-under-section-529a-qualified-able-programs>](https://www.federalregister.gov/articles/2015/06/22/2015-15280/guidance-under-section-529a-qualified-able-programs)). Practitioners are encouraged to follow the development of ABLE regulations in their own state.

IDEA

IDEA provides a definition for *transition services* that are mandated to all students receiving special education who are age 16 years:

[A] results-oriented process, that is focused on improving the academic and functional achievement of the child with a disability to facilitate the child's movement from school to post-school activities, including postsecondary education, vocational education, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation; [it] is based on the individual child's needs, taking into account the child's strengths, preferences, and interests. (§1401[34][A][B]).

Transition is not a predetermined program, such as a prevocational training program that all students attend. It is a longitudinal process that should lead the students' educational experiences throughout their school career (Orentlicher, 2013; Webb, Patterson, Syverud, & Seabrooks-Blackmore, 2008). Students' postsecondary goals should guide the types of classes in which students participate, their community-based experiences, and the types of specialized supports provided. An example of matching education, experiences, and supports with postsecondary goals can be seen in Adam's story. Frank met with the school staff to determine Adam's classes and vocational experiences in the SAIL program to prepare him for the community-based programs at CCF.

Transition planning

Transition planning must begin no later than age 16 years, with some states mandating schools to begin the transition process at age 14 years (e.g., Delaware, Iowa, Virginia) or 15 years (e.g., New York). The student must be invited to all IEP planning meetings in which transition is discussed (IDEA, 34 CFR §300.321[a]). Each student's IEP must include “appropriate measurable postsecondary goals based upon age-appropriate transition assessments related to training, education, employment, and, where appropriate, independent living skills” (IDEA, §1414[d][1][A][VIII]). Services, delivered

by the education agency or by agencies outside of the school, must be provided to assist students in meeting these goals.

Summary of performance

Before leaving school, each student must be provided with a **summary of performance (SOP; IDEA, §614[c][5][B][ii])**, which summarizes the student's current academic and functional abilities; postsecondary goals; and recommendations on methods to assist the student in achieving these goals, including accommodations and adaptations that proved beneficial in school. IDEA and its regulations clearly require an accountability system to assess the efficacy of services. For example, states must report on educational results and functional outcomes of students with disabilities in an annual State Performance Plan (34 CFR §300.600[b][1]).

2020 Federal Youth Transition Plan

A federal initiative that was developed to specifically support transition and improved outcomes for young adults with disabilities is the **2020 Federal Youth Transition Plan**, which was developed by the Federal Partners in Transition (FPT). The **FPT** is a workgroup with representatives from several federal agencies, including the U.S. Departments of Education, Health and Human Services, and Labor, and the Social Security Administration. It was formed in 2005 to establish interagency collaborations and to work together to support all youth, including youth with disabilities, in successfully transitioning from school to adult life. Its vision is to promote the full inclusion, integration, and participation of youth and adults with disabilities in the workforce and beyond (FPT Workgroup, 2015).

The report *2020 Federal Youth Transition Plan: A Federal Interagency Strategy* (FTP Workgroup, 2015) outlines how the partner agencies should work together to ultimately improve outcomes for youth with disabilities by 2020. Specifically, the workgroup is evaluating, establishing, and prioritizing policies so youth with disabilities will have an equal opportunity to

- Access health care services to better understand how to manage their physical, mental, and emotional well-being

- Access integrated work experiences in high school to enhance their job-readiness skills and career planning
- Develop self-determination, leadership, and advocacy skills and engage in self-directed individualized planning to prepare them for postsecondary education, health care management, vocational training, or employment
- Connect to programs, services, activities, information, and supports for which they are eligible
- Become financially literate and make informed choices about their lives
- Receive support from family members and other caring adults with high expectations to support them in achieving their goals.

For more about potential roles for occupational therapy in the 2020 Federal Youth Transition Plan, see Chapter 2, "Occupational Therapy and Transition."

Adult Services and Disability Benefits

To better conceptualize and plan for students' transition, it is important to understand the array of adult services and benefits available to eligible young adults upon leaving high school. Table 5.1 describes the main funding sources and providers of adult disability benefits for education, employment, and community living. Health care and medical benefits are discussed in Chapter 8, "Health Care Transition."

Transition Areas

IDEA identifies the following 7 focus outcome areas when planning and preparing for the transition to adult life:

1. Postsecondary education
2. Vocational education
3. Integrated employment (including supported employment)
4. Continuing and adult education
5. Adult services
6. Independent living
7. Community participation.

These transition areas are similar to the **areas of occupation** in the *Occupational Therapy Practice Framework*:

Table 5.1. Major Federal and State Disability Benefit Programs

Program	Description
State Vocational Rehabilitation (VR) Programs	State VR services offer a range of employment and independent living services with the goal of promoting a greater level of independence in work and living environments. Services provided include vocational counseling, vocational training, job placement, and consultation on disability, advocacy, and antidiscrimination rights through local independent living centers.
Medicaid's Home-and Community-Based Services (HCBS) Waiver Programs	The HCBS Waiver programs offer benefits for people with IDD, on a long-term basis, to remain in the community. Waiver recipients can choose where to live on their own or in smaller settings, rather than with their families or in large and restrictive institutions. Reimbursable services may include day and residential habilitation; employment supports such as job coaching; in-home assistance with ADLs; case management; speech, physical, and occupational therapy; assistive technology; transportation; behavior management; and respite care. A new type of HCBS Waiver, the self-directed waiver, is discussed in detail in Chapter 10, "Supportive Environments for Transition."
Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI)	The Social Security Administration's SSDI and SSI disability programs provide financial assistance to qualified people who have a disability and meet medical criteria. SSDI is an insurance program that pays benefits to people and qualified family members based on how long the person has worked and paid Social Security taxes. SSI pays benefits based on financial need.
Plan to Achieve Self-Support (PASS) of the Social Security Administration	PASS is a work incentive program that allows the use of personal income or assets to reach employment goals. When a person with disabilities obtains paid employment, rather than losing unemployment benefits such as SSI, the person can set aside the money for education or specialized training for a job or to start a business.

Note. ADLs = activities of daily living; IDD = intellectual and developmental disabilities.

Domain and Process (3rd ed., *Framework*; American Occupational Therapy Association [AOTA], 2014).

Postsecondary Education and Continuing and Adult Education

The focus on postsecondary education includes preparation for both college and lifelong learning. The *Higher Education Opportunity Act of 2008* (Pub. L. 110–315) expanded the opportunities for students with disabilities to access postsecondary education programs by providing grants and loans for both credit and noncredit programs. Colleges and universities around the country now provide educational programs specifically tailored for young adults with disabilities such as IDD and ASD (Grigal & Hart, 2010).

Hart, Grigal, Sax, Martinez, and Will (2006) described three types of programs available to students with disabilities:

1. *Mixed or hybrid model.* This model combines both academic classes and social experiences with

typical students and classes specifically tailored to students with disabilities, such as life and social skills. This is the type of program Adam was considering attending at his local community college.

2. *Substantially separate model.* All classes taken are designed specifically for students with disabilities. Interaction with typical students occurs mainly through social functions on campus.
3. *Inclusive individual support model.* Students with disabilities enroll in the typical classes offered at the college, with or without reasonable accommodations.

College preparation includes deciding on the size and type of college and appropriate residential solutions, identifying academic supports and accommodations, and developing effective study skills. Lifelong learning includes identifying interests and learning new hobbies and avocations. While in school, students with disabilities should be given opportunities to try different areas of learning and experience new activities.

Vocational Education and Integrated Employment

The most substantiated best practices in transition are paid and unpaid work experiences, employment preparation emphasizing job-searching skills, and vocational training (Landmark et al., 2010). Young adults who participate in **vocational training** in community employment sites throughout high school and who obtain paid or unpaid jobs before graduation are more successful in obtaining and maintaining paid work in the community as adults (Colley & Jamison, 1998; Fabian, 2007; Luecking & Gramlich, 2003; McDonnell & Crudden, 2009; White & Weiner, 2004).

Note that although 71% of adults with disabilities are currently served in **segregated day programs** (i.e., programs in which people with disabilities participate in nonwork activities during the day with other people with disabilities, usually in a specialized location) or **sheltered workshops** (i.e., a facility that exclusively employs persons with disabilities, below minimum wage, with little or no contact with people without disabilities); (Braddock, Rizzolo, & Hemp, 2010), these programs are not considered acceptable employment outcomes for young adults with disabilities (Bates-Harris, 2012; Rogan & Rinne, 2011; Wehman & Brooke, 2013). Emphasis on integrated employment options in the community is based on the belief that everyone, including those with intellectual or other severe disabilities, can work, with the appropriate short- or long-term supports (Migliore, Mank, Grossi, & Rogan, 2007; TASH, 2009; Wehman & Brooke, 2013).

“Being employed” or “having a job” means participating in and contributing to the work environment in some way. For young adults with severe physical and intellectual disabilities, this may mean identifying the one or several tasks that they can do to contribute to a work setting in their community (Hughes, Pitkin, & Lorden, 1998; Orentlicher, 2013; TASH, 2009; Wehman & Brooke, 2013).

Successful employment outcomes include self-employment, internships, competitive or supported employment, or customized employment. **Supported employment** means integrated employment in the community, within typical companies, for people with disabilities who traditionally have not had access to the job market. Supports are provided inside and outside of the workplace and may include a job coach, task and environmental adaptations, assistive

technology, and specialized transportation to and from work (Wehman, Inge, Revell, & Brooke, 2007). This is the type of program attended by Adam at CCF.

Customized employment is a process in which a new job is created within a business that matches the person’s abilities and skills. Better outcomes produced by supported employment were affirmed in a study by Wehman, Chan, Ditchman, and Kang (2014). Young adults with IDD who participated in supported employment had, on average, a 12.49% higher employment rate than those who did not participate in supported employment.

Adult Services

While still in high school, students should be connected with and begin the process of obtaining adult disability benefits. Table 5.1 provides an overview of the main funding programs for employment, education, independent living, and community integration. Chapter 8, “Health Care Transition,” provides considerations for securing medical benefits. Students and families should also be provided with information to help them connect to organizations that provide advocacy support and help protect the rights of people with disabilities, such as local independent living centers or other disability volunteer network groups.

As seen in Adam’s story, his parents were encouraged to connect with a disability lawyer to establish a disability trust. Another complex legal matter to consider is guardianship. Guardianship, by definition, limits opportunities for people with disabilities to make independent choices and exercise self-determination (Millar, 2014).

Other, less restrictive options are available, including **supported decision making**, which allows the person with disabilities to get help from trusted friends, family members, or professionals in making decisions but to retain control over who provides that help and what the ultimate decisions will be (Jameson et al., 2015). Most adults with disabilities are able to enter into an agreement for supported decision making even if the law would not recognize them as having the capacity to enter into a contract (Blanck & Martinis, 2015; Quality Trust for Individuals With Disabilities, 2013). It is important to connect with an expert familiar with the legal intricacies of selecting the right supported-decision model for the person. It is also important to get an identification card for the student, even if the student does not drive or is not expected to live alone.

Independent Living

Choosing a residential option is a tough choice for families to make. For example, Adam and his family were not ready to consider independent living options at the time of his high school graduation. Owning a home is expensive and requires careful planning and resource allocation, as described by Cheryl in the “Prologue.” In some towns, people with disabilities are eligible to apply for subsidized housing. Other specialized options include supported housing, small or large group homes, or intermediate care facilities. Even if a student may not be ready to leave home upon graduation, it is important to consider possible options for the future because many specialized residential programs have long wait lists and other more independent options require long-term financial planning.

Independent living skills, including both basic and instrumental, should be taught to students while in high school. Examples of life skills that all students should learn are taking care of health needs; handling emergencies; using household appliances; managing finances; and taking care of laundry, cleaning, and other housekeeping tasks.

Community Participation

Adolescents with disabilities may have fewer opportunities than typical adolescents to participate in social and leisure activities. It is important to promote the participation of young adults in activities outside of work, specifically activities that provide opportunities for socialization and for the young adult to demonstrate special interests and talents (Orentlicher & Olson, 2010). In her study exploring the transition experiences of young adults with severe disabilities, Orentlicher (2008) found that promoting socialization and securing recreational options are especially important for young adults who work in integrated settings but who do not make friends or become socially involved with coworkers. These young adults reported being socially isolated.

Leisure activities can be typical community-based options, such as swimming in the local pool, working out in a local gym, or joining a book club or a bowling team. Specialized options for young adults with disabilities include Special Olympics and programs offered by disability service organizations.

For example, Adam chose to attend the leisure program at CCF. In addition, many young adults with disabilities take advantage of opportunities for socialization online, specifically through social media. It is important to provide Internet safety training so students can learn about communicating with familiar people and strangers, securing personal information, and practicing netiquette.

Another important aspect of community integration is transportation. Consideration of program options should include how the young adult will travel there. For example, Adam chose not to attend the community college program because he felt uncomfortable using the local bus on his own. Travel training should be provided to students who plan to use public transportation. Specialized transportation services tend to be costly but may be covered by the young adult’s disability benefit program.

Occupational Therapy and Transition From School to Adult Life

Occupational therapy practitioners are uniquely qualified to support students with disabilities as they prepare for and engage in the transition from school to adult life. Practitioners understand human occupation and function as they relate to individual skills and interests, task demands, and environmental contexts and cues (Michaels & Orentlicher, 2004; Orentlicher, 2013). They can perform analysis of anticipated roles and requirements, evaluate skills and needs in relation to specific tasks within these roles, and suggest environmental or task adaptations to increase function and participation (Handley-More, Wall, Orentlicher, & Hollenbeck, 2013; Orentlicher, 2007; Spencer, Emery, & Schneck, 2003).

Moreover, the philosophy of occupational therapy practice closely resembles the philosophy of practice promoted by IDEA. Best practices in transition focus on providing opportunities for students with disabilities to identify preferences, make choices in everyday life, and participate in meaningful current and future activities. This focus is consistent with occupational therapy’s specific focus on occupational engagement in meaningful activities within natural environments and client-centered interventions.

Transition Evaluation

The Division on Career Development and Transition (DCDT) of the Council for Exceptional Children defines *age-appropriate transition assessment* as,

an ongoing process of collecting information on the youth's needs, strengths, preferences, and interests as they relate to measurable postsecondary goals and the annual goals that will help facilitate attainment of postsecondary goals. This process includes a careful match between the characteristics of the youth and the requirements of secondary environments and postsecondary environments along with recommendations for accommodations, services, supports, and technology to ensure the match. Youth and their families are taught how to use the results of transition assessment to drive the transition requirements in the IEP process, develop the SOP document, and advocate for needed or desired supports to succeed in meeting postsecondary goals. (Neubert & Leconte, 2013, p. 74)

Types of Evaluation

The National Secondary Transition Technical Assistance Center (2013) recommended a combination of several types of evaluation, including formal and informal pencil-and-paper tests, structured student and family interviews, community- or work-based situational assessments, and curriculum-based assessments.

Formal measures include standardized tools that measure performance skills, client factors, aptitude, interests, adaptive behavior, independent living skills, transition readiness, career abilities, and self-determination. **Informal measures** are nonstandardized and include interviews or questionnaires, direct observations, anecdotal records, and environmental or situational analyses. The primary strength of informal measures is their direct relevance to the individual student and the environments in which he or she plans to learn, work, and live. In addition, informal measures can be developed or modified to focus on specific skills relevant to the student's daily life rather than generic traits or abilities (Hughes & Carter, 2002). The *Framework* (AOTA, 2014) also

directs occupational therapists to consider contexts for participation and include observations of task performance in natural environments. Informal assessments should be student centered, allowing students to participate in decisions regarding which procedures to use, possible modifications, and interpretation and application of the results (Hughes & Carter, 2002).

Evaluation Frameworks

The transition evaluation process can be viewed within a framework. One useful framework, the *Assess, Plan, Instruct, and Evaluate model*, was proposed by Sitlington, Neubert, Begun, Lombard, and Leconte (2007). It incorporates a variety of methods for assessing the student and potential future work, education, and living environments. Results help occupational therapy practitioners make decisions about how best to match the student with his or her potential environments and what accommodations or modifications may be required to enhance participation, which is the most important contribution occupational therapists can make to the evaluation process. The four steps for this model include

- *Step 1. Assess.* Assess the student's interests, preferences, and needs related to desired postschool outcomes using formal and informal assessments.
- *Step 2. Plan.* Interpret the results from the assessments and incorporate them into the student's IEP.
- *Step 3. Instruct.* Teach the student the skills he or she will need to reach the postschool goals. Recommend accommodations, modifications, and adaptations.
- *Step 4. Evaluate.* Evaluate whether progress has been made toward achieving the transition goals and whether the student is better able to engage in desired activities in the potential environments.

Sitlington and Clark (2001) suggested that the transition evaluation should answer these three questions:

1. Where is the student presently?
2. Where is the student going?
3. How will the student get there?

The transition evaluation is an ongoing and a dynamic process, particularly because new self-discoveries and interests, which are a natural part of adolescent development, foster new goals and aspirations for the future (Orentlicher, 2007).

Occupational Profile

Occupational therapists can contribute to the transition evaluation process by completing an *occupational profile* and analyzing the gap between current and desired occupational performance. When occupational performance is analyzed, the therapist should consider the following factors (Orentlicher, 2007):

- Interests and student and family preferences
- Sensory and motor skills
- Cognitive performance
- Daily living and community living skills
- Vocational skills
- Socialization skills
- Skills in self-determination and self-advocacy.

Table 5.2 lists a sample of recommended transition assessment tools for occupational therapy. Additional tools can be found in the Transition Assessment Toolkit of the National Secondary Transition Technical Assistance Center (2013).

Informal Approaches

Occupational therapists should use informal approaches (Orentlicher, 2007), such as

- Functional assessments (i.e., the measurement of purposeful behavior in interaction with the environment),
- Situational assessments (i.e., behavioral assessments in real settings),
- Ecological inventories (i.e., environmental assessments), and
- Task and activity analyses.

In addition to these approaches, the transition literature recommends creating portfolios that include “collections of information by and about a student to give a broad view of his or her achievement” (Mabry, 1999, p. 17). A portfolio can include samples of student work, narrative descriptions,

résumés, grades, student self-evaluations, and photographic records (e.g., pictures of the student performing job tasks). The portfolio can also serve as a starting point for the SOP.

Discovery for Employment

Another informal method for getting to know the student and securing employment is known as *discovery* (Wehman & Brooke, 2013). *Discovery* means learning about the student and creating a profile of his or her interests and strengths, the ideal employment conditions, and available employment opportunities in his or her community. Once the profile is created, young adults can then pursue internships, competitive or supported employment, or customized employment close to home.

Occupational therapy practitioners should play a key role in the process of discovery because it is similar to creating an occupational profile (Orentlicher, 2013). An occupational profile begins with the person's desired meaningful occupations and continues with an analysis of the gap between current and desired occupational performance. When occupational performance is analyzed as part of the process of discovery for employment, the formal and informal strategies described previously should be included, with a specific focus on meaningful engagement in potential work environments.

Person-Centered Planning

Person-centered planning is an alternative process for transition evaluation that is frequently suggested as a best-practice approach that can empower students' self-determination and increase their involvement in transition planning (Austin & Wittig, 2013; Orentlicher, 2011). *Person-centered planning* is an umbrella term that is used to describe a group of procedures and planning strategies that propose an informal but structured way of setting goals and implementing transition plans for young adults with disabilities (Austin & Wittig, 2013).

Although the various person-centered planning tools are slightly different from each other, in general, they all require professionals and unpaid people (e.g., family members, friends, community members) to follow specific steps to learn about the young adult and his or her interests, preferences, and desired lifestyle;

Table 5.2. Sample Recommended Transition Assessments

Tool	Description
School Function Assessment (SFA); Coster, Deeney, Haltiwanger, & Haley, 1998	The SFA is used to evaluate and monitor students' performance of functional tasks and activities. Although the SFA was designed for students through sixth grade, it can be used to identify relative strengths and weaknesses and measure students against themselves in subsequent years.
Children's Assessment of Participation and Enjoyment (CAPE) and Preferences for Activities of Children (PAC; King et al., 2004)	The CAPE and PAC are questionnaire-based assessments that are completed by self-report or by interview. The CAPE measures multiple dimensions of participation, including participation diversity, intensity, with whom and where participation occurs, and enjoyment. The PAC measures activity preference. Both measures include 55 informal and formal activities that are organized into five activity types: recreational, active-physical, social, skill based, and self-improvement.
Canadian Occupational Performance Measure (COPM; Law et al., 2005)	The COPM measures students' self-perception of performance in everyday living activities over time.
Community-Based Skills Assessment (CSA; Autism Speaks, 2014)	The CSA's purpose is to help create transition plans for students. It assesses a student's knowledge, skills, and social communication abilities.
Transition Assessment and Goal Generator (TAGG; Martin et al., 2015)	TAGG is a new web-based assessment to help identify students' skills, strengths, and needs and to suggest measurable annual transition goals referenced to common core standards.
BRIGANCE® Transition Skills Inventory (TSI; Brigance, 2010)	The TSI assesses job-oriented, academic, and functional life skills in the context of employment, postsecondary education, and community participation. It focuses on a broad range of skills, including preemployment and functional writing, career awareness, job seeking, postsecondary opportunities, functional reading, speaking and listening, math, money and finance, technology, housing, food and clothing, health, travel and transportation, and community resources.
Transition Planning Inventory—Updated Version (Clark & Patton, 2009)	The Transition Planning Inventory evaluates students' readiness for transition in nine areas: employment, further education and training, daily living, leisure activities, community participation, health, communication, self-determination, and interpersonal relationships. It can be given in three ways: oral, self-administration, or guided administration, and input is gained from the student, parent, and school staff.
Arc Self-Determination Scale (Wehmeyer & Kelchner, 1995)	The Arc Self-Determination Scale is a student self-report that measures self-determination. It has 72 items in four sections: autonomy, self-regulation, psychological empowerment, and self-realization.
Picture Interest Career Survey (PICS; Brady, 2011)	The PICS is a quick measure that identifies students' occupational interests by using pictures of people at work rather than text-based items.
Reading Free Vocational Interest Inventory-Revised (R-FVII:2; Becker, 2000)	The R-FVII:2 measures the vocational interests of students with disabilities by using 55 sets of pictures of people engaged in different occupations.
McCarron-Dial System (McCarron & Dial, 2005)	The McCarron-Dial System identifies strengths and needs in five areas of functioning: verbal-cognitive language, learning ability and achievement; sensory perceiving and experiencing the environment; motor muscle strength, speed and accuracy of movement, balance, and coordination; emotional response to interpersonal and environmental stress; and integration-coping adaptive behavior.

describe what needs to be done to help the young adult move toward the desired lifestyle; and outline an action plan to achieve the desired goals (Michaels & Orentlicher, 2004). The meetings are typically held in less formal settings, such as the student's home, with the student's choice of food and music.

The goal of person-centered planning is to create a structure of future activities for the student that will reduce the student's social isolation and segregation, provide opportunities for new friendships, develop the student's competence, and promote respect for the student (Holburn & Vietze, 2002). This process strongly emphasizes the student making choices, taking initiatives, accepting responsibilities, and learning from his or her failures and achievements.

Person-centered planning tools

Commonly used person-centered planning tools include Personal Futures Planning (Mount, 2000), Group Action Planning (Turnbull & Turnbull, 1996), Essential Lifestyle Planning (Smull, 1997), Making Action Plans (O'Brien, Pearpoint, & Kahn, 2010), PATH, and Circles of Support (Falvey, Forest, Pearpoint, & Rosenberg, 1997; Forest & Pearpoint, 1992). Each tool outlines specific steps that the team must follow throughout the planning process.

For example, when facilitating Adam's person-centered planning, Frank used the PATH. The PATH emphasizes goal development, starting with the long-term goals that are based on the student's vision and dreams for the future and ending with short-term objectives and a specific plan to achieve the goals. The short-term objectives are broken further into small steps that can be done immediately (Michaels, 1998; Orentlicher, 2011). In the "Prologue," Cheryl described how the person-centered planning process assisted them in developing a transition plan for Renzo. The plan has been reevaluated and revised several times to ensure that it continues to reflect Renzo's dreams and vision for his life.

Resources for person-centered planning

Person-centered planning is now commonly used to plan the person with disabilities' individual service plan (ISP) when applying for Medicaid self-directed Home- and Community-Based Services (HCBS) Waivers (see Chapter 10, "Supportive Environments for Transition"). Thus, many states began to offer a

variety of workshops, at no cost, on person-centered planning. Readers are encouraged to look for training in their state or online through organizations such as

- Person-Centered Planning Center at Cornell University (<http://www.personcenteredplanning.org/>),
- Institute on Disability at the University of New Hampshire (http://www.iod.unh.edu/projects/archived/if/training_workshops.aspx),
- Inclusion Network (<http://www.inclusion.com/inclusionnetwork.html>), or
- Learning Community for Person Centered Practices (<http://www.learningcommunity.us/home.html>).

See Appendix 5.A for a list of resources to support transition from school to adulthood.

Transition Interventions and Services

Practitioners can use data obtained from transition interventions such as standardized assessments, informal interviews and observations, ecological inventories, and task and activity analyses to create services such as specific training and activities or task and environmental adaptations and modifications. These services may include strategies to promote competence, environmental strategies to promote participation, strategies to promote self-determination, and working with families.

Strategies to Promote Competence

Almost 20 years ago, Hughes et al. (1997) identified critical support strategies that proved to be most effective in achieving student competence and positive outcomes across transition focus areas. These support strategies are still valued today and include development of social skills, social competence and emotional regulation, self-management and independent living skills (basic and instrumental), time management, financial management and budgeting, health maintenance, choice and decision making, vocational skills and work behaviors, and specific skills related to the student's chosen recreational activities. Several examples of these support strategies for occupational therapy services in transition are provided in Exhibit 5.2.

Exhibit 5.2. Sample Strategies for Occupational Therapy Service Delivery in Transition

- Social skills, social competence, and emotional regulation*
- Teach discrete skills, such as initiating or taking turns in conversations, or clusters of skills, such as cooperation or assertion skills in group settings, using role-play and social stories.
 - Teach peers and coworkers how to interact with the student with disabilities.
 - Teach students to use their emotions as cues and guides in social interactions. For example, anger can be a cue that one's rights are not being recognized and that a social situation is not fair or comfortable. Teach students to strategize and advocate for getting their needs and desires met in an assertive and productive way.
 - Teach students to identify signs of impending emotional stress and explore strategies to proactively regulate their emotions in their everyday environments. For example, teach students to walk outside to a quiet place, politely excuse themselves from stressful social interactions, or go for a run.

Self-management and independent living skills

- Use backward chaining: Require students to perform the last step of a task.
- Use forward chaining: Teach the steps to complete a task in order. Teach Step 1 first. When Step 1 is mastered, teach Step 2. Continue until all steps are mastered.
- Use visual checklists, which are task analyses or schedules that include steps that students can read and then check off once completed. Visual checklists can be created using words or pictures on dry-erase boards, laminated index cards, or electronic devices such as smart phones or iPads.
- Use video self-modeling. Create a short video, using the student as the "star." In the video, the student performs the desired skill. The video is then used for further teaching and reinforcement.

Time management

- Teach the concept of time (as opposed to reading time) by adding a time component to every task analysis. Ask young adults to estimate and then measure how long it takes to perform various tasks and their component steps.

- Use an analog clock. Although digital clocks are easier to read, analog clocks give children a better sense of how swiftly time passes.
- Set timers and alarms to motivate targeted behaviors. For example, to help with transitions, tell students how long they have to complete a task, and then set an alarm to signal when time is up.
- Help young adults to establish routines that eliminate wasted time and allow them to move smoothly from one activity to the next. For example, schedule restroom breaks for maximum efficiency.
- Help young adults create visual schedules and refer to them throughout the day, noting the time allotted for each activity. Attach a daily to-do list to the schedule, and teach young adults to cross off accomplished tasks. Have them add personal reminders, such as "bring lunch money" or "go to grocery store after work," and practice prioritization.

Financial management and budgeting

- Provide students with a budget and ask them to "shop" online for groceries, clothing, music and books, and more. Practice making adjustments to stay within the budget limit.
- Provide students with a budget and ask them to plan how to use the money for 1 week or 1 month to maintain a household. Provide scenarios such as a leaking roof or a flat tire.
- Provide students with "credit cards" to use at the school lunchroom or student-managed store.
- Bring in sample pay stubs and teach students how to read them. Focus on the difference between gross and net income.

Vocational skills and work behaviors

- Schedule work experiences for students at the school, and have students treat them like real jobs. For example,
 - Have students create a résumé to send to the school employee in charge (i.e., head of cafeteria, gardener, nurse, librarian), inquire about jobs, practice interviewing skills, schedule interviews, and ask for reasonable accommodations.
 - Have students come to school in appropriate work clothes on work days. To encourage appropriate dress, display visual reminders that include pictures of young adults wearing appropriate clothing for each season and for different occasions (e.g., job interview, company outing).

(Continued)

Exhibit 5.2. Continued

- Recommend optimal shifts and working hours that correspond to students' needs. For example, a young adult who is fed by a gastronomy tube may need to work around feeding schedules.
- Recommend the optimal workstation location for students. For example, a young adult who uses a wheelchair should work close to the accessible bathroom and fire exit.

Study skills in preparation for postsecondary education

- Teach students to break large assignments into small steps. Use schedules and calendars to establish "mini due dates" for completing the small steps.
- Color code the assignment schedule by subject.
- Use flash cards (or the app gFlashPro [gWhiz, Annapolis, MD]) to summarize major concepts.
- Tour students' college, and select the preferred environments for studying. Make sure that the sensory characteristics (i.e., noise level, light) of these environments match the student's needs.
- Use technology to assist in studying (e.g., personal digital assistants, tablets, assistive technology).

Note. Adapted from "Best Practices in Postsecondary Transition Planning With Students," by M. L. Orentlicher. In G. Frolek Clark & B. E. Chandler (Eds.), *Best Practices for Occupational Therapy in Schools*, Bethesda, MD: AOTA Press, p. 250. Copyright © 2013 by the American Occupational Therapy Association. Used with permission.

Environmental Strategies to Promote Participation

To promote student participation, the following environmental strategies can be used:

- Identify coworkers, peers, and family members who can provide supports to students in naturally occurring events (e.g., neighbor who takes the bus to work can assist the student with getting on the bus in the morning).
- Use naturally existing cues (e.g., clock on the wall that signals break time, sign that directs employees to wash hands).
- Modify and adapt the environment, tasks, or tools (e.g., using an electric stapler instead of a manual one, securing a tray on the person's wheelchair for carrying paper or other items).

Strategies to Promote Self-Determination

Evidence shows that self-determination is the most necessary skill for students with disabilities to succeed in adult life. For example, self-determination correlates with better work experiences and financial stability (Barnard-Brak, Schmidt, Wei, Hodges, & Robinson, 2013; Lee & Carter, 2012; McConnell et al., 2013).

A program directed at enhancing students' self-determination should be a mandatory part of the transition planning process. Students with disabilities should be encouraged to practice self-determination skills. For example, throughout the school day, students should have opportunities to make choices, solve problems, set goals, and take risks (Wehmeyer, Palmer, Youngsun, Williams-Diehm, & Shogren, 2011; Wehmeyer & Shogren, 2013).

Provide opportunities

Using client-centered practice, occupational therapy practitioners should provide students with disabilities with opportunities for self-determination. When setting goals students should be given several options and discuss possible consequences of choosing one goal over another. Detailed plans should be made on how to achieve the selected goals, including possible challenges and their solutions. Students should be encouraged to evaluate their own performance toward achieving their goals. Wehmeyer, Agran, and Hughes (1998) included independent living skills as components of self-determination, arguing that independence in living skills increases a person's sense of dignity, which is vital for self-determination.

Mentoring

Mentoring by older adults with disabilities is a strategy that has proved successful in teaching students self-determination skills. For example, Barnard-Brak et al. (2013) implemented a mentoring program during the transition process for students with disabilities. Each mentor met with a student for 1 hour a week throughout the school year to practice skills such as self-advocacy. The mentors also discussed and provided examples on how self-determination improved their lives,

allowing them to be independent. In addition, the mentors taught the students how to independently fill out forms and apply for programs such as financial aid in college.

Working With Families

Widely recognized as important to successful transition, family involvement has been substantiated as a best practice (Landmark et al., 2010; Test et al., 2009). Although professionals come and go, parents, and especially mothers, are often the ones that piece together their children's programs and services and serve as their advocates (Ankeny, Wilkins, & Spain, 2009; Caldwell, 2006; Kim & Turnbull, 2004; Orentlicher, 2008).

Evidence suggests that the impact of family involvement lasts way beyond high school and into adult life, even when young adults move away from their parents' home to other settings, such as group homes (Baker & Blacher, 1993; Blacher & Baker, 1994; Hagner et al., 2012; Kraemer & Blacher, 2001; McIntyre, Kraemer, Blacher, & Simmerman, 2004; Seltzer, Krauss, Hong, & Orsmond, 2001). For example, Lee and Carter (2012) affirmed that "parents can play an important role in shaping their children's career identities" (p. 993). They explained that family members can offer support and guidance to youth with disabilities and help them develop interests and strengths for their future and look for jobs, fill out applications, and provide transportation to and from the job site.

Involvement, participation, and feedback on services by families of young adults with IDD were also correlated with increased engagement in the community (Wituk, Pearson, Bomhoff, Hinde, & Meissen, 2007). People with IDD have become increasingly more likely to be living with family members while receiving Medicaid HCBS Waiver services than living on their own (Hewitt, Agosta, Heller, Williams, & Reinke, 2013). However, Hewitt et al. (2013) identified large gaps between families' needs and the type, quality, and amount of available supports and services provided.

The *Framework* (AOTA, 2014) identifies contexts for occupational therapy intervention, which include family members and others in the young adult's environment (i.e., the social context). Occupational therapy practitioners can address the challenges of

family involvement (Orentlicher, 2013) by using the following strategies:

- Assist parents to establish daily routines that balance taking care of their child with disabilities with their own desired meaningful occupations that promote self-actualization. For example, for several years, Cheryl neglected her own meaningful occupations to take care of Renzo and manage his household (see "Prologue"). A more balanced occupational profile would include her devoting time to painting and writing, two of her most meaningful occupations.
- Encourage parents to seek opportunities that will promote both their and their children's quality of life. For example, search for respite or weekend programs offered by local organizations. The child may benefit from the recreational activities, while the parents may receive much-needed time off.
- Research and learn about the disability services system in your state and county. Provide information to and assist families in navigating the system and in advocating for their needs.

Transition Preparation Throughout School: From Elementary to High School

Although IDEA mandates that transition services should begin no later than age 16 years, literature on best practices in transition recommends beginning to teach even younger students transition-related skills appropriate for their development stage such as instrumental activities of daily living (IADLs), organizational skills, following directions, social skills, and self-determination (Brinckerhoff, 2008; Michaels & Orentlicher, 2004; Wehmeyer, 2015). For example, Brinckerhoff (2008) recommended that eighth-grade students learn skills such as time management, money management, and communication skills and explore career areas through field trips, job shadowing, and volunteer work. Luecking (2009) promoted addressing work readiness and work training experiences before high school to better prepare students for work experiences in high school and beyond.

Occupational therapy practitioners are in an excellent position to teach IADLs, social skills, and work readiness skills to students in elementary and middle school. These skills can be taught to entire

classrooms or groups of selected students. The following are some suggested strategies for teaching such skills:

- *Baking and cooking group.* In addition to baking and cooking skills, students learn about healthy nutrition and how to design balanced menus, budget for and purchase ingredients, and organize and clean the kitchen. To further learn budgeting and basic business management skills, the students can bake cookies and sell them to staff.
- *Supplies and recycling program.* Students can “run errands” for other classrooms, such as getting supplies from the stock room; using the copier; and collecting, shredding, or recycling paper.

Summary

Best practices in transition advocate that successful transition can be achieved through engaging young adults with disabilities in meaningful community-based activities and by addressing performance skills, performance patterns, client factors, activity demands, and contexts in ways that are directly aligned with the young adult’s dreams, strengths, and desires. Occupational therapy practitioners should gain information about the young adult’s desired life and meaningful occupations. It is the practitioner’s responsibility to create a match between the young adult and his or her desired environments so that he or she is better able to engage in meaningful occupations.

Transition evaluation should use both formal and informal approaches and person-centered planning. Service delivery should include both young adult training and environmental and task adaptations in employment, higher education, recreation, and independent living. While still in school, connections should be made between the young adult and the adult disability services in his or her community. Additional supports should be provided to families, so they, too, can reach self-actualization.

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References

- Achieving a Better Life Experience (ABLE) Act, Pub. L. 113–29, 128 Stat. 4010.
- American Occupational Therapy Association. (2014). Occupational therapy practice framework: Domain and process (3rd ed.). *American Journal of Occupational Therapy*, 68(Suppl. 1), S1–S48. <http://dx.doi.org/10.5014/ajot.2014.682006>
- Americans With Disabilities Act Amendments Act of 2008, Pub. L. 110–325, 122 Stat. 3553.
- Ankeny, E. M., Wilkins, J., & Spain, J. (2009, July/August). Mothers’ experiences of transition planning for their children with disabilities. *Teaching Exceptional Children*, 41, 28–36.
- Austin, K., & Wittig, K. M. (2013). Individualized transition planning: Building the roadmap to adulthood. In P. Wehman (Ed.), *Life beyond the classroom: Transition strategies for young people with disabilities* (5th ed., pp. 95–119). Baltimore: Paul H. Brookes.
- Autism Speaks. (2014). *Community-Based Skills Assessment (CSA): Developing a personalized transition plan*. Retrieved from http://www.autismspeaks.org/sites/default/files/documents/family-services/community_assessment_tool_kit.pdf
- Badia, M., Orgaz, M. B., Verdugo, M. Á., & Ullán, A. M. (2013). Patterns and determinants of leisure participation of youth and adults with developmental disabilities. *Journal of Intellectual Disability Research*, 57, 319–332. <http://dx.doi.org/10.1111/j.1365-2788.2012.01539.x>
- Baer, R. M., Daviso, A. W., Flexor, R. W., McMahan, Q. R., & Meindl, R. (2011). Students with intellectual disabilities: Predictors of transition outcomes. *Career Development for Exceptional Individuals*, 33, 132–141. <http://dx.doi.org/10.1177/0885728811399090>
- Baker, B. L., & Blacher, J. (1993). Out-of-home placement for children with mental retardation: Dimensions of family involvement. *American Journal on Mental Retardation*, 98, 368–377.
- Barnard-Brak, L., Schmidt, M., Wei, T., Hodges, T., & Robinson, E. L. (2013). Providing post-secondary transition services to youth with disabilities: Results of a pilot program. *Journal of Postsecondary Education and Disability*, 26, 135–144.
- Bates-Harris, C. (2012). Segregated and exploited: The failure of the disability service system to provide quality work. *Journal of Vocational Rehabilitation*, 36, 39–64.
- Becker, R. L. (2000). *Reading Free Vocational Interest Inventory—Revised (R-FVII:2)*. Austin, TX: Pro-Ed.

- Blacher, J., & Baker, B. L. (1994). Family involvement in residential treatment of children with retardation: Is there evidence of detachment? *Journal of Child Psychology and Psychiatry and Allied Disciplines*, 35, 505–520.
- Blanck, P., & Martinis, J. G. (2015). "The right to make choices": The National Resource Center for Supported Decision-Making. *Inclusion*, 3, 24–33.
- Braddock, D., Rizzolo, M., & Hemp, R. (2010). Most employment services growth in developmental disabilities during 1988–2002 was in segregated settings. *Mental Retardation*, 42, 317–320.
- Brady, R. P. (2011). *Picture Interest Career Survey (PICS)* (2nd ed.). Austin, TX: Pro-Ed.
- Brigance, A. H. (2010). *Brigance Transition Skills Inventory (TSI)*. Retrieved from <http://www.brigance.net/>
- Brinckerhoff, L. C. (2008). Appendix 11A: A timetable for transition planning for students with learning disabilities. In G. Blalock, J. R. Patton, P. Kohler, & D. Bassett (Eds.), *Transition and students with learning disabilities* (2nd ed., pp. 301–305). Austin, TX: Hammill Institute on Disabilities.
- Caldwell, J. (2006). Consumer-directed supports: Economic, health, and social outcomes for families. *Mental Retardation*, 44, 405–417.
- Carter, E. W., Swedeon, B., Walter, M. J., Moss, C. K., & Hsin, C. T. (2011). Perspectives of young adults with disabilities on leadership. *Career Development for Exceptional Individuals*, 32, 57–67. <http://dx.doi.org/10.1177/0885728810387411>
- Certo, N., Luecking, R. G., Murphy, S., Brown, L., Courey, S., & Belanger, D. (2008). Seamless transition and long-term support for individuals with severe intellectual disabilities. *Research and Practice for Persons With Severe Disabilities*, 33, 85–95.
- Cimera, R. E., Burgess, S., & Wiley, A. (2013). Does providing transition services early enable students with ASD to achieve better vocational outcomes as adults? *Research and Practice for Persons With Severe Disabilities*, 38, 88–93.
- Clark, G. M., & Patton, J. R. (2009). *Transition Planning Inventory: Updated version*. Austin, TX: Pro-Ed.
- Colley, D., & Jamison, D. (1998). Post-school results for youth with disabilities: Key indicators and policy implications. *Career Development for Exceptional Individuals*, 21, 145–160.
- Common Core State Standards Initiative. (n.d.). *Mission statement*. Retrieved from <http://www.corestandards.org/>
- Coster, W., Deeney, T., Haltiwanger, J., & Haley, S. (1998). *School Function Assessment*. San Antonio, TX: Psychological Corp.
- Davies, M. D., & Beamish, W. (2009). Transitions from school for young adults with intellectual disability: Parental perspectives on "life as an adjustment." *Journal of Intellectual and Developmental Disabilities*, 34, 248–257. <http://dx.doi.org/10.1080/1366825090310367>
- Fabian, E. S. (2007). Urban youth with disabilities: Factors affecting transition employment. *Rehabilitation Counseling Bulletin*, 50, 130–138.
- Falvey, M. A., Forest, M., Pearpoint, J., & Rosenberg, R. L. (1997). *All my life's a circle: Using the tools: Circles, MAPS, and PATH*. Toronto: Inclusion Press.
- Federal Partners in Transition Workgroup. (2015). *The 2020 Federal Youth Transition Plan: A federal interagency strategy*. Retrieved from <http://www.dol.gov/odep/pdf/20150302-FPT.pdf>
- Flexor, R. W., Daviso, A. W., Baer, R. M., Queen, R. M., & Meindl, R. S. (2011). An epidemiological model of transition and postschool outcomes. *Career Development for Exceptional Individuals*, 34, 83–94. <http://dx.doi.org/10.1177/0885728810387922>
- Foley, K. R., Jacoby, P., Girdler, S., Bourke, J., Pikora, T., Lennox, N., ... Leonard, H. (2013). Functioning and post-school transition outcomes for young people with Down syndrome. *Child: Care, Health and Development*, 39, 789–800. <http://dx.doi.org/10.1111/cch.12019>
- Forest, M., & Pearpoint, J. (1992). Common sense tools: MAPS and Circles. In J. Pearpoint, M. Forest, & J. Snow (Eds.), *The inclusion papers: Strategies to make inclusion work* (pp. 40–51). Toronto: Inclusion Press.
- Forum for Youth Investment. (2010). *Ready by 21: Insulating the education pipeline to increase postsecondary success*. Retrieved from http://forumfyi.org/files/RB21_Credentialed-by-26_Brief-1%5B1%5D.pdf
- Grigal, M., & Hart, D. (2010). *Think college!: Postsecondary education options for students with intellectual disabilities*. Baltimore: Paul H. Brookes.
- Grigal, M., Hart, D., & Migliore, A. (2011). Comparing the transition planning, postsecondary education, and employment outcomes of students with intellectual and other disabilities. *Career Development for Exceptional Individuals*, 34, 4–17. <http://dx.doi.org/10.1177/0885728811399091>
- Hagner, D., Kurtz, A., Cloutier, H., Arakelian, C., Brucker, D. L., & May, J. (2012). Outcomes of family-centered transition process for students with autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities*, 27, 42–50. <http://dx.doi.org/10.1177/1088357611430841>
- Handley-More, D., Wall, E., Orentlicher, M. L., & Hollenbeck, J. (2013, June). Working in early intervention and school settings: Current views of best practice. *Early Intervention and School Special Interest Section Quarterly*, 20, 1–4.
- Hart, D., Grigal, M., Sax, C., Martinez, D., & Will, M. (2006). Postsecondary education options for students with intellectual

- disabilities. *Research to Practice*, 45, 1–4. Retrieved from http://www.communityinclusion.org/article.php?article_id=178&type=topic&id=7
- Hewitt, A., Agosta, J., Heller, T., Williams, A. C., & Reinke, J. (2013). Families of individuals with intellectual and developmental disabilities: Policy, funding, services, and experiences. *Intellectual and Developmental Disabilities*, 51, 349–359. <http://dx.doi.org/10.1352/1934-9556-51.5.349>
- Higher Education Opportunity Act of 2008. Pub. L. 110–315, 20 U.S.C. §1001 et seq.
- Holburn, S., & Vietze, P. M. (Eds.). (2002). *Person-centered planning: Research, practice, and future directions*. Baltimore: Paul H. Brookes.
- Hughes, C., & Avoke, S. K. (2010). The elephant in the room: Poverty, disability, and employment. *Research and Practice for Persons With Severe Disabilities*, 35, 5–14.
- Hughes, C., & Carter, E. W. (2002). Informal assessment procedures. In C. L. Sax & C. A. Thoma (Eds.), *Transition assessment: Wide practices for quality lives* (pp. 51–69). Baltimore: Paul H. Brookes.
- Hughes, C., Kim, J. H., Bogseon, H., Killian, D. J., Fischer, G. M., Brock, M. G., . . . Houser, B. (1997). Practitioner-validated secondary transition support strategies. *Education and Training in Mental Retardation and Developmental Disabilities*, 32, 201–212.
- Hughes, C., Pitkin, S. E., & Lorden, S. W. (1998). Assessing preferences and choices of persons with severe and profound disabilities. *Education and Training in Mental Retardation and Developmental Disabilities*, 33, 299–316.
- Individuals With Disabilities Education Improvement Act of 2004, Pub. L. 108–446, 20 U.S.C. §§ 1400–1482.
- Institute on Disability. (2014). *Annual disability statistics compendium*. Retrieved from <http://disabilitycompendium.org/home>
- Jameson, J. M., Riesen, T., Polychronis, S., Trader, B., Mizner, S., Martinis, J., & Hoyle, D. (2015). Guardianship and the potential of supported decision making with individuals with disabilities. *Research and Practice for Persons With Severe Disabilities*. Advance online publication. <http://dx.doi.org/10.1177/1540796915586189>
- Kim, K. H., & Turnbull, A. (2004). Transition to adulthood for students with severe intellectual disabilities: Shifting toward person-family interdependent planning. *Research and Practice for Persons With Severe Disabilities*, 29, 53–57.
- Kim, R. K., & Dymond, S. K. (2012). A national study of community living: Impact of type of residence and hours of in-home support. *Research and Practice for Persons With Severe Disabilities*, 37, 116–129.
- King, G., Law, M., King, S., Hurley, P., Hanna, S., Kertoy, M., . . . Young, N. (2004). *Children's Assessment of Participation and Enjoyment (CAPE) and Preferences for Activities of Children (PAC)*. San Antonio, TX: Harcourt Assessment.
- Kraemer, B. R., & Blacher, J. (2001). Transition for young adults with severe mental retardation: School preparation, parent expectations, and family involvement. *Mental Retardation*, 39, 423–435.
- Landmark, L. J., Ju, S., & Zhang, D. (2010). Substantiated best practices in transition: Fifteen plus years later. *Career Development for Exceptional Individuals*, 33, 165–176. <http://dx.doi.org/10.1177/0885728810376410>
- Law, M., Baptiste, S., Carswell, A., McColl, M. A., Polatajko, H., & Pollock, N. (2005). *Canadian Occupational Performance Measure* (4th ed.). Ottawa, ON: CAOT Publications.
- Lee, G. K., & Carter, E. W. (2012). Preparing transition-age students with high-functioning autism spectrum disorders for meaningful work. *Psychology in the School*, 49, 988–1000. <http://dx.doi.org/10.1002/pits.21651>
- Lindstrom, L., Doren, B., & Miesch, J. (2011). Waging a living: Career development and long-term employment outcomes for young adults with disabilities. *Exceptional Children*, 77, 423–434.
- Luecking, R. G. (2009). *The way to work*. Baltimore: Paul H. Brookes.
- Luecking, R., & Gramlich, M. (2003). Quality work-based learning and postschool employment success. *Issue Brief: Examining Current Challenges in Secondary Education and Transition*, 2, 1–5.
- Mabry, L. (1999). *Portfolios plus: A critical guide to alternative assessment*. Thousand Oaks, CA: Corwin Press.
- Magill-Evans, J., Galambos, N., Darrah, J., & Nickerson, C. (2008). Predictors of employment for young adults with developmental motor disabilities. *Work*, 31, 433–442.
- Martin, J., Hennessey, M., McConnell, A., Terry, R., Willis, D., & Bailey, C. (2015). *Transition Assessment and Goal Generator (TAGG)*. Retrieved from <https://tagg.ou.edu/tagg/>
- McCarron, L., & Dial, J. G. (2005). *McCarron-Dial Evaluation System*. Dallas T: McCarron-Dial Systems. Available from <http://www.mccarrondial.com/>
- McConnell, A. E., Martin, J. E., Juan, C. Y., Hennessey, M. N., Terry, R. A., El-Kazimi, N. A., . . . Willis, D. M. (2013). Identifying nonacademic behaviors associated with post-school employment and education. *Career Development for Exceptional Individuals*, 36, 174–187. <http://dx.doi.org/10.1177/2165143412468147>
- McDonnell, M. C., & Crudden, A. (2009). Factors affecting the successful employment of transition-age youths with visual impairments. *Journal of Visual Impairment and Blindness*, 103, 329–341.
- McDougall, J., Evans, J., & Baldwin, P. (2010). The importance of self-determination to perceived quality of life

- for youth and young adults with chronic conditions and disabilities. *Remedial and Special Education*, 31, 252–260. <http://dx.doi.org/10.1177/0741932509355989>
- McIntyre, L. L., Kraemer, B. R., Blacher, J., & Simmernan, S. (2004). Quality of life for young adults with severe intellectual disability: Mothers' thoughts and reflections. *Journal of Intellectual and Developmental Disability*, 29, 131–146.
- Michaels, C. A. (1998). *Transition to employment*. Austin, TX: Pro-Ed.
- Michaels, C. A., & Orentlicher, M. L. (2004). Capacity building evaluation and transition services: Implications for school-based occupational therapy practice in the United States. *Occupational Therapy International*, 11, 209–228.
- Migliore, A., Mank, D., Grossi, T., & Rogan, P. (2007). Integrated employment or sheltered workshops: Preferences of adults with intellectual disabilities, their families, and staff. *Journal of Vocational Rehabilitation*, 26, 5–19.
- Millar, D. S. (2014). Extending transition to address guardianship alternatives: An issue concerning students who have intellectual disability. *Education and Training in Autism and Developmental Disabilities*, 49, 449–463.
- Mount, B. (2000). *Person-centered planning: Finding directions for change using personal futures planning*. New York: Graphic Futures.
- National Secondary Transition Technical Assistance Center. (2013). *Age-appropriate transition assessment toolkit*. Retrieved from <http://nsttac.org/content/age-appropriate-transition-assessment-toolkit-3rd-edition>
- Neubert, D. A., & Leconte, P. J. (2013). Age-appropriate transition assessment: The position of the Division on Career Development and Transition. *Career Development for Exceptional Individuals*, 36, 72–83. <http://dx.doi.org/10.1177/2165143413487768>
- No Child Left Behind Act of 2001, Pub. L. 107–110, 20 U.S.C. §§ 6301–8962.
- Nonnemacher, S. L., & Bambara, L. M. (2011). "I'm supposed to be in charge": Self-advocates' perspectives on their self-determination support needs. *Intellectual and Developmental Disabilities*, 49, 327–340. <http://dx.doi.org/10.1352/1934-9556-49.5.327>
- O'Brien, J., Pearpoint, J., & Kahn, L. (2010). *The PATH and MAPS handbook: Person-centered ways to build community*. Toronto, ON: Inclusion Press.
- Orentlicher, M. L. (2007). Transition from school to adult life. In L. Jackson (Ed.), *Occupational therapy services in schools and early childhood settings* (pp. 143–167). Bethesda, MD: AOTA Press.
- Orentlicher, M. L. (2008). *Striving for typical: Collective experiences of person-centered planning for young adults with disabilities during transition* (Doctoral dissertation). New York University, New York. Retrieved from <http://search.proquest.com/docview/304527683?pq-origsite=summon&https://erms.tourolib.org/database/277>
- Orentlicher, M. L. (2011, January 24). Continuing education article: Person-centered planning: An innovative approach for transition planning. *OT Practice*, 16, CE1–CE8.
- Orentlicher, M. L. (2013). Best practices in postsecondary transition planning with students. In G. Frolek Clark & B. E. Chandler (Eds.), *Best practices for occupational therapy in schools* (pp. 245–259). Bethesda, MD: AOTA Press.
- Orentlicher, M. L., & Olson, L. J. (2010). Transition from school to adult life for students with an autism spectrum disorder. In H. Miller-Kuhaneck & R. Watling (Eds.), *Autism: A comprehensive occupational therapy approach* (3rd ed., pp. 665–700). Bethesda, MD: AOTA Press.
- Patient Protection and Affordable Care Act, Pub. L. 111–148, 42 U.S.C. §§ 18001–18121 (2010).
- Powers, L. E., Garner, T., Valnes, B., Squire, P., Turner, A., Couture, T., & Dertinger, R. (2007). Building a successful adult life: Findings from youth-directed research. *Exceptionality*, 15, 45–56.
- Quality Trust for Individuals With Disabilities. (2013). *Supported decision-making: An agenda for action*. Retrieved from <http://jennyhatchjusticeproject.org/node/264>
- Rehabilitation Act Amendments of 1998, Pub. L. 105–220, 29 U.S.C. §§ 701 et seq.
- Rehabilitation Research and Training Center on Disability Statistics and Demographics (2014). *2014 disability statistics annual report*. Retrieved from <http://www.disabilitycompendium.org/docs/default-source/2014-compendium/annual-report.pdf>
- Rogan, P., & Rinne, S. (2011). National call for organizational change from sheltered to integrated employment. *Intellectual and Developmental Disabilities*, 49, 248–260. <http://dx.doi.org/10.1352/1934-9556-49.4.248>
- Rowe, D. A., Mazzotti, V. L., & Sinclair, J. (2015). Strategies for teaching self-determination skills in conjunction with the Common Core. *Intervention in School and Clinic*, 50, 131–141. <http://dx.doi.org/10.1177/1053451214542043>
- Seltzer, M. M., Krauss, M. W., Hong, J., & Orsmond, G. I. (2001). Continuity or discontinuity of family involvement following residential transitions of adults who have mental retardation. *Mental Retardation*, 39, 181–194.
- Shogren, K., Wehmeyer, M., Palmer, S., Rifenbark, G., & Little, T. (2015). Relationships between self-determination and postschool outcomes for youth with disabilities. *Journal of Special Education*, 48, 256–267.
- Sitlington, P. L., & Clark, G. M. (2001). Career/vocational assessment: A critical component of transition planning. *Assessment for Effective Intervention*, 26(4), 5–22.

- Sitlington, P. L., Neubert, D. A., Begun, W. H., Lombard, R. C., & Leconte, P. J. (2007). *Assess for success: A practitioner's handbook on transition assessment* (2nd ed.). Thousand Oaks, CA: Corwin Press.
- Smull, M. W. (1997). *A blueprint for essential lifestyle planning*. Napa, CA: Allen, Shea & Associates.
- Spencer, J. E., Emery, L. J., & Schneck, C. M. (2003). Occupational therapy in transitioning adolescents to post-secondary activities. *American Journal of Occupational Therapy*, 57, 435–441. <http://dx.doi.org/10.5014/ajot.57.4.435>
- TASH. (2009). *TASH resolution on integrated employment*. Retrieved from <http://tash.org/advocacy-issues/employment/>
- Test, D. W., Fowler, C. H., Richter, S. M., White, J., Mazzotti, V., Walker, A. R., ... Kortering, L. (2009). Evidence-based practices in secondary transition. *Career Development for Exceptional Individuals*, 32, 115–128.
- Tichá, R., Lakin, K. C., Larson, S. A., Stancliffe, R. J., Taub, S., Engler, J., ... Moseley, C. (2012). Correlates of everyday choice and support-related choice for 8,892 randomly sampled adults with intellectual and developmental disabilities in 19 states. *Intellectual and Developmental Disabilities*, 50, 486–504. <http://dx.doi.org/10.1352/1934-9556-50.06.486>
- Turnbull, A., & Turnbull, R. (1996). Group action planning as a strategy for providing comprehensive family support. In L. K. Koegel, R. L. Koegel, & G. Dunlap (Eds.), *Positive behavioral support: Including people with difficult behavior in the community* (pp. 99–114). Baltimore: Paul H. Brookes.
- Wagner, M., Cameto, R., & Newman, L. (2003). *Youth with disabilities: A changing population*. Menlo Park, CA: SRI International.
- Webb, K. W., Patterson, K. B., Syverud, S. M., & Seabrooks-Blackmore, J. J. (2008). Evidence-based practices that promote transition to postsecondary education: Listening to a decade of expert voices. *Exceptionality*, 16, 192–206.
- Wehman, P., & Brooke, V. (2013). Securing meaningful work in the community. In P. Wehman (Ed.), *Life beyond the classroom: Transition strategies for young people with disabilities* (5th ed., pp. 309–337). Baltimore: Paul H. Brookes.
- Wehman, P., Chan, F., Ditchman, N., & Kang, H. J. (2014). Effect of supported employment on vocational rehabilitation outcomes of transition-age youth with intellectual and developmental disabilities: A case control study. *Intellectual and Developmental Disabilities*, 52, 296–310.
- Wehman, P., Inge, K. J., Revell, W. G., & Brooke, V. A. (2007). *Real work for real pay*. Baltimore: Paul H. Brookes.
- Wehmeyer, M. (2015). Framing the future: Self determination. *Remedial and Special Education*, 36, 20–23.
- Wehmeyer, M. L., Agran, M., & Hughes, C. (1998). *Teaching self-determination to students with disabilities: Basic skills for successful transition*. Baltimore: Paul H. Brookes.
- Wehmeyer, M., & Kelchner, K. (1995). *The Arc's Self-Determination Scale: Adolescent version*. Available from <http://www.thearc.org/document.doc?id=3670>
- Wehmeyer, M. L., Palmer, S. B., Soukup, J. H., Garner, N. W., & Lawrence, M. (2007). Self-determination and student transition planning knowledge and skills: Predicting involvement. *Exceptionality*, 15, 31–44.
- Wehmeyer, M. L., Palmer, S. B., Youngsun, L., Williams-Diehm, K., & Shogren, K. (2011). A randomized trial evaluation of the effect of Whose Future Is It Anyway? On self-determination. *Career Development for Exceptional Individuals*, 34, 45–56. <http://dx.doi.org/10.1177/0885728810383559>
- Wehmeyer, M. L., & Shogren, K. A. (2013). Self-determination: Getting students involved in leadership. In P. Wehman (Ed.), *Life beyond the classroom: Transition strategies for young people with disabilities* (5th ed., pp. 41–68). Baltimore: Paul H. Brookes.
- White, J., & Weiner, J. S. (2004). Influence of least restrictive environment and community-based training on integrated employment outcomes for transitioning students with severe disabilities. *Journal of Vocational Rehabilitation*, 21, 149–156.
- Wituk, S., Pearson, R., Bomhoff, K., Hinde, M., & Meissen, G. (2007). A participatory process involving people with developmental disabilities in community development. *Journal of Developmental and Physical Disabilities*, 19, 323–335. <http://dx.doi.org/10.1007/s10882-007-9052-x>
- Woodman, A. C., Mailick, M. R., Anderson, K. A., & Esbensen, A. J. (2014). Residential transitions among adults with intellectual disability across 20 years. *American Journal on Intellectual and Developmental Disabilities*, 116, 496–515.
- Workforce Innovation and Opportunity Act of 2014, Pub. L. 113–128, 128 Stat. 1425.
- Workforce Investment Act of 1998, Pub. L. 105–220, 112 Stat. 936.

Appendix 5.A. Resources to Support Transition From School to Adulthood

General Transition Information

- **National Secondary Transition Technical Assistance Center (NSTTAC):** <http://nstattac.org/>
Provides technical assistance and disseminates information on evidence-based practices in transition.
- **Transition Coalition:** <http://transitioncoalition.org/transition/index.php>
Offers professional development focused on secondary school reform and transition at the national, state, and local levels.
- **The National Longitudinal Transition Study 2:** <http://www.nlts2.org/links.html>
Offers many resources on transition.

College Transition

- **Office of Civil Rights document “Students With Disabilities Preparing for Postsecondary Education: Know Your Rights and Responsibilities”:** <http://www2.ed.gov/about/offices/list/ocr/transition.html>

Provides information in a Q&A format on academic accommodations, documentation needed, and basic rights and responsibilities in higher education.

- **ThinkCollege.net:** <http://www.thinkcollege.net/think-college-learn>

A national organization that focuses on inclusive higher education options for people with ID and provides self-paced modules on various postsecondary education topics for these students and their families.

Parental Involvement

- **The Division on Career Development and Transition (DCDT):** <http://community.cec.sped.org/dcct/publications/fast-facts>
Provides a “Fast Facts” document on parental involvement and on topics such as independent living, self-determination, and transition planning.
- **The PACER Center:** <http://www.pacer.org/tatra/planning/transitionemp.asp>
Offers a wealth of resources geared toward families.

Youth Transportation

- **AOTA documents on youth transportation:** <http://www.aota.org/-/media/corporate/files/secure/practice/children/faq-safe-youth-transportation-july-2014.pdf>
Outlines the role of occupational therapy in addressing youth transportation.
- **Easter Seals Project ACTION:** <http://www.projectaction.org/AboutESPA.aspx>
Offers resources specifically designed to facilitate the use of transportation by students and young adults with and without disabilities.

CHAPTER 6.

TRANSITION AND WORK

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Chapter Objectives

At the completion of this chapter, readers will be able to

- ❖ Discuss the key perspectives of occupational therapy work services, including the importance of the occupation of work in an adult's life and use of a self-determination approach to work interventions;
- ❖ Describe federal and state supports to people with disabilities seeking work; and
- ❖ Explain the variety of occupational therapy interventions for people seeking to transition into adult work, including evaluations, work choice and job seeking, supported employment, work task analysis and adaptations, and life balance.

Key Terms and Concepts

- ❖ Career awareness
- ❖ Career decision making
- ❖ Career exploration
- ❖ Career placement
- ❖ Career preparation
- ❖ Competitive employment
- ❖ Customized employment
- ❖ Ergonomics
- ❖ Integrated employment
- ❖ Job analysis
- ❖ Job carving
- ❖ Job coach
- ❖ Job developers
- ❖ Occupational balance
- ❖ Remunerative employment
- ❖ Self-determination
- ❖ Sheltered workshops
- ❖ Soft work skills
- ❖ Supported employment
- ❖ Task analysis
- ❖ Vocational rehabilitation
- ❖ Volunteer participation
- ❖ Work
- ❖ Worker's compensation
- ❖ Workforce Innovation and Opportunity Act of 2014
- ❖ Youth at risk

This chapter discusses occupational therapy services for clients for whom work is an essential part of their lives but who face challenges in transitioning to suitable employment. Topics include historical perspectives on occupational therapy and work transitions, economic realities, and legislation that affect occupational therapy work interventions, and the profession's important and unique contributions in this area. It discusses how occupational therapy practitioners can facilitate successful transitions to work for their clients returning to work after an injury or disease, preparing for a first job, or serving others through volunteer work. This chapter highlights interventions and strategies that occupational therapy practitioners can use to facilitate positive transition-to-work experiences for individuals and families.

Scott's Story: From the Challenges of Tourette Disorder to Paid Game Designer

In kindergarten, Scott was diagnosed with Tourette disorder, attention deficit hyperactivity disorder, and obsessive-compulsive disorder. He received a variety of support services throughout grade school. In high school, at age 15 years, he participated in a state youth transition program for students with disabilities for preparation for competitive employment. This program evaluated Scott's skills and interests using a variety of assessments.

Finding a Job

Scott was encouraged to find a job in the community or to work on campus, but as a result of his diagnoses, he did not enjoy interacting with people. Therefore, he had no interest in volunteer work or typical customer service jobs available to teenagers, nor did he want a job on campus, not even with financial incentives. He stated, "It's not in any way interesting to do that sort of job to me. It's not worth the \$6 an hour just to spend my time that way." Scott believed that he would do better at a job that matched his interests in computers and also minimized his need to interact with other people. He did not want a job merely for the sake of being employed.

Scott began his postsecondary education at a community college with accommodations for reading

(e.g., audiobooks) and test taking (e.g., separate room, extra time). He worked toward a certification in computer installation and repair but then decided to focus instead on classes that would help him secure a bachelor's degree. He later functioned well at a small state university without accommodations. As a result of his excellent in-class performance in science and math, he was offered a job as a student worker on a grant. With coaching from his mother (an occupational therapist), Scott followed up on this offer of a job writing computer software. Similar to his transition-to-work services in high school, he required coaching on how to ask a professor for permission to list her as a reference on his application, how to update his résumé, and how to choose appropriate clothing for the interview.

Scott successfully worked at this part-time position for 9 months during the school year and then moved into full-time work for the summer. He stated that the benefits of this job are "actually working a real job and with other people on a real project, which is something I'll have to do in the future—work with other teams of people and learn specific skills like open GL [graphics language] and so forth."

As this book goes to press, Scott is age 25 years. He graduated from college with a bachelor of science degree in computer science (interactive multimedia) with an art minor. After graduation, Scott began to pursue a career in either game design or digital animation. For a year, Scott regularly reviewed job opportunities on the Internet for computer software engineers, targeted jobs advertised by specific companies (e.g., Electronic Arts, an entertainment software company), signed up as a client with VOLT (an employment agency geared toward information technology and engineering jobs), and opened a LinkedIn page. He applied for jobs and paid internships that appeared to fit his abilities and job preferences. His mother assisted him by encouraging and helping him to develop a résumé and cover letter, searching out job advertisements, and obtaining advice from his college professor who had hired him to work on the grant.

After a year of unsuccessful efforts at obtaining a job, Scott's mother suggested he speak to his professor about the possibility of finding an unpaid internship. The professor gave him a list of tasks to accomplish within a week, including posting some of Scott's game design work on the Internet.

The professor also gave Scott a list of three possible places he might intern (where other students had previously interned) and recommended that he join a nearby group of game designers who met on a weekly basis for ongoing educational purposes and independent game design.

Scott met the owners of a small game design company (one of the three suggested by his professor) at one of these meetings. He contacted them regarding an internship, and they subsequently came to an agreement. During his 3-month internship, Scott worked on game design projects and learned about running a small business. After a month of interning, the owners of the company hired Scott as a contract worker. After working for a month as an employee, Scott found an apartment; moved out of his parents' home; and assumed the adult responsibilities of paying for rent, utilities, food, and gasoline.

Having Occupational Therapy Support

How did occupational therapy support Scott's path toward employment? The occupational therapist focused on developing Scott's self-determination and ability to advocate for himself as a member of the transition team and to be an active participant at his individualized education program meetings. In the program, Scott learned about his rights and responsibilities, how to develop support systems, and about community collaboration. The therapist facilitated Scott's ability to describe his disability and articulate his needs for accommodations and helped him prepare for his transition meetings. Scott learned how to write a résumé, develop a PowerPoint presentation to express his job-related skills, and interview for positions. He explored his interests and researched employment and salary data and, as a result, interviewed several software engineers about their work.

Scott's story illustrates the need to think about work skills development as a continuum that begins in the early years and can extend beyond the school years. Beyond traditional occupational therapy for transition to work, Scott required intermittent assistance over a long period of time. His story demonstrates the long period of time over which the transition to work may occur for a nontypical worker.

A lengthy time frame does not fit well within a strictly school-based setting (because needs extend beyond high school) or a traditional rehabilitation

setting that requires results in a relatively short period of time. Although Scott began receiving transition-to-work assistance in high school, the assistance did not result in a job at that time. He was resistant to getting a job during high school but did learn about the jobs that matched his interests and abilities. When the right career opportunity became available, Scott's earlier transitional assistance allowed him to feel confident that he could obtain the position, successfully perform the work, and then use the experience to enter his preferred career after college.

Scott benefited from having a mother who was an occupational therapist. Otherwise, he would not have had access to the further assistance needed to obtain a job once he left behind the transition support he received in high school. His need for customized employment based on his strengths also might have been missed in a traditional occupational therapy setting. His resistance to taking a job, whether paid or volunteer, just for the sake of experiencing work could have been viewed as being uncooperative or being a "bad" patient. He was fortunate to have the opportunity presented to him to work in a job that fit his specific skills and could contribute to his ability to obtain a future job in his desired career path.

Questions

Scott's case brings the following questions to light in relation to transition to work:

- How did Scott perceive and develop his personal identity as a worker within the context of his opportunities and disabilities?
- What school and government supports shaped Scott's trajectory?
- What role did occupational therapy play in Scott's success?
- What transitions to work have you observed in your own practice, and what facilitated or hindered these transitions?

Occupational Therapy Work Services

People have traditionally engaged in work to earn a living. However, occupational therapy practitioners recognize that work brings additional benefits to people through different types of employment. This section explores the concept of work as an occupation.

Occupation and Work

Historically, occupational therapy practitioners have been important advocates for people to be engaged in work. The term *occupation* has always included work (American Occupational Therapy Association [AOTA], 1993, 2014; Bing, 1981; Christiansen, Clark, Kielhofner, Rogers, & Nelson, 1995; Hinojosa & Blount, 2014; Meyer, 1922), which is, and always has been, an area of occupation defined within the profession's scope of practice. In the *Occupational Therapy Practice Framework: Domain and Process* (3rd ed.; *Framework*; AOTA, 2014), **work** is defined as "Labor or exertion; to make, construct, manufacture, form, fashion, or shape objects; to organize, plan, or evaluate services or processes of living or governing; committed occupations that are performed with or without financial reward" (p. S20).

Employment

Remunerative employment is that for which one is paid. Most employment is remunerative and **competitive**, that is, one must strive to obtain employment by competing with others who desire the same job. Experiencing remunerative employment may or may not prepare one for competitive employment. In Scott's case, he refused to compete for competitive employment in low-wage jobs as a teenager, dreading the high level of social interaction they would require and perceiving that such an experience would not prepare him for the type of work he wished to do as an adult.

Supported employment has been found to be more effective than vocational rehabilitation alone in producing functional outcomes, including in competitive employment (AOTA, 2009b).

Carved employment, or **customized employment**, is another work option for people who are not ready or able to assume competitive employment. It means creating a new job within a business that matches the person's abilities and skills. The new job may include only one or several tasks that the person can do that contributes in some way to the work setting.

Volunteer work

Although many work to earn income, some choose to work to serve others. According to the *Framework* (AOTA, 2014), **volunteer participation** is "performing unpaid work activities for the benefit of selected causes, organizations, or facilities" (p. S21).

In general, one thinks of volunteer work as something done by people who can afford to spend their time in work that is not reimbursed. Usually, this work is in an area of interest to the volunteer. Volunteering can also be seen as a transitional position for a person who is not yet ready to apply for competitive employment but wants to be involved in a meaningful occupation and gain work experience.

Work as occupation

Christiansen (1999) asserted that "occupations are key not just to being a person, but to being a particular person, and thus creating and maintaining an identity" (p. 547). Moreover, research has shown that work as occupation is an essential element in most people's identities. In the United States, employed adults spend 40 or more hours per week at a job, which makes work one of their primary occupations. Most adults have a job by the time they are age 18 years, but if they complete college first, in their early 20s. They most often work until retirement at about age 65 years.

In a report published jointly by the World Health Organization (WHO) and the International Labour Organization, Harnois and Gabriel (2000) stated, "Although it is difficult to quantify the impact of work alone on personal identity, self-esteem and social recognition, most mental health professionals agree that the workplace environment can have a significant impact on an individual's mental well-being" (p. 5).

In a qualitative study of the adaptive nature of work, Spencer and colleagues (1998) found that work contributed to identity by "achieving values such as a sense of accomplishment and independence or attainment of a valued lifestyle" (p. 481). Values and interests related to work varied and fell into two general categories of people: (1) those who pursued employment because they valued what they considered to be a good income that gave them a sense of independence and (2) those who pursued jobs they were interested in because they represented their special knowledge and expertise, such as Scott in this chapter's case example.

Farnworth (1995) also found that employees valued a job that had the right challenge for their skills, arguing, "Being employed in any job may not be enough to maintain one's well-being. What is more critical is the quality of that employment as indicated by its skill utilization" (p. 27).

Male medical students in Canada expressed that they valued both their work time and their family time and were interested in doing their fair share as fathers

and in practicing medicine (Wada & Beagan, 2006). Studies of employees with multiple sclerosis and with rheumatoid arthritis highlighted the importance and value to these participants in remaining employed despite their chronic and debilitating illnesses (Crooks, Stone, & Owen, 2009; Jakobsen, 2009).

Clients in Occupational Therapy Work Services

Occupational therapy practitioners traditionally serve clients who have had work-related injuries. Close to 3 million work-related injuries occur in the workplace each year (U.S. Bureau of Labor Statistics, 2013). Many people who experience work-related injuries need occupational therapy to treat their conditions, including, but not limited to, hand, upper-extremity, and back injuries. Occupational therapy practitioners also treat people who were injured off the job but whose injuries affect their employability. For example, a person with a spinal cord injury may need rehabilitation to return to his or her pre-accident job or develop new work skills.

Although many work-related services involve physical challenges, occupational therapy practitioners also assist those with mental illness. WHO (2008) identified mental illness as the leading cause of disability. In the United States, 26.2% of adults have a mental illness (Kessler, Chiu, Demler, & Walters, 2005), and many have difficulty functioning at work. Practitioners may work in community settings to help these people improve their ability to function at a job. Treatment may focus on soft work skills such as time management and communicating with supervisors or coworkers rather than direct work skills. It may seem obvious that employees would have these soft work skills, but some people with mental illness struggle with these challenges the most. People with disabilities or injuries often struggle financially in the best of times; therefore, their employability becomes even more important during tough economic times.

Work and Self-Determination

How well does occupational therapy prepare an individual for work? When facilitating the return to work or engagement in work of occupational therapy clients, practitioners need to understand and appreciate the cultural, economic, physical, and social systems of the work environment within which their clients spend a large portion of their daily lives. Such

understanding is essential to achieving success with interventions to support the transition to work. Transition planning for entry or return to a work setting is important, whether the client is a child, adolescent, adult, or older adult.

Self-Determination

The client's desire for *self-determination* to guide his or her own life plays an important role in successful transition planning (see Chapter 1, "Foundations of Transition," for more information on self-determination). Research shows a relationship between self-determination in people with disabilities and improved outcomes in a wide variety of adult roles, including employment (Carter, Lane, Pierson, & Glaeser, 2006). Wehmeyer and Schwartz (1997) demonstrated that youth with mild cognitive disabilities who were taught self-determined behaviors (e.g., stating their own employment goals in their vocational planning meeting) were twice as likely to be employed, earned significantly more, and lived more independently than those who had not had that preparation.

In a follow-up study, Wehmeyer and Palmer (2003) found similar results. High school students with learning disabilities who had higher levels of self-determination had better employment outcomes, such as having a full- or part-time job or receiving job training, having employment benefits, living independently, and maintaining a bank account. Other studies have shown that people with cognitive disabilities who were taught self-determination skills, such as self-management and self-regulation, increased their job performance and their employers' perception of them as valued employees (Browder & Minarovic, 2000; Woods & Martin, 2004).

Although the concept of self-determination emerged to empower people with little or no voice in the management of their lives, and especially to empower people with disabilities, it is important to remember that this approach can help all people during work transitions. Choosing one's own work and earning one's own income is empowering. Using self-determination helps people find employment and supports them in advocating for themselves to create fulfilling lives within their communities.

Career Development

Because secondary students with disabilities have difficulty finding and keeping living-wage jobs after

graduation, it is necessary to increase understanding of the importance of employment in secondary transition planning. Various vocational education and transition program models have been advanced for persons with disabilities, typically incorporating five stages of career development:

1. **Career awareness.** Developing awareness of one's work potential, abilities, interests, and values
2. **Career exploration.** Activities allowing people to develop self-awareness to enable them to gather information about suitable careers
3. **Career decision making.** Selection of careers based on self-knowledge
4. **Career preparation.** Developing specific skills necessary to function in a particular work setting
5. **Career placement.** Involvement in a career, including the supports put in place to sustain successful job performance (Izzo & Lamb, 2003).

Youth at Risk

Youth at risk are adolescents at risk of failure to be adequately prepared for adult life, due to learning or other disabilities, emotional or behavioral concerns, absenteeism, low academic performance, or a lack of interest in or connection to school or community. Such students often have difficulty transitioning into adulthood and work roles (Lindstrom Johnson, Jones, & Cheng, 2014).

With their understanding of typical and atypical patterns of time use, school function, behavior, and social skills, occupational therapy practitioners are well-suited to assist adolescents in the development of the skills they will need to successfully function in adult roles. Additional considerations for the transition from school to adult life of youth with disabilities are discussed in Chapter 5, "Transition From School to Adult Life."

Types of Work Transitions

Throughout life, most people will encounter multiple work transitions. As teenagers, their first paid job may be babysitting; mowing lawns; or working during summers at a pool, store, or other business. Later, as young adults, they begin to look to the future and plan a career path, which may or may not include education or training beyond high

school. Unlike previous generations of workers, who often worked at the same job or company for long periods or entire careers, people now change jobs frequently throughout their lives—either by choice or as a result of economic changes—about every 5 years (Mullins, 2009).

Many industrialized societies are encountering dramatic changes in the workplace. One change is that older workers are remaining in the workplace longer, because of financial reasons, enjoyment, or the desire to do something different before retiring (Dale, 2004; Gupta & Sabata, 2010; Stikeleather, 2004). In the United States, in particular, the retirement age has increased and more resources are available to older persons with physical, intellectual, or psychological disabilities. (Transitions related to older adults are discussed in Chapter 7, "Transition and Aging.")

Because work is often vital to quality of life, occupational therapy practitioners use their skills and expertise to help people improve their ability to transition into, and function within, a work setting. Traditionally, practitioners have helped rehabilitate people with physical disabilities, work injuries, or mental illnesses so that they might return to jobs (AOTA, 2011a; see Appendix C, *Occupational Therapy Services in Facilitating Work Performance*). Practitioners can build on their knowledge of transitioning work skills to serve other populations, such as the newly retired, the unemployed, youth with disabilities, and prisoners returning to the community.

Policy and Work Interventions

As occupational therapy practitioners collaborate with clients to reach their long-term goal of employment, it is the practitioners' professional obligation to understand the various federal and state laws influencing service delivery.

Federal Laws

Regardless of the population being served or the type of organization employing occupational therapy practitioners, several federal laws and policies affect the delivery of occupational therapy services and payment (Table 6.1). Practitioners must understand these laws and policies to provide high-quality legal and ethical services, which are components of best practice.

Table 6.1. State and Federal Programs and Laws Affecting Occupational Therapy and Transition to Work

Title	Major Features	Relevance to Occupational Therapy
Americans With Disabilities Act of 1990 (ADA; Pub. L. 101-336) and Americans With Disabilities Act Amendments Act of 2008 (Pub. L. 110-325)	ADA has five titles. Title I is focused on employment and protects people with disabilities by prohibiting discrimination during recruitment, hiring, evaluation, promotion, or any other facet of employment. Employers are further required to provide reasonable accommodations to enable people with disabilities to successfully perform their jobs.	Occupational therapy practitioners can identify reasonable accommodations for people with disabilities that may be required during the hiring process or for job performance.
Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (PRWORA; Pub. L. 104-193)	PRWORA added a workforce development component to welfare legislation, encouraging employment among the poor, especially single-parent families. It requires welfare recipients to begin working or participate in work training programs after 2 years of receiving benefits. It places a lifetime limit of 5 years on benefits paid by federal funds.	Welfare recipients can qualify for vocational rehabilitation programs provided by occupational therapy.
Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI)	The Social Security Administration's (2011) SSDI and SSI disability programs are the largest of several federal programs that provide financial assistance to people with disabilities. Although these two programs are different in many ways, both are provided only to qualified people who have a disability and meet medical criteria. SSDI is an insurance program that pays benefits to qualified people and their family members on the basis of how long the person has worked and paid social security taxes. SSI benefits are based on financial need.	Because people with disabilities may be apprehensive about working, fearing that they may lose social security benefits, occupational therapy practitioners can consult with social security administrators to determine how benefits may change with employment.
Workforce Innovation and Opportunity Act (Pub. L. 113-128)	This is a reauthorization and amendment to the Workforce Investment Act of 1998 (Pub. L. 105-220) to improve access to employment, including adult education and vocational rehabilitation services.	As advocates for their clients, occupational therapy practitioners must be aware of their clients' rights to work in integrated job sites.
State worker's compensation	Worker's compensation provides benefits and care for workers injured on the job.	Occupational therapy services, including work hardening and work conditioning, are reimbursed under medical benefits.

(Continued)

Table 6.1. State and Federal Programs and Laws Affecting Occupational Therapy and Transition to Work (*Cont.*)

Title	Major Features	Relevance to Occupational Therapy
Rehabilitation Act of 1973 (RA; Pub. L. 93-112; amended in 1993 and 1998)	RA requires access for people with disabilities to programs and activities that are funded by federal agencies and to federal employment. It provides vocational counseling, training assistance, job placement, and antidiscrimination measures.	Occupational therapy practitioners may assist the person with disabilities and the employer in identifying reasonable accommodations that may be required during the hiring process or for job performance.
American Recovery and Reinvestment Act of 2009 (ARRA; Pub. L. 111-115)	The primary objective of ARRA was to save and create jobs, in direct response to the economic crisis. To achieve this goal, ARRA provides funding for tax cuts, benefits for working families and businesses, and entitlement programs such as unemployment benefits.	Occupational therapy practitioners can collaborate with vocational rehabilitation counselors to better understand the benefits available to their clients.
Individuals With Disabilities Education Improvement Act of 2004 (IDEA; Pub. L. 108-446)	IDEA requires public schools to have transition plans by the time students reach age 16. The transition plans must include goals to address vocational training and employment.	Occupational therapy practitioners in the public schools need to be a part of the development and implementation of these transition plans (see Chapter 5, "Transition From School to Adult Life").

Note. Adapted from *Work: Promoting Participation and Productivity Through Occupational Therapy*, by B. Braveman & J. J. Page, 2012, Philadelphia: F. A. Davis, and *Legal Rights of the Catastrophically Ill and Injured: A Family Guide* (2nd ed.), by J. L. Romano, 1998, Norristown, PA: Author. Adapted with permission.

State Legislation

The state programs that are available for people transitioning back to work after a work-related injury or other injury causing a disability are vocational rehabilitation and worker's compensation. These two programs emerged from federal law but are enacted by each state and administered by state agencies. Appreciating the intents and processes of these programs will help the practitioner facilitate the client's transition to work. For the purposes of this discussion, *work* means paid employment.

Vocational rehabilitation

The Office of Vocational Rehabilitation (OVR) is a state agency within the Department of Labor in most states with the purpose of providing **vocational rehabilitation** through therapy services for people

with disabilities, ages 17 years or older, to return to work. To qualify for services, a person must have a condition or disability that prevents him or her from working but that could be improved through vocational rehabilitation so the person can engage in or return to work (Romano, 1998).

Occupational therapy is a service covered by the OVR, under Physical and Mental Restoration Services, which also includes medical, surgical, psychological, and other therapy services such as physical and speech therapy. A vocational rehabilitation counselor determines whether a client meets the criteria and establishes the plan of care for the client. It is important for occupational therapy practitioners to determine whether a client has a vocational rehabilitation counselor and to collaborate with this professional to ensure the most effective transition to work.

Within each state's Department of Health and Human Services, or similar agency, is a division

with several bureaus to address the needs of people with disabilities. Each state may divide the services among the bureaus differently or call them by different names, but bureaus usually include child development services, developmental disabilities services, and rehabilitation services such as vocational rehabilitation and independent living.

In addition, each state has an agency that is responsible for administering programs offering services for people who are blind and visually impaired, who are deaf and hard of hearing, and with mental illness and addiction. Both the Department of Health and Human Services and social service agencies offer a variety of employment-related programs and benefits, including vocational rehabilitation, ***supported employment*** (i.e., people with disabilities receiving vocational services and on-the-job supports to help them find and maintain a job in an integrated and competitive workplace; Wehman, Inge, Revell, & Brooke, 2007), assistive technology, community integration, and more. Occupational therapy practitioners providing transition-to-work services should be aware of their state's services and how to connect clients to the supports they offer.

Worker's compensation

State ***worker's compensation*** is the employer insurance used when an employee is injured on the job and is sometimes referred to as *worker's comp*. Some form of worker's compensation is required by the state to cover loss of income, medical and rehabilitation expenses, and other expenses. At times this insurance can be used if the employee has developed a health condition due to the work environment. Worker's compensation programs are determined and administered by individual state legislature or departments of insurance at the state level. Occupational therapy practitioners working in this area of practice should be familiar with this payment system.

Work Interventions

Providing interventions to increase participation in the performance area of work is in occupational therapy's scope of practice (AOTA, 2014). In addition, occupational therapy practitioners should be involved in helping clients of all ages and ranges of skills

to build on their strengths, skills, and preferences (Phillips et al., 2009). Work interventions can include exploring employment interests and pursuits, assisting with job seeking and acquisition, and increasing job performance by improving work skills through both physical and mental capacities. In addition to paid employment, practitioners can also assist people, such as new retirees, to explore and participate in unpaid volunteer work (AOTA, 2014).

Promoting Soft Skills

During a child's early years, occupational therapy is offered in schools, homes, and clinics. Starting in elementary school, occupational therapy can include beginning work skills to help prepare students for their future (AOTA, 2009a, 2011b). Children should be exposed to many career choices starting at a young age to begin to understand what is possible. Practitioners can help the child explore interests in vocations.

Children and youth also need to develop the skills and values essential to success in the workplace. Such workforce-readiness skills are referred to as ***soft work skills***. They include taking initiative, understanding how one's behavior affects others, accepting criticism and responding appropriately, and ethical problem solving and decision making (U.S. Department of Labor, 2011). Occupational therapy practitioners who already address these areas in traditional practice can transfer that knowledge to early school-based and community practice.

For example, practitioners can help children learn skills such as being on time and following rules that can be transferred to work later in life. As children develop into young adults, practitioners can help them refine these skills and identify and improve other employment skills, including employment search skills.

For adults, the focus of intervention for soft work skills, including how to appropriately interact with supervisors and manage time efficiently, is to develop clients' work capacity in these areas. This intervention may be used when, for example, people with mental illness transition back to work or enter employment for the first time. Soft work skills training, combined with follow-up support for people with mental illnesses, has shown to increase the likelihood of maintaining employment (Gutman et al., 2007).

In Scott's case, he was fortunate to be supported by a family member who was an occupational therapist, without whom he may not have bridged

the social demands of reaching out to his professor, joining a game design work group, and then requesting an internship placement that later became paid employment.

Helping to Choose and Find Work

For clients who have never worked before or want a career change, occupational therapy practitioners should collaborate with them to explore job interests. Practitioners should use their knowledge and expertise in evidence-based practices to discover individuals' strengths and interests (Arbesman & Logsdon, 2011; Case-Smith, 2003; Cocks & Boaden, 2009; Larson & Ellexson, 2000; Test, Fowler, et al., 2009; Test, Mazzotti, et al., 2009). In Scott's case, this process of discovering his best self occurred primarily during his high school transition-to-work services.

Occupational therapy practitioners need to consider clients' characteristics, including interests, values, culture, skills, and abilities, as well as the demands of the "work role, task demands, work environment, and available resources," including work actions, tools, and ergonomic stressors (AOTA, 2005, p. 627).

For example, if a client has a great knowledge of computers but does not like to interact with a lot of people, computer repair may be more appropriate than working in a busy technology store. In addition, if a client has an interest but no skills in computers, a practitioner can help him or her learn skills, such as computer operation, or help identify where the client can learn more vocational skills such as computer programming.

The first step in the process of gathering information about clients should involve performing an assessment such as the standardized Worker Role Interview (Braveman et al., 2005) or developing an occupational profile to learn more about their skills and interests. (For more suggestions on work assessments, see Exhibit 6.1.) Once a particular job or work skills have been identified, occupational therapy practitioners can collaborate with clients to acquire the desired employment by helping them prepare applications and practice interviews (AOTA, 2005). Such interventions can be individually tailored or provided as consultation to a group. Practitioners work in a variety of settings where they can help people transition to work, including rehabilitation clinics, mental health facilities, community centers, and businesses and industry.

Using Customized Employment, Job Development, and Job Coaching

Most people think of employment as competitive and *remunerative*, that is, a person applies for a job and then starts working and earning a paycheck. Most people obtain jobs through a competitive process. However, some people do not function well in the competitive market but still have skills to offer.

Customized employment

According to the U.S. Department of Labor's (2015) Office of Disability Employment Policy, ***customized employment*** occurs when a new job is created within a business that matches a person's abilities and skills. This model uses a self-determination approach in which the person sets his or her own requirements for employment instead of an agency or rehabilitation counselor dictating what job a person should have. Another form of customized employment is ***job carving***, in which a new job is created from the combined or reduced tasks of one or more jobs (Citron et al., 2008).

A U.S. Government Accountability Office (2001) report on subminimum wage and supported employment stated that 420,000 people with disabilities spent their work days at ***sheltered workshops*** earning a subminimum wage (National Council on Disability, 2012; Note. This statistic is the most recent available.). These workshops provide a protective yet segregated environment where workers with disabilities perform portions of tasks surrounded by others with disabilities. Although 71% of adults with disabilities are currently served in segregated day programs or sheltered workshops (Braddock, Rizzolo, & Hemp, 2010), these placements are not considered acceptable employment outcomes for adults with disabilities (Bates-Harris, 2012; Wehman & Brooke, 2013).

Current best practice emphasizes ***integrated employment*** options in the community, an approach based on the belief that everyone, including those with intellectual or severe disabilities, can work with the appropriate short- or long-term supports such as customized employment (Migliore, Mank, Grossi, & Rogan, 2007; TASH, 2009; Wehman & Brooke, 2013). Scott was provided with an intermediary step as an unpaid intern, an excellent way to gain skills and build the interpersonal network that supported his entry into paid employment. The ***Workforce***

Exhibit 6.1. Work Assessments**Standardized Assessments**

- *Adolescent/Adult Sensory Profile* (Brown & Dunn, 2002): Identifies sensory processing patterns and their effects on functional performance.
- *Jebson Test of Hand Function* (Jebson, Taylor, Trieschmann, Trotter, & Howard, 1969): Assesses a broad range of unilateral hand functions required for daily activities.
- *Minnesota Rate of Manipulation Tests* (American Guidance Service, 1957): Measures eye–hand coordination and gross arm movements.
- *Nine-Hole Peg Test* (Mathiowetz, Weber, Kashman, & Volland, 1985): Measures finger dexterity.
- *Occupational Self-Assessment* (Baron, Kielhofner, Iyenger, Golhammer, & Wolenski, 2006): Measures clients' perceptions of their own competence and the value they assign to different occupations.
- *Purdue Peg Board* (Tiffin & Asher, 1948): Measures manual dexterity and bilateral coordination.
- *Self-Directed Search* (Holland, 1994): Helps people identify a career in a field that matches their aspirations, activities, skills, and interests.
- *Valpar Component Work Samples* (BASES of Virginia, n.d.): Uses a variety of work task samples that are similar to tasks in actual jobs to appraise people's physical and mental abilities, interests, and other work-related characteristics.
- *Vocational Cognitive Rating Scale* (Greig, Nicholls, Bryson, & Bell, 2004): Measures cognitive work-related skills such as attention and initiation in people with mental illness.
- *West Tool Sort* (Matheson, 1988): Measures a person's perception of his or her ability to perform work tasks, and explores the person's attitude toward his or her disability.
- *Work Behavior Inventory* (Bryson, Bell, Lysaker, & Zito, 1997): Measures behavioral work styles, specifically the characteristics of how people act and interact at work.
- *Work Environment Impact Scale* (Moore-Corner, Kielhofner, & Olson, 1998): Measures people's views on their workspace and how these views affect their work performance.
- *Work Environment Scale* (Insel & Moos, 1974): Measures the social environments in a variety of work settings, focusing on employee characteristics such as productivity, satisfaction, and stress.
- *Worker Role Interview* (Braveman et al., 2005): Measures psychosocial and environmental factors that influence a person's ability to return to work.

Nonstandardized Assessments

- *Functional capacity evaluation* (AOTA, 2012): Evaluates a person's capacity to perform work activities related to his or her participation in employment.
 - *Job analysis* (AOTA, 2005): Determines the duties, responsibilities, necessary skills, outcomes, and work environment of a particular job.
 - *Occupational profile* (AOTA, 2014): Explores a person's occupational history and experiences, patterns of daily living, interests, values, and needs.
-

Innovation and Opportunity Act (2014; Pub. L. 113–128) helps support integrated employment for people with disabilities.

Job development

Practitioners can serve as ***job developers***, who serve as representatives for clients, presenting their skills to and negotiating with potential employers. If the needs of the client and the employer match,

everyone benefits from the company hiring a person with a disability.

For example, a person with autism may have great computer-programming skills but have difficulty with the interviewing process because of poor social skills. In the role of job developer, practitioners present the client's strengths to the employer and explains that although the client probably will not perform well in a formal interview, his or her skill-set will overcome that issue on the job.

Job coach

Once individuals with disabilities have a job, they may need some continued on-site support from a **job coach** to learn new job skills and fit into the new environment. As people are able to perform tasks, the need for the job coach's support will be reduced.

Although vocational rehabilitation frequently provides this service, occupational therapy practitioners can use their expert knowledge of clients to break down their jobs into smaller tasks, enabling them to teach the skills needed to perform the work (see below).

Performing a Work Task Analysis

When a person is learning a new work skill, **task analysis** is frequently completed to break down the job into discrete, small steps (Wilson & Landry, 2014), making learning the task easier, especially for people with cognitive disabilities. Occupational therapy practitioners are experts in performing task analysis (AOTA, 2007; Wilson & Landry, 2014).

The task analysis process is also beneficial when a task needs to be modified for people who do not have the physical or mental skills to perform the task. For example, if a box is too heavy for a person to lift, a practitioner can suggest an alternative way to perform this step, such as using a cart to move the box.

In addition to task analysis, practitioners may perform a **job analysis**, which encompasses an examination of all job tasks and the skills required to perform them, and of the workplace environment (Snodgrass & Gupta, 2014). Job analysis is frequently part of work conditioning or work hardening programs, which use varying levels of strengthening to restore function and the ability to work.

For example, if a truck driver sustains an injury that causes weakness, but his or her job requires the ability to lift 75 pounds, then a goal of rehabilitation will be to improve the injured worker's strength. The intervention may include a technique such as using the PRIMUS BTE™ (Hanover, MD) truck steering wheel attachment and gradually adding resistance to simulate the turning of the truck in a sitting posture.

Promoting Health and Safety

Occupational therapy practitioners use their knowledge to help injured workers recover, but they can also

help prevent injuries from occurring by promoting the health and safety of workers. Practitioners frequently assess work settings to improve the ability of employees to perform their jobs while avoiding injuries, either through safety training or instruction in **ergonomics**, that is, safe body mechanics.

For example, the practitioner may analyze the body positions used by employees to reach the lever of a machine or the force applied to arm joints when employees tighten a bolt and develop adaptations to body positions or tools to lessen the chance of injury. Certification for safety training and ergonomics is available.

Practitioners may address health and safety concerns through administrative mechanisms, such as advocating for the human resources department to deliver in-service training on how to work more safely by using neutral positioning techniques or rotating job tasks to prevent repetitive injuries or by taking short breaks. Practitioners may also suggest engineering controls, such as redesigning work stations or tools. Other factors to address include aspects of the work environment such as noise, temperature, and lighting.

Identifying Barriers

Barriers to a satisfying work life may exist beyond the work setting. If a person finds a job and can perform the tasks but cannot arrive at the site, he or she may be prevented from keeping the job.

For example, an occupational therapy practitioner may need to help a client with cerebral palsy who uses a wheelchair or a client with a cognitive disability learn how to negotiate public transportation or find transportation supports in the community. (For more information about environmental interventions, including transportation, see Chapter 10, "Supportive Environments for Transition".)

Supporting Development of Financial Skills

With a job usually comes income but not necessarily financial skills. For some people, their first job may be the first time they have had their own money to spend or have had to manage their finances. Because of their expertise in basic and instrumental activities of daily living (ADLs and IADLs), occupational

therapy practitioners can help people develop budgeting skills, use an automated teller machine, balance a checking account, and use online banking. Best practice for an occupation-based approach includes supporting clients to practice and perfect these skills in natural settings as much as possible.

Promoting Work and Life Balance

When occupational therapy practitioners develop intervention plans with clients who are experiencing work transitions, they need to look beyond the clients' work patterns to their full occupational profile and occupational patterns, that is, consider the work and life balance. Although work is how people earn their income and often how they identify themselves, which can centralize work within the occupational pattern, *occupational balance* is recognized as the key to health (Stamm et al., 2009; Wilcock, 1998).

Occupational therapy's founders recognized the need for occupational balance among work, rest, and play and that it should be a goal of therapy (Christiansen, 1996; Primeau, 1996). Because engagement in a variety of occupations, including self-care, leisure, rest, and work, is vital to quality of life, practitioners should work with clients to examine and reflect on the balance within their occupational patterns.

For example, for a recently unemployed person or at-risk youth who have not developed healthy leisure and work activities, practitioners help them find new occupations to improve their quality of life (Farnsworth, 1995). However, an ambitious executive who spends a great deal of time working and not enough time with family, restoring himself or herself, or sleeping may require a different type of assistance to find better work and life balance.

In Renzo's story in the "Prologue," Renzo's mother described how one of the goals for Renzo's transition to postsecondary pursuits was making sure that his life was balanced. For Renzo, a healthy occupational balance meant incorporating valued occupations in the contexts of community college, employment at the guitar company, art, exercise, and social activities. This example emphasizes that practitioners must be aware of their clients' full occupational patterns to help them achieve a satisfactory work and life balance.

Juan's Story: Transition Back to Work After an Injury

Juan is age 36 years, Hispanic, and raising two children alone in an urban area. He has an associate's degree in bookkeeping and is a bookkeeper for a small (50 employees), family-owned furniture business. He has worked for this employer since he was 18.

When Juan was walking through the warehouse, the forklift driver lost control of the forklift and pinned him between the blades and a wall. Subsequently, Juan had T10 paraplegia. As a result of his injury, Juan initially received worker's compensation and then social security disability insurance. After an occupational therapist completed an initial occupational therapy profile and evaluation, Juan began receiving occupational therapy services.

Juan was seen by the occupational therapist for functional mobility, including bed mobility and transfers; ADL retraining, including dressing, bathing, and toileting; and home and work discharge planning. After he was stabilized, Juan was transferred to acute rehabilitation, where occupational therapy services continued with the addition of IADLs, community mobility, and work reintegration. Juan received approval from his vocational rehabilitation counselor for the occupational therapist to perform a job site analysis to determine what modifications would be necessary for him to return to work as a wheelchair user, which was selected and ordered by the therapist.

Juan's employer approved payment for the occupational therapist to do a home assessment. Juan lived on the third floor of his apartment complex with no elevator. The therapist met with the apartment management and Juan to discuss whether a ground-level apartment with wheelchair accessibility was available and, if not, when one would be available. Juan did not want to move from the complex because his children might have to change schools. The complex was also on the public transportation route, which would be important for Juan to use to return to work until he received funding to adapt his car with hand controls. The therapist assisted not only with the transition to work but also with Juan's transition into his home.

Questions

- Why is it important for occupational therapy interventions to be initiated in the acute care setting?
- Explain why a home evaluation and car assessment were necessary areas for the occupational therapist to complete with Juan.
- Discuss the importance of community mobility and participation in Juan's case.

Summary

Work is an occupation that is essential to people's quality of life and is central to occupational therapy. As people live their lives, they encounter many transitions in work between starting a first job and retiring from a long career. Some of these changes are positive, and others present challenges.

Because of the strong connection between work and occupational therapy, occupational therapy practitioners should help people build on their strengths to lead fuller and richer lives through participating in the occupation of work. Appendix 6.A offers AOTA resources to support occupational therapy and work transitions.

References

- American Guidance Service. (1957). *Minnesota Rate of Manipulation: Examiner's manual*. Circle Pines, MN: Author.
- American Occupational Therapy Association. (1993). Position paper: Purposeful activity. *American Journal of Occupational Therapy*, 47, 1081–1082.
- American Occupational Therapy Association. (2005). Occupational therapy services in facilitating work performance. *American Journal of Occupational Therapy*, 59, 676–679. <http://dx.doi.org/10.5014/ajot.54.6.626>
- American Occupational Therapy Association. (2007). *Occupational therapy services at the workplace: Transitional return-to-work programs*. Retrieved from <http://www.aota.org/about-occupational-therapy/professionals/wi/transitional.aspx>
- American Occupational Therapy Association. (2009a). *Occupational therapy and school mental health*. Retrieved from <http://www.aota.org/-/media/Corporate/Files/AboutOT/Professionals/WhatIsOT/CY/Fact-Sheets/OT%20%20School%20Mental%20Health%20Fact%20Sheet%20for%20web%20posting%20102109.pdf>
- American Occupational Therapy Association. (2009b). *Persons with serious mental illness*. Retrieved from <http://www.aota.org/-/media/corporate/files/secure/practice/ccl/mental%20illness%20cat.pdf>
- American Occupational Therapy Association. (2011a). Occupational therapy in facilitating work performance. *American Journal of Occupational Therapy*, 65(Suppl.), S55–S64. <http://dx.doi.org/10.5014/ajot.2011.65S55>
- American Occupational Therapy Association. (2011b). Occupational therapy services in early childhood and school-based settings. *American Journal of Occupational Therapy*, 65(Suppl.), S46–S54. <http://dx.doi.org/10.5014/ajot.2011.65S46>
- American Occupational Therapy Association. (2012). *Occupational therapy's role in functional capacity evaluation*. Retrieved from <http://www.aota.org/about-occupational-therapy/professionals/wi/capacity-eval.aspx>
- American Occupational Therapy Association. (2014). Occupational therapy practice framework: Domain and process (3rd ed.). *American Journal of Occupational Therapy*, 68(Suppl. 1), S1–S48. <http://dx.doi.org/10.5014/ajot.2014.682006>
- American Recovery and Reinvestment Act of 2009, Pub. L. 111–5, 123 Stat. 115, 516.
- Americans With Disabilities Act of 1990, Pub. L. 101–336, 42 U.S.C. §§ 12101–12213.
- Americans With Disabilities Act Amendments Act of 2008, Pub. L. 110–325, 122 Stat. 3553.
- Arbesman, M., & Logsdon, D. (2011). Occupational therapy interventions for employment and education for adults with serious mental illness: A systematic review. *American Journal of Occupational Therapy*, 65, 238–246.
- Baron, K., Kielhofner, G., Iyenger, A., Goldhamer, V., & Wolenski, J. (2006). *The Occupational Self-Assessment (version 2.2)*. Chicago: Model of Human Occupation Clearinghouse, University of Illinois at Chicago.
- BASES of Virginia. (n.d.). *Valpar component work samples*. Retrieved from <http://www.basesofva.com/>
- Bates-Harris, C. (2012). Segregated and exploited: The failure of the disability service system to provide quality work. *Journal of Vocational Rehabilitation*, 36(1), 39–64.
- Bing, R. (1981). Occupational therapy revisited: A periphrastic journey. *American Journal of Occupational Therapy*, 35, 499–518.
- Braddock, D., Rizzolo, M., & Hemp, R. (2010). Most employment services growth in developmental disabilities during 1988–2002 was in segregated settings. *Mental Retardation*, 42, 317–320.
- Braveman, B., & Page, J. (2012). *Work: Promoting participation and productivity through occupational therapy*. Philadelphia: F. A. Davis.
- Braveman, B., Robson, M., Velozo, C., Kielhofner, G., Fisher, G., Forsyth, K., & Kerschbaum, J. (2005). *Worker Role Interview, Version 10.0*. Chicago: Model of Human Occupation Clearinghouse, University of Illinois at Chicago.
- Browder, D., & Minarovic, T. (2000). Utilizing sight words in self-instruction training for employees with moderate mental

- retardation in competitive jobs. *Education and Training in Mental Retardation and Developmental Disabilities*, 35, 78–89.
- Brown, C., & Dunn, W. (2002). *Adolescent/Adult Sensory Profile users' manual*. San Antonio, TX: PsychCorp.
- Bryson, G. J., Bell, M. D., Lysaker, P. H., & Zito, W. (1997). The Work Behavior Inventory: A scale for the assessment of work behavior for people with severe mental illness. *Psychiatric Rehabilitation Journal*, 20, 47–55.
- Carter, E. W., Lane, K. L., Pierson, M. R., & Glaeser, B. (2006). Self-determination skills and opportunities of transition-age youth with emotional disturbance and learning disabilities. *Exceptional Children*, 72, 333–346.
- Case-Smith, J. (2003). Outcomes in hand rehabilitation using occupational therapy services. *American Journal of Occupational Therapy*, 57, 499–506. <http://dx.doi.org/10.5014/ajot.57.5.499>
- Christiansen, C. (1996). Managed care: Opportunities and challenges for occupational therapy in the emerging systems of the 21st century. *American Journal of Occupational Therapy*, 50, 409–412. <http://dx.doi.org/10.5014/ajot.50.6.409>
- Christiansen, C. H. (1999). Defining lives: Occupation as identity: An essay on competence, coherence, and the creation of meaning. *American Journal of Occupational Therapy*, 53, 547–558.
- Christiansen, C., Clark, F., Kielhofner, G., Rogers, J., & Nelson, D. (1995). Occupation: A position paper. *American Journal of Occupational Therapy*, 49, 1015–1018.
- Citron, T., Brooks-Lane, N., Crandell, D., Brady, K., Cooper, M., & Revell, G. (2008). A revolution in the employment process of individuals with disabilities: Customized employment as the catalyst for system change. *Journal of Vocational Rehabilitation*, 28, 169–179.
- Cocks, E., & Boaden, R. (2009). Evaluation of an employment program for people with mental illness using the Supported Employment Fidelity Scale. *Australian Occupational Therapy Journal*, 56, 300–306.
- Crooks, V. A., Stone, S. D., & Owen, M. (2009). Multiple sclerosis and academic work: Socio-spatial strategies adopted to maintain employment. *Journal of Occupational Science*, 16, 25–31.
- Dale, L. (2004). Challenges for the older academic in balancing work and wellness. *Work*, 22, 89–99.
- Farnworth, L. (1995). An exploration of skill as an issue in unemployment and employment. *Journal of Occupational Science: Australia*, 2, 22–29.
- Greig, T. C., Nicholls, S. S., Bryson, G. J., & Bell, M. D. (2004). The Vocational Cognitive Rating Scale: A scale for the assessment of cognitive functioning at work for clients with severe mental illness. *Journal of Vocational Rehabilitation*, 21, 71–81.
- Gupta, J., & Sabata, D. (2010). Maximizing occupational performance of older workers. *OT Practice*, 15(7), CE-1–CE-8.
- Gutman, S. A., Schindler, V. P., Furphy, K. A., Klein, K., Lisak, J. M., & Durham, D. P. (2007). The effectiveness of a supported education program for adults with psychiatric disabilities: The Bridge Program. *Occupational Therapy in Mental Health*, 23, 21–38. http://dx.doi.org/10.1300/J004v23n01_02
- Harnois, G., & Gabriel, P. (2000). *Mental health and work: Impact, issues and good practices*. Geneva: World Health Organization & International Labour Organization.
- Hinojosa, J., & Blount, M.-L. (2014). Occupation, activities, and occupational therapy. In J. Hinojosa & M.-L. Blount (Eds.), *The texture of life: Occupations and related activities* (4th ed., pp. 1–16). Bethesda, MD: AOTA Press.
- Holland, J. L. (1994). *Self-Directed Search*. Odessa, FL: Psychological Assessment Resources.
- Individuals With Disabilities Education Improvement Act of 2004, Pub. L. 108–446, 20 U.S.C. §§ 1400–1482.
- Insel, R., & Moos, R. H. (1974). *Work Environment Scale*. Palo Alto, CA: CPP.
- Izzo, M. V., & Lamb, P. (2003). Developing self-determination through career development activities: Implications for vocational rehabilitation counselors. *Journal of Vocational Rehabilitation*, 19, 71–78.
- Jakobsen, K. (2009). The right to work: Experiences of employees with rheumatism. *Journal of Occupational Science*, 16, 120–127.
- Jebsen, R. H., Taylor, N., Trieschmann, R. B., Trotter, M. J., & Howard, L. A. (1969). An objective and standardized test of hand function. *Archives of Physical Medicine and Rehabilitation*, 50, 311–319.
- Kessler, R., Chiu, W., Demler, O., & Walters, E. (2005). Prevalence, severity, and comorbidity of twelve-month DSM-IV disorders in the National Comorbidity Survey Replication (NCS-R). *Archives of General Psychiatry*, 62, 617–627.
- Larson, B., & Ellekson, M. (2000). Blueprint for ergonomics. *Work*, 15, 107–112.
- Lindstrom Johnson, S., Jones, V., & Cheng, T. (2014). Promoting successful transition to adulthood for urban youths: Are risk behaviors associated with career readiness? *Social Work Research*, 38(3), 144–153.
- Matheson, L. (1988). Integrated work hardening in vocational rehabilitation: An emerging model. *Vocational Evaluation and Work Adjustment Bulletin*, 22(2), 71–76.
- Mathiowetz, V., Weber, K., Kashman, N., & Volland, G. (1985). Adult norms for the Nine Hole Peg Test of finger dexterity. *Occupational Therapy Journal of Research*, 5, 24–38.
- Meyer, A. (1922). The philosophy of occupational therapy. *Archives of Occupational Therapy*, 1, 1–10.
- Migliore, A., Mank, D., Grossi, T., & Rogan, P. (2007). Integrated employment or sheltered workshops: Preferences of

- adults with intellectual disabilities, their families, and staff. *Journal of Vocational Rehabilitation*, 26(1), 5–19.
- Moore-Corner, R. A., Kielhofner, G., & Olson, L. (1998). *Work Environment Impact Scale (WEIS), version 2.0*. Chicago: Model of Human Occupation Clearinghouse, University of Illinois at Chicago.
- Mullins, J. (2009). Career planning the second time around. *Occupational Outlook Quarterly, Summer*, 12–15.
- National Council on Disability. (2012). *Subminimum wage and supported employment*. Retrieved from http://www.ncd.gov/NCD/publications/2012/August232012/default_page
- Personal Responsibility and Work Opportunity Reconciliation Act of 1996, Pub. L. 104–193, 110 Stat. 2105.
- Phillips, W., Callahan, M., Shumpert, N., Puckett, K., Petrey, R., Summers, K., & Phillips, L. (2009). Customized transitions: Discovering the best in us. *Journal of Vocational Rehabilitation*, 30, 49–55.
- Primeau, L. A. (1996). Work and leisure: Transcending the dichotomy. *American Journal of Occupational Therapy*, 50, 569–577.
- Rehabilitation Act of 1973, Pub. L. 93–112, 29 U.S.C. §§ 701–796l.
- Romano, J. L. (1998). *Legal rights of the catastrophically ill and injured: A Family Guide* (2nd ed.). Norristown, PA: Author.
- Social Security Administration. (2011). *Social security*. Retrieved from www.socialsecurity.gov
- Snodgrass, J., & Gupta, J. (2014). Work occupations. In J. Hinojosa & M.-L. Blount (Eds.), *The texture of life: Occupations and related activities* (4th ed., pp. 317–336). Bethesda, MD: AOTA Press.
- Spencer, J., Daybell, P. J., Eschenfelder, V., Khalaf, R., Pike, J. M., & Woods-Petitti, M. (1998). Contrasting perspectives on work: An exploratory qualitative study based on the concept of adaptation. *American Journal of Occupational Therapy*, 52, 474–484. <http://dx.doi.org/10.5014/ajot.52.6.474>
- Stamm, T., Lovelock, L., Stew, G., Nell, V., Smolen, J., Machold, K., . . . & Sandlo, G. (2009). I have a disease but I am not ill: A narrative study of occupational balance in people with rheumatoid arthritis. *Occupational Therapy Journal of Research: Occupation, Participation and Health*, 29, 32–39.
- Stikeleather, J. (2004). An older worker's decision to push or protect self following a work-related injury. *Work*, 22, 139–145.
- TASH. (2009). *TASH resolution on integrated employment*. Retrieved from <http://tash.org/advocacy-issues/employment/>
- Test, D. W., Fowler, C. H., Richter, S. M., White, J., Mazzotti, V., Walker, A. R., . . . Kortering, L. (2009). Evidence-based practices in secondary transition. *Career Development for Exceptional Individuals*, 3, 115–128.
- Test, D. W., Mazzotti, V. L., Mustain, A. L., Fowler, C. H., Kortering, L., & Kohler, P. (2009). Evidence-based secondary transition predictors for improving postschool outcomes for students with disabilities. *Career Development for Exceptional Individuals*, 32, 160–181.
- Tiffin, J., & Asher, E. J. (1948). The Purdue Pegboard: norms and studies of reliability and validity. *Journal of Applied Psychology*, 32, 234–247.
- U.S. Bureau of Labor Statistics. (2013). *Employer-reported workplace injury and illness summary*. Retrieved from <http://www.bls.gov/news.release/osh.nr0.htm>
- U.S. Department of Labor. (2011). *Soft skills to pay the bills—Mastering soft skills for workplace success*. Retrieved from <http://www.dol.gov/odep/topics/youth/SoftSkills.htm>
- U.S. Department of Labor. (2015). *What is customized employment?* Retrieved from <http://www.dol.gov/odep/categories/workforce/CustomizedEmployment/what/index.htm>
- U.S. Government Accountability Office. (2001). *Special minimum wage program: Centers offer employment and support services to workers with disabilities, but labor should improve oversight*. Retrieved from <http://www.gao.gov/new.items/d01886.pdf>
- Wada, M., & Beagan, B. (2006). Values concerning employment-related and family-related occupations: Perspectives of young Canadian male medical students. *Journal of Occupational Science*, 13, 117–125.
- Wehman, P., & Brooke, V. (2013). Securing meaningful work in the community. In P. Wehman (Ed.), *Life beyond the classroom: Transition strategies for young people with disabilities* (5th ed., pp. 309–37). Baltimore: Paul H. Brookes.
- Wehman, P., Inge, K. J., Revell, W. G., & Brooke, V. A. (2007). *Real work for real pay*. Baltimore: Paul H. Brookes.
- Wehmeyer, M. L., & Palmer, S. B. (2003). Adult outcomes for students with cognitive disabilities three years after high school: The impact of self-determination. *Education and Training in Development Disabilities*, 38, 131–144.
- Wehmeyer, M. L., & Schwartz, M. (1997). Self-determination and positive adult outcomes: A follow-up study of youth with mental retardation or learning disabilities. *Exceptional Children*, 63, 245–255.
- Wilcock, A. (1998). *An occupational perspective of health*. Thorofare, NJ: Slack.
- Wilson, S. A., & Landry, G. (2014). *Task analysis: An individual, group, and population approach* (3rd ed.). Bethesda, MD: AOTA Press.
- Woods, L., & Martin, J. (2004). Improving supervisor evaluations through the use of self-determination contracts. *Career Development for Exceptional Individuals*, 27, 207–220.
- World Health Organization. (2008). *The global burden of disease: 2004 update*. Retrieved from http://www.who.int/healthinfo/global_burden_disease/GBD_report_2004update_AnnexA.pdf
- Workforce Innovation and Opportunity Act. H.R. 803, Pub. L. 113–128 (2014).
- Workforce Investment Act of 1998, Pub. L. 105–220, 112 Stat. 936.

Appendix 6.A. AOTA Resources for Work Transitions

Available to Consumers

- **Driving and Community Mobility Across the Lifespan:** <http://www.aota.org/-/media/Corporate/Files/AboutOT/Professionals/WhatIsOT/CY/Fact-Sheets/Driving.pdf>

Fact sheet aimed at anticipating community mobility needs throughout life's trajectory for people with and without disabilities.

Available to Members

- **Ergonomics and Occupational Therapy: Improving Workplace Productivity:** <http://www.aota.org/About-Occupational-Therapy/Professionals/WI/Articles/Improving-Productivity.aspx>

Fact sheet on use of ergonomics in the workplace.

- **Facilitating Employment of People With Developmental Disabilities:** <http://www.aota.org/-/media/Corporate/Files/AboutOT/Professionals/WhatIsOT/WI/Facts/Workers%20with%20DD%20fact%20sheet.pdf>

Fact sheet on occupational therapy's role in facilitating work opportunities.

- **FAQ: Occupational Therapy's Role in Transition Services and Planning:** <http://www.aota.org/-/media/Corporate/Files/Secure/Practice/Children/transitions.pdf>

Synopsis on the role of occupational therapy for practitioners.

- **Functional Capacity Evaluation:** <http://www.aota.org/About-Occupational-Therapy/Professionals/WI/Capacity-Eval.aspx>

Fact sheet on Functional Capacity Evaluation and the role of occupational therapy.

- **Occupational Therapy Practitioners and Ergonomics:** <http://www.aota.org/About-Occupational-Therapy/Professionals/WI/Ergonomics.aspx>

Fact sheet on occupational therapy and ergonomics.

- **Occupational Therapy Services in Facilitating Work Performance:** <http://ajot.aota.org/article.aspx?articleid=1872136>

American Occupational Therapy Association. (2011). Occupational therapy services in facilitating work performance. *American Journal of Occupational Therapy*, 65(Suppl.), 55–64. <http://dx.doi.org/10.5014/ajot.2011.65S46>
AOTA official document.

- **OT Practice Article: Transitions Throughout the Lifespan:** <http://www.aota.org/-/media/Corporate/Files/Secure/Publications/OTP/2010/OTP%20Vol%202015%20Issue%202011.pdf>

Gibson, R., Nochajski, S., Schefkind, S., Myers, C., Sage, J., & Marshall, A. (2010, June 28). The role of transitions throughout the lifespan. *OT Practice*, 15, 11–14.

Article with a broad view of occupational therapy's role in transitions in multiple systems, populations, and settings.

- **Returning to Work With Cognitive Impairments:** <http://www.aota.org/About-Occupational-Therapy/Professionals/WI/Cognitive-Impairments.aspx>

Fact sheet on helping people with cognitive impairments return to work.

- **Standards of Practice for Occupational Therapy:** <http://www.aota.org/-/media/Corporate/Files/AboutAOTA/OfficialDocs/Standards/Standards-Practice-OT-2010.PDF>

American Occupational Therapy Association. (2010). Standards of practice for occupational therapy. *American Journal of Occupational Therapy*, 64, S106–S111. <http://dx.doi.org/10.5014/ajot.2010.64S106>
AOTA official document.

- **Transitional Return-to-Work Programs:** <http://www.aota.org/About-Occupational-Therapy/Professionals/WI/Transitional.aspx>

Fact sheet on helping injured employees gradually return to work.

- **Work Rehabilitation:** <http://www.aota.org/About-Occupational-Therapy/Professionals/WI/Work-Rehab.aspx>

Fact sheet on occupational therapy's role in rehabbing people for return to work.

Available for Purchase

- **Online course: Creating Successful Transitions to Community Mobility Independence for Adolescents:** http://www1.aota.org/shop_aota/prod-view.aspx?TYPE=D&PID=825&SKU=4833

Review of adolescent transitions toward independence in driving and other community mobility issues.

- **Online course: Driving Assessment and Training Techniques: Addressing the Needs of Students With Cognitive and Social Limitations Behind the Wheel:** http://myaota.aota.org/shop_aota/prodview.aspx?TYPE=D&SKU=4837

Review of screening and working with adolescents with cognitive and social impairments to improve their driving and community mobility.

CHAPTER 7.

TRANSITION AND AGING

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Chapter Objectives

After reading this chapter, readers will be able to

- ❖ Describe the role of occupational therapy in addressing the significant transitions often navigated in older adulthood;
- ❖ Identify *health-related transitions*, *contextual transitions*, and *occupational transitions* of older adults;
- ❖ Identify occupational therapy interventions that facilitate successful transition to productive aging, including *personal well-being*, *contextual harmony*, and *occupational participation*;
- ❖ Identify occupational therapy interventions with an emphasis on health promotion to facilitate successful navigation of *predictable* transitions of older adulthood; and
- ❖ Identify occupational therapy interventions with a restorative approach, often required for navigation of *unpredictable* transitions

Key Terms and Concepts

- ❖ Acceptance
- ❖ Action
- ❖ Adaptive modifications
- ❖ Age in place
- ❖ Age-friendly cities
- ❖ Age-related illnesses and disabilities
- ❖ Cardiopulmonary disorders
- ❖ Certified aging-in-place specialists
- ❖ Community mobility
- ❖ Compartmentalization
- ❖ Comprehensive driving evaluation
- ❖ Contemplation
- ❖ Dementia
- ❖ Driving rehabilitation specialists
- ❖ Engagement
- ❖ Gerotranscendence
- ❖ Health-related transitions
- ❖ Maintenance
- ❖ Occupational adaptation
- ❖ Persistent depressive disorder
- ❖ Precontemplation
- ❖ Predictable health-related transitions
- ❖ Preparation
- ❖ Presbycusis
- ❖ Readiness for change
- ❖ Readiness to change
- ❖ Restorative occupational therapy
- ❖ Sensorimotor disorders

- ❖ Situational transitions
- ❖ Successful aging
- ❖ Supportive social environment
- ❖ Temporal context
- ❖ Transactionalism
- ❖ Transtheoretical model
- ❖ Universal design
- ❖ Unpredictable health-related transitions
- ❖ Virtual context
- ❖ Vision impairment
- ❖ Vulnerable populations

When one chapter of life ends, turn the page and begin the new chapter.
—Emma Roxanna, age 101 years (personal communication, August 22, 2010)

Throughout the lifespan, we transition to new stages of life, from decade to new decade, from youth to old age. Older adults often receive occupational therapy at times of transition, when one chapter of life is ending and another is beginning (Spencer, Davidson, & White, 1996). Successful transitions contribute to health and well-being.

Transitions across the lifespan may be categorized as health-related and situational transitions (Liddle, Carlson, & McKenna, 2004). **Health-related transitions** are changes in the well-being of body functions. **Situational transitions** include environmental transitions and occupational transitions. Blair (2000) suggested that the point of transition is a transactional event that causes discontinuity. Humans strive for equilibrium during times of transition through a reappraisal of their identity with new roles, routines, and habits of everyday occupations.

Older adulthood is a period of profound transitions. This chapter describes the role of occupational therapy in addressing the significant transitions often navigated in older adulthood, including health-related transitions, environmental transitions, and occupational transitions. Facilitators of successful transition to productive aging include personal well-being, environmental harmony, and occupational participation.

Occupational therapy interventions with an emphasis on wellness, prevention, and health promotion can facilitate successful navigation of predictable transitions of older adulthood, and a restorative approach is often required for navigation of unpredictable transitions. Case examples will illustrate successful transitions and transitions requiring facilitation.

Changing Demographics

Health care systems must adequately address the specialized needs of the growing population of older adults. Worldwide, the population is aging. In the United States, the number of older adults and the average life expectancy are increasing. According to the 2010 United States census (Werner, 2011), the population ages 65 years or older grew 15.1%, but the total growth of the U.S. population was only 9.7%. The fastest growing segment of the U.S. population is ages 45–64 years (a 31.5% increase from 2000 to 2010), primarily due to the aging of the baby boom generation. Additionally, the U.S. population is living longer, as indicated by an increase in median age. The older population of the United States grew at a faster rate than the younger populations, is expected to continue to increase, and is living longer (Howden & Meyer, 2011).

Emma's Story

Emma is a 101-year-old woman who received in-patient occupational therapy at a subacute facility at several points in her life. After each admission and rehabilitation, she was discharged to live at home with a home health aide. Despite age-related changes, illness, injuries, and disabilities, her lifestyle promoted healthy transitions to productive aging.

Emma was widowed at the age of 74. She has three grown children, nine grandchildren, 14 great-grandchildren, and one great-great-grandchild. She is a retired kindergarten teacher. In her retirement, Emma traveled extensively. She is an avid card player and loves to play bridge and canasta. At age 86 years, Emma fell when leaving a supermarket. She hit her

head and fractured her patella, which negatively affected her confidence and thereby her lifestyle.

At age 88 years, she moved from her private home to reside in an apartment with a home health aide near where her adult daughter and family lived. At that time, she decided to stop driving.

By the age of 101, Emma had accumulated several diagnoses, including hypertension, carpal tunnel syndrome, fractures from falls, total hip replacement, congestive heart failure, and transient ischemic attacks with memory loss. She had had several experiences within the health care system in general and with occupational therapy specifically. This chapter illustrates how Emma successfully navigated many predictable and unpredictable transitions of older adulthood in health, environment, and occupation.

Mae's Story

Mae is a 62-year-old woman who was referred for an occupational therapy home evaluation and consultation. At age 60 years, Mae was diagnosed with right cerebrovascular accident (CVA) with resultant left hemiplegia, left somatosensory extinction, and left visual field impairment. Mae struggled with her transition to older adulthood with a disability.

Mae retired from her job as an administrative assistant and ceased to drive at the onset of her CVA. She loved to shop and cook prior to her disability but has not cooked since. She lives in a private home with a home health aide. She was widowed at age 55 years. Her adult daughter and teenage granddaughter reside with her on weekends. Mae is nonambulatory and experiences pain in her shoulder and her hand. She experienced an unpredictable health-related transition with resultant secondary transitions in environment and occupational participation.

This chapter describes Mae's struggle with various predictable and unpredictable transitions of older adulthood in health, environment, and occupation and her progress toward a sense of mastery and satisfaction as she worked toward independence.

Health-Related Transitions in Older Adulthood

Health-related transitions mark changes in how well a body functions. Practitioners often provide intervention to address occupational performance of

older adults at times of health-related transitions of mental, sensory, neuromusculoskeletal, and cardiovascular body functions. Additionally, health-related transitions can be experienced in hematological, immunological, respiratory, digestive, metabolic, endocrine, genitourinary, and reproductive body functions (American Occupational Therapy Association [AOTA], 2014).

Predictable Health-Related Transitions

Predictable health-related transitions are those changes in the well-being of body functions that can be universally expected in older adulthood. Aging results in predictable, involuntary, developmental changes. Age-related developmental changes in older adulthood occur in musculoskeletal, visual, other sensory, mental, cardiopulmonary, and systemic body functions (Bonder & Bello-Haas, 2009). As a result of these changes, older adults typically experience changes in strength and endurance, visual acuity, taste, hearing, memory, and other functions. These changes are gradual in nature and may not have a distinct starting point like many transitional events.

More significant than the changes in body functions in older adulthood is how those changes affect occupations. For example, if one develops *presbyopia*, age-related far-sightedness, but obtains glasses and does not lose the ability to read or drive, the loss is considered negligible. According to Hayase et al. (2004), in typically developing people with no significant medical history, between ages 51–91 years, there can be an expected and gradual decline in motor ability to perform activities of daily living (ADLs). Between ages 55–93 years, there is a gradual decline in the mental process skills affecting ADLs.

Age-related changes, combined with developmental disabilities or disabilities acquired in youth, can compound issues. For example, a person who has successfully adapted to occupational performance with cerebral palsy since birth may need to navigate age-related physical changes that create new challenges. Health professionals, including occupational therapy practitioners, who work with such individuals must recognize and address the transition of persons with disabilities as they age. Emma's transition follows a more predictable path; Mae experiences unpredicted health events.

Unpredictable Health-Related Transitions

Unpredictable health-related transitions are changes in the well-being of body functions that occur unexpectedly, often due to illness or disability. Predictable age-related changes in body functions should be distinguished from illnesses and disabilities that are unpredictable and not universally experienced. **Age-related illnesses and disabilities** are those that are more likely to occur in older adulthood but not all older adults will develop. Most older adults will experience age-related changes but may not develop age-related illnesses and disabilities.

The transition from healthy living to living with a disability or an illness is a profound transitional event at any age. There is a greater propensity for some disabling conditions in older adulthood than in other life stages, such as cardiopulmonary disorders, dementia, sensorimotor disorders, vision impairment, and mental health issues.

Cardiopulmonary disorders

Cardiopulmonary disorders such as atherosclerosis, coronary artery disease, and emphysema are more likely to develop in older adults (Dean & DeAndrade, 2009). Cardiopulmonary disorders can affect performance skills, including endurance and pacing for occupations. Prolonged cardiopulmonary disorders can cause secondary disease processes that can affect other body functions and, thereby, additional occupations and performance skills, including process skills and social interaction skills (AOTA, 2014).

Dementia

Dementia refers to symptoms of disorders of the brain that impair mental functions and may interfere with ADLs (U.S. National Library of Medicine, 2015). Although most older adults do not develop dementia, including dementia of the Alzheimer's type, older adults have a greater propensity toward dementia disorders (Riley, 2009).

Sensorimotor disorders

Sensorimotor disorders, such as CVA, which can affect sensory and motor neurological function, are

also not experienced by the majority of older adults but are more likely to occur in older adulthood. The effects of sensorimotor disorders vary widely and can impair motor skills, process skills, or social interaction skills necessary for occupational performance.

Vision impairment

Aging affects **vision impairment**, often resulting from age-related pathologies such as macular degeneration, cataracts, and glaucoma (Hooper & Bello-Haas, 2009). Vision impairment has implications for occupations such as reading, cooking, driving, and functional mobility. For example, age-related changes in vision can affect an older adult's ability while driving to see road signs, a car instrument panel, or road maps or to have difficulty with color perception or adapting to headlight glare (American Optometric Association, 2014; Elgin, Owsley, & Classen, 2012).

According to the Centers for Disease Control and Prevention (CDC; 2011), the risk of being injured or killed in a motor vehicle crash increases as one ages; 57% of men and 81% of women report avoidance of driving under certain conditions, primarily at night and in bad weather (CDC, 2011). There is also a need for practitioners to consider the impact of visual impairments on fall risk. Each year, one out of three older adults ages 65 years or older falls, which is the leading cause of death and injury (CDC, 2014).

Mental health

Although not a normal part of aging, older adults are at risk of changes in mental health. Depression is a significant consideration in the transitional health of older adults. There was a disproportionately high incidence of suicide among older Americans ages 65 years or older, who made up 12% of the U.S. population in 2004 but who accounted for 16% of deaths by suicide (National Institute of Mental Health [NIMH], 2007).

Persistent depressive disorder, or depression experienced most days over a 2-year period or longer (American Psychiatric Association, 2013), is commonly associated with suicide, and is often left undiagnosed and untreated in older adults (NIMH, 2007). Health care professionals often erroneously consider depression to be an acceptable response to typical changes in health and function. However,

depressive disorder can be treated effectively by health care professionals, including occupational therapists and occupational therapy assistants, to reduce the detrimental effect to health and function of older adults (NIMH, 2007).

Sadness, grief, loss, and temporary emotions are normal responses to losses experienced at any age. Older adults may expect to experience temporary emotional responses to loss, such as disability or death of a family member or friend as their cohort ages. Preparing for the unexpected is possible, but, certainly, there is an unpredictable element to these occurrences for which it is difficult to prepare.

Personal Well-Being and Transition

Transitions through the lifespan and into older adulthood, whether predictable or unpredictable, can alter one's dreams, expectations, and goals. Because of the potential for multiple transitions, older adults may need assistance in maintaining roles and minimizing the detriment to health and well-being (Liddle et al., 2004).

Occupational Therapy's Role

Occupational therapy promotes healthy lifestyles and a state of well-being in physiological functions of the body, thereby enabling readiness for transitions and facilitating successful navigation through predictable and unpredictable transitions in older adulthood. Detrimental effects of predictable transitions can be minimized through prevention and wellness. Unpredictable transitions, such as disability, are likely to require restorative interventions.

Interventions such as consultation, education, and advocacy with a focus on wellness, prevention, and health promotion can prepare older adults, their families, and their communities for predictable transitions in older adulthood. Facilitating older adults' acceptance of predictable changes as well as means of effective communication with loved ones and health professionals is essential for personal well-being. Recognition of the warning signs of pathologies can promote appropriate and timely intervention. Knowledge of risk factors, such as fall risk factors, can reduce risk and prevent injury.

Accessible and livable homes, neighborhoods, and other environmental contexts can support function through the transitions associated with aging. Maintenance of an active and healthy lifestyle promotes well-being. Occupational therapy promotes healthy lifestyles and a state of well-being in physiological functions of the body, enabling readiness for and recovery from the stress of transitions. For more about the role of occupational therapy in prevention and wellness during transitions, see Chapter 11, "Transition in Prevention and Wellness."

Restorative Occupational Therapy

In the face of unexpected transitions, such as an impairment or disability, *restorative occupational therapy* enables clients to participate in meaningful and purposeful occupations. Occupational therapy evaluation and intervention address engagement in areas of occupation, performance patterns, environment or context, performance skills, and client factors (AOTA, 2014). Assessments that are appropriate for practitioners to use in geriatric settings are annotated in Asher (2014) and are summarized in Appendix 7.A. Occupation-based activities, purposeful activities, preparatory methods, and education facilitate the restoration of personal health and well-being after unpredictable transitions (AOTA, 2014).

Successful Aging

Liu and Richardson (2012) suggested that one can age successfully, even with a disability. *Successful aging* may be thought of as maintaining health, avoiding disability, and maintaining function throughout the aging process. Ideally, one ages with health, but illness or disability should not relegate one to a category of the unsuccessful aged. Successful aging in the face of illness or disability may be more related to subjective well-being, self-perception, and identity than to the absence of illness or disability (Liu & Richardson, 2012).

The ability to successfully transition through age-related changes in health and maintain active engagement in meaningful and purposeful activities to the extent one is able is essential to well-being. Factors such as health status, cognitive function, income, marital status, engagement in exercise, and engagement in meaningful occupation, including socialization and employment or volunteer work,

may contribute to subjective well-being (Liu & Richardson, 2012; Wilcock, 1993).

Gerotranscendence

Tornstam (1997) derived the theory of *gerotranscendence*, which is a developmental theory of positive aging that can lead to life satisfaction. The theory describes positive aging as a progression to maturation and wisdom. In attaining gerotranscendence, a person achieves a deepened affinity with the past; appreciation for the commonplace; and communion with the universe, time, life, and death.

Gerotranscendence refers to acceptance of change and continued emphasis on self-development and improvement. Additionally, gerotranscendence refers to social change, which may include a greater need for solitude, more selective social ties, and emancipation from social convention. Gerotranscendence may contribute to successful transitions.

Readiness and Change

Transition to a state of well-being requires either readiness for change or readiness to change (Walker, 2002). *Readiness for change* is the preparation for predictable transitions. *Readiness to change* is the acceptance of the need for change in reaction to transitions. Readiness for transitions in older adulthood is essential because of the frequency of predictable and unpredictable transitions. Resisting or ignoring aging is a futile battle.

Rossen, Knafl, and Flood (2008) studied older women's perception of successful aging and determined three categories of facilitators of transition:

1. Acceptance
2. Engagement
3. Compartmentalization.

According to Rossen et al.'s study, essential to successful transition of the older adult women was *acceptance* of the physical, relational, and environmental changes common in older adulthood. To accept the changes, those women who maintained *engagement* in social and self-care activities perceived themselves as aging successfully. Finally, Rossen and colleagues described *compartmentalization*, which refers to how a person perceives the

attributes of life and the demeanor of others as a factor in successful aging.

Transtheoretical Model

The *transtheoretical model*, developed to describe the process of intentionally changing behavior, is sometimes, and controversially, applied to other transitions. The stages of change described by the model are

- Precontemplation,
- Contemplation,
- Preparation,
- Action, and
- Maintenance (Prochaska, DiClemente, & Norcross, 1992, cited in Liddle et al., 2004).

Precontemplation refers to the stage before a person acknowledges the impact of a behavior on health and prior to the intention to take action to change a behavior. *Contemplation* refers to the stage when a person recognizes how changing behaviors would affect health and considers initiating a change in behavior.

The process of change then progresses to the stage of *preparation*, in which a person takes preparatory steps toward initiating change. The next stage is *action*, in which change is made. *Maintenance* is the stage in which the new healthy behavior is continued. Long-term personal well-being in older adulthood may be enhanced by intentionally changing behaviors in preparation for the predictable and unpredictable changes of older adulthood. Many people spend years in precontemplation in their youth, young adulthood, and middle adulthood avoiding acknowledgment of the inevitable changes that can be expected when transitioning to older adulthood.

The transtheoretical model suggests that preparation and action before older adulthood to develop healthy behaviors and modify practices in anticipation of aging may promote maintenance of healthy aging. For example, applying universal design principles to one's home, before the need for changes, allows for the variation in ability that may occur with aging, perhaps maintaining one's ability to age in place.

Preparation and action taken prior to retirement—financially, socially, and occupationally—may assist with maintaining a healthy retirement. Intentionally

developing healthy behaviors in activity and nutrition may assist with maintaining health in older adulthood.

Readiness for Transition and Well-Being: Emma

Emma demonstrated readiness for change and readiness to change, which facilitated her transitions in her older adulthood. When storytelling was used to build an occupational profile, Emma described productive routines, habits, and leisure activities as a youth, including singing hymns at the piano and playing games. As a teenager, she recalled sewing clothing for her doll, playing tennis, crocheting, and roller skating. In Emma's older adulthood, she maintained involvement in favored pastimes to the extent that she was able. She played games often with her grandchildren. She incorporated card playing into her routine with regularity. She continued to sew and crochet for as long as she was able and gave it up when it was painful for her hands.

Emma was ready to accept changes in her abilities. She honored her limitations, but she engaged in physical and mental activities to the extent to she was able. Occupational therapy interventions with a focus on education, wellness, prevention, and health promotion helped prepare Emma for successful transitions, as well as with communication about the changes with family.

Emma became aware of several changes as she aged. In her 80s, she recognized a significant decline in her endurance for activities such as walking and could no longer travel as she had done. Visual acuity began to decline, necessitating the use of enlarged playing cards with high contrast to enable her to adequately see to continue to play card games.

Emma also developed *presbycusis*, age-related hearing loss that is particularly notable with high-pitched sounds and voices. It was often difficult for her to follow conversations at the dinner table with her boisterous and giggling grandchildren in the background. Emma made a point of visiting with her family in small groups and letting them know that communication was significantly clearer when the person faced her, lowered the pitch of the voice, spoke clearly and slowly, and reduced background noises such as TV sounds and chatter.

Despite disabling conditions, at age 101 years, after each discharge from the inpatient subacute rehabilitation, Emma lived and functioned in her own apartment with a live-in home health aide. She used a rolling walker. She was able to perform ADLs with minimal assistance to set up supplies and equipment and contributed to the performance of many instrumental activities of daily living (IADLs). She had frequent contact with her adult daughter and family who lived nearby.

When Emma lost her spouse and several friends, she described times of profound grief but coped with the support of family and friends. Emma perceived life as a book with many chapters. She often expressed the importance of closing one chapter, turning the page, and moving on with the story of her life.

Readiness for Transition and Well-Being: Mae

Mae exhibited signs of depression. She stated that she never expected her life to be like this. She tearfully expressed loneliness and feelings of frustration and helplessness. She was dependent on a live-in home health aide for all basic ADLs and IADLs. At the time of occupational therapy evaluation, she had not been outside of her home in 2 years and rarely got out of bed. She spent her time watching television and no longer engaged in any aspect of occupations she enjoyed, such as meal preparation.

Mae found it challenging to accept the unexpected transition to an age-related disability and had a negative sense of subjective well-being, self-perception, and identity. To enable Mae's recovery from the stress of transitions, occupational therapy interventions addressed environmental contexts to support function, promoted healthy lifestyles, and promoted a state of well-being in physiological functions.

Inpatient occupational therapy intervention, prior to discharge home, addressed motor and process skills, pain, sensation, vision, upper-body dressing, and tub and toilet transfers; a power wheelchair was provided. Occupational therapy consultation in the home addressed Mae's transition to the discharge environment. The practitioner educated the family and builders on application of accessible and adaptable design concepts for her home, particularly regarding the bathroom access, bedroom and kitchen

setup, and egress from the house. Occupational roles within the home were addressed, including incorporation of simple aspects of meal preparation into daily routine, education of the caregivers for effective carryover, and social participation within her local community.

Questions

- What are the predictable and unpredictable transitions of Emma and Mae in health?
- Current literature indicates that the following can facilitate personal well-being and successful transitions: prevention, wellness, acceptance of change, social engagement, engagement in activities, compartmentalizing and perceiving the attributes of others and of life, gerotranscendence, readiness for change, and readiness to change. What are the aspects of personal well-being that may have facilitated or may have been barriers for successful transitions for Emma and Mae?
- What are the potential roles of occupational therapy with Emma and Mae that would facilitate readiness for predictable transitions?
- What are the potential roles of occupational therapy in facilitating Emma's and Mae's successful navigation of the challenges of unexpected transitions?

Environmental Transitions in Older Adulthood

The environment should fit the needs of the person to support occupational performance. Older adulthood can be a time of major change in the relationship of the person-to-environmental context (Spencer et al., 1996). Practitioners can educate older adults to prepare for those aspects of environmental fit in which change can be anticipated. When an older adult is faced with unpredictable changes in environmental fit, occupational therapy can facilitate the transition.

Predictable Environmental Transitions

Research shows that most older adults would prefer to *age in place*, within their home and community, rather than move to accommodate their changing needs (Heatwole & Cutchin, 2010). The benefits of aging in place include the continuity of home

and community for the person and the reduction in cost of long-term care expenses, especially with a growing cohort of older adults. Age-related physical changes demand environmental accommodations to maintain performance, mobility, and safety during daily activities in the home and community.

Older adults have a greater propensity for falls and must be more mindful of reducing environmental hazards that increase the risk of falls. Environmental hazards in the home are a significant risk factor for falls, particularly in community-dwelling older adults who use mobility aids and have had multiple falls (Letts et al., 2010). To reduce the risk, the home environment should be free of clutter and tripping hazards. Lighting should be adequate for accommodating the age-related changes in vision. Frequently used items should be easily accessible without excessive reach or maneuvering, and other hazards should be reduced. Altering the physical environment is further discussed later in this chapter.

Although aging in place is a desirable option for many, it is not the best option for all older adults. It is important to keep in mind the need for additional care or social support by some older adults that cannot be adequately provided in the home. Alternative living arrangements, including moving in with family members or long-term-care options, may be a better choice. Successful transition within one's home and community or to alternative living arrangements to accommodate changing needs as one ages is essential.

Unpredictable Environmental Transitions

The onset of disability is a transition in itself that precipitates further unexpected transitional events, such as transitions within the health care continuum. Acute care hospitals are intended to promote medical stability. Next, the client may be transferred to another facility such as acute inpatient rehabilitation or subacute rehabilitation for nursing care or rehabilitation services.

Each transition to a new hospital and setting with different people, layout, schedules, and staff requires adjustment. Current payment mechanisms lack financial incentives for collaboration between the health care settings (Coleman, 2003; Coleman & Berenson, 2004; Coleman et al., 2004).

During hospital stays, the older adult is required to adapt to the institutional environment, which often fosters dependence and complacency. Upon discharge to the place of residence, the person is abruptly expected to manage his or her recovery and resume a degree of functional independence not expected in the inpatient setting (Coleman et al., 2004).

Vulnerable populations

Vulnerable populations (e.g., those who experience poverty, disability, illness, and aging) are at a greater risk of abusive environments, particularly when cared for in the home or in long-term care. The transition to vulnerability can be disconcerting. Elder abuse may be an intentional or negligent act and affects approximately 4.3% of older adults, or 1.6 million people each year (Pinto & Schub, 2010). Frequently, the abuse is committed by a family member or caregiver and can be physical, emotional, verbal, sexual, or financial.

Abuse

For vulnerable populations, including people who are frail, ill, or have cognitive impairments, recourse and resources for defense against the abuse can be out of reach. Vigilance and advocacy by health care professionals, including occupational therapists and occupational therapy assistants, is essential. Signs of abuse include physical injuries, signs of neglect, changes in mental status (e.g., anger, aggression, withdrawal, confusion), or lack of interest in socialization.

In older adults, signs of abuse can be misidentified as results of accidental injuries or physical and mental changes for which older adults are at greater risk. If abuse is suspected, the National Center for Elder Abuse (www.ncea.aoa.gov) may be a source of guidance for course of action (Pinto & Schub, 2010). Healthy transition to older adulthood will be hindered by abusive environments.

Environmental Harmony

Engagement in meaningful occupations within the client's environment is essential and must be the focus of health care professionals in collaboration with family, caregivers, and the client (Orentlicher, 2011).

Practitioners must be in tune with the transactions between the client and his or her environment.

Transactionalism describes the immediate and distant physical, social, and political environments, not as external and separate from the person but as the medium through which humans engage in occupation (Dewey & Bentley, 1949; Dickie, Cutchin, & Humphry, 2006; Mernar, 2011). This theory views the interplay among the person and his or her health, environment, and occupations as intimately related. The better they fit, the better the person's performance (Christiansen & Baum, 2005; Law et al., 1996).

Social Environment

A **supportive social environment** can facilitate transitional ease in older adulthood. Building and maintaining significant relationships with family, peers, and the community supports readiness for change. Family involvement and familial support can assist in promoting older adults' occupational well-being in the midst of other age-related changes. Lifelong and newly formed peer relationships can also be a significant support. Communities in which older adults live may provide opportunities for enablement through neighborhoods, support groups, senior centers, adult day care, and religious or other affiliations.

Altering the Physical Environment

The physical environment can facilitate or stymie transitional ease. Altering the environment to be ready for change may be accomplished through universal design and adaptive modifications.

Universal design

Universal design of homes or buildings is the adherence to principles that make environments usable by people of various abilities without adaptation prior to an event or changing needs. Examples of universal design include the initial design of environments without steps at thresholds and entrances rather than requiring the addition of ramps in the event of changing mobility abilities, designing 32 × 36-in. doorways, and use of lever-style door knobs and rocker-style light switches. The design should be simple and flexible and should require low physical effort to

accommodate varied and changing abilities (National Association of Home Builders, 2007). (For more information on home modifications, see Chapter 10, "Supportive Environments for Transition.")

Adaptive modifications

Frequently, when universal design principles have not been used, **adaptive modifications** to the home environment are necessary to accommodate changes in ability due to age or disability (Siebert, Smallfield, & Stark, 2014). Adaptive designs address the needs of the person in the environment for function and safety. He or she may need grab bars, adequate space to maneuver a wheelchair, and access to the bathtub or toilet (generally a 5–6-ft radius). Someone who uses a wheelchair may need light switches or outlet height adjusted for easy reach (generally no lower than 18" above floor and no higher than 48" above floor). A client may benefit from an open area with no cabinets under the counter so a wheelchair can roll up to the sink. (*Note.* Pipes under the sink should be insulated to prevent scalding from hot water in the pipes.)

A walk-in shower with low or no threshold may benefit a person with limited mobility or who is nonambulatory. Adequate drainage and reduced-slip flooring should also be considered. Some people benefit from stair lifts for access up and down stairs or ceiling lifts that can lift and transport a person to designated essential areas of access. There are many informative resources on home modification and aging in place for practitioners and their clients (see Appendix 7.B).

Practitioners can evaluate occupation within an environmental context and make simple suggestions for safety and performance. Some occupational therapists are specialists in assessing the environmental fit and suggesting extensive modifications. **Certified aging-in-place specialists (CAPS)** are therapists and builders who specialize in environmental modifications to accommodate the needs of older adults who wish to age in place (see Appendix 7.B).

Relocation

If aging in place at one's home and neighborhood is not an appropriate option, an older adult's relocation to a long-term-care institution need not be unpleasant. The amount of control given to the older adult in areas over which he or she can exert control,

especially with involuntary admittance, can affect successful transition. A sense of control may be enhanced by providing choices in the transition to a new living space, such as in decorations, socialization or privacy, scheduling, attire, or meals.

In addition, helping the person prepare for the move can facilitate smoother transitions. Spencer et al. (1996) expounded on continuity of the person's past experience as an adaptive repertoire in occupational adaptation during times of transition. The new residences should also be assessed for person-environment disharmony.

Health Care Environments

People with complex medical conditions, regardless of dwelling place, often require care from various health care settings and professions. The transition through the continuum of care increases a person's vulnerability to experience failures of communication and relocation from one care setting to another.

Effective care transition requires communication between the health care professionals at the receiving and sending institutions. Essential points of communication include plan of care, goals and preferences, updated lists of problems, preparation, and education of the client and caregiver. Although health care in the United States does not have established systems and incentives for communication through the continuum of care, such systems could include

- Identifying health care practitioners, including occupational therapists, as care managers to initiate the transition of care and follow the client through the transition;
- Using technology and Internet-based tools to share a plan of care and client information across settings; and
- Establishing financial incentives to reimburse services and communication between health care settings and practitioners (Coleman, 2003; Coleman et al., 2004).

Temporal Context

Temporal context, or time and its impact on occupation (AOTA, 2014), can also support or hinder well-being. The older adults' and health care professionals' awareness and incorporation of temporal needs into routines can facilitate healthier transitions.

One consideration is that with frailty often comes a need for a slower pace. Often the pace needed by the frail older adult is much slower than the typical health care system is accustomed to accommodating. To support persons managing the stress of transitions, consideration of the temporal aspects of healthy habits, routines, roles, or rituals can be a beneficial part of an occupational therapy intervention plan. Rhythm, duration, time of day, pace, and other aspects of time can affect the quality of care and occupational participation.

Virtual Context

The *virtual context*, or use of technology instead of physical presence (AOTA, 2014), to participate in occupations can be a facilitator of transitional ease. For example, shopping can be done or classes can be taken online; communication can be accomplished by text or email. People of the baby boom generation are late bloomers to digital use (Cohn & Taylor, 2010), and the lack of technology use by many older adults can forfeit the multitude of benefits. Hickman, Rogers, and Fisk (2007) proposed that technology can compensate for age-related changes and can promote health and well-being. Providing training in technology to older adults that is consistent with their abilities, previous experience, and skills can improve usage (Vrkljan, 2010).

Functioning in a virtual environment rather than a poorly accommodating physical environment could enable such occupations as computer-based shopping or communication and use of applications to compensate for low vision or impaired cognition. (See Appendix 7.B; for information about technology adaptations, see Chapter 10, “Supportive Environments for Transition.”)

Environmental Harmony: Emma

At age 88 years, Emma sold her home and moved to a smaller apartment near her adult daughter. She brought familiar furniture, decorations, and memorabilia from her old home to her new home. Although still very healthy, she was aware of the likelihood of changes to come as she aged, so she readied herself for the anticipated changes by placing herself within a supportive physical and social environment for productive aging.

After she experienced a transient ischemic attack and medical complications at the age of 98, she began to lose her ability to independently perform ADLs. She would frequently state that she could no longer rush and she had “earned the right to take her time for her own well-being.”

Emma demonstrated acceptance of the need for change, such as the need for a live-in home health aide and several environmental adaptations and changes in occupational performance. There were 10 steps to exit her home. Environmental modifications, including the installation of a stair lift, allowed access to her community and social participation with her family and friends. Simple environmental modifications, such as tub bench, installation of a gate at the top of the stairs to reduce risk of inadvertent fall, and elongation of the ceiling fan chain over her bed for ease of access, also enabled performance.

Environmental Harmony: Mae

Mae’s home did not adhere to the principles of universal design and was not ready for the unexpected changes in her ability. The 23-in. doorway to a narrow bathroom did not permit wheelchair access. The six steps to enter the house did not allow egress for community mobility and participation. The manual hospital bed was positioned with the sensory-deprived side of her body toward the wall, providing little additional sensory challenge or input. Because the environmental disharmony was not addressed, Mae was deprived of occupational participation within the confines of her environment.

Collaboration between Mae and her family, Rebuilding Together, volunteers, builder, and occupational therapist allowed environmental facilitators to be implemented (Exhibit 7.1). A ramp was built to allow entrance and exit to the home, and the bed was moved away from the wall to allow sensory and motor engagement to both sides of Mae’s body. Recommendations were made to set up the kitchen in a manner that allowed access to a table upon which Mae could assist with simple aspects of meal preparation. Modifications to the bathroom were suggested but were refused by Mae and her family. It was recommended that Mae speak to her physician regarding the need for continued occupational therapy services.

Exhibit 7.1. Examples of Community-Based Resources for Accessible Environments

Rebuilding Together

AOTA has an alliance with Rebuilding Together (<http://rebuildingtogether.org>), a national organization that recruits volunteers to work together to remodel and rehabilitate homes of low-income people, older adults, and people with disabilities in their community. Some occupational therapists volunteer with Rebuilding Together to provide an evaluation of safety and function in the home for the older adult who qualifies. In addition, Rebuilding Together and many organizations identified by local departments of aging can provide assistance in home modifications for older adults who meet the criteria.

World Health Organization

The World Health Organization (2007) developed a model for age-friendly cities that support active aging and protect those who are most vulnerable. The model describes structures and services that would be accessible and inclusive of older adults with varying abilities. The model describes age-friendly aspects of outdoor spaces and buildings, transportation, housing, social participation and inclusion, civic participation and employment, communication and information, community support, and health services.

Questions

- What are the predictable and unpredictable transitions for Emma and Mae in environment?
- What aspects of Emma's and Mae's social and physical environments, as well as temporal or virtual contexts, act as facilitators or barriers to successful transition?
- What additional ways can occupational therapy address environmental harmony to facilitate Emma's and Mae's successful transition to productive aging?

Occupational Transitions in Older Adulthood

Aging leads to many expected changes in occupations. As Heatwole and Cutchin (2010) discussed, occupational participation and the meaning

realized through it are vulnerable to the dynamic processes of living and aging.

Predictable Occupational Transitions

Retirement

The transition from work to retirement is commonly considered to be a profound event in older adulthood. A significant portion of life is devoted to preparation for performance in the paid workforce. Work satisfies the human need to use knowledge and skills, to occupy time, to develop a social and self-image, and to establish status. Retirement results in the loss of a significant role and routine, which may negatively affect well-being.

However, according to Moody (2010), data from a health and retirement study conducted by Cohn and Taylor in 2010 showed that more than 90% of the participants who were newly retired were "very" or "moderately" happy. Moody denounced the notion that active aging through work is better than leisure or disengagement. Pascale, Primavera, and Roach (2012) emphasized the value of planning and preparing for retirement. The ability to adequately prepare for retirement may positively or negatively affect a person's health and well-being.

Successful retirement depends on contextual influences, the planning process (including financial planning), and the outcome of the planning. Wiseman and Whiteford (2009) studied older rural men and their experience with retirement. Retirement as a life transition requires occupational adaptation. The men who transitioned satisfactorily to retirement maintained a sense of competence and satisfaction with their engagement in meaningful occupations. They also maintained a link between the way of life, people, and occupations before and after retirement.

With the transition from work to retirement comes transitions in financial management in older adulthood. Income is fixed at a quantity that may or may not meet the needs of the person. Additionally, there may be changes in the financial management and third-party reimbursement of health care needs. The resources available to a person can affect the ability to cope with other life events and transitions.

Relationships

Many older adults experience other predictable transitions in their occupational roles and relationships.

For example, their successful transition to parenthood of adult children requires the ability to allow the relationship to evolve. In addition, the transition to grandparenthood can be a significant event. Spousal relationships also evolve as people age, and parental and grandparental roles change.

Successfully developing and maintaining healthy family and other relationships can be a facilitator of transitional ease through other significant events of aging. Certainly the degree of challenge in transitioning relationships is dependent on many factors. There are added complexities for aging caregivers. For example, an aging parent of an adult child with a developmental disability will need to make careful plans for the future care of his or her dependent child. In the Prologue, Cheryl describes her painstaking planning for Renzo's future as she, his primary caregiver, ages.

Unpredictable Occupational Transitions

Transition in occupational participation that occurs unexpectedly imposes challenges at any age. There may be unexpected transitions in an older adult's ability to engage in occupation secondary to transitions in personal well-being or environment.

Poor health status

Poor health status and poor environmental fit can hinder performance of basic ADLs, IADLs, work, education, leisure or play, and social participation. The older adult may need to transition from independence to requiring assistance for basic ADLs. Becoming a recipient of care from a spouse, family, home health aide, or others often requires the ability to change perceptions of one's self-image and still maintain a sense of self-worth. Occupational therapy intervention can promote autonomy of the care recipient to the extent possible and can educate caregivers on essential aspects of caregiving and stress management.

Caregiving

Conversely, an older adult may experience the unexpected transition of becoming a caregiver for a spouse or family member with disability or illness. Caregiving can be a service of love but can deplete

a caregiver's emotional, physical, and financial resources. Caregivers often experience physical and emotional strain and few social contacts (Lavela & Ather, 2009; Roth, Perkins, Wadley, Temple, & Haley, 2009).

Multicomponent, interdisciplinary interventions can address caregivers' many needs. For example, effective intervention methods address caregiver burden, depression, well-being, knowledge, respite, problem-solving training, use of telephone-based interventions to reduce caregiver stress, relaxation training, psycho-educational coping programs, and programs to improve management of self-care and problem behaviors. As part of an interdisciplinary care team, practitioners provide individual intervention and education to address identified needs in occupational performance of care recipients and their caregivers (Dooley & Hinojosa, 2004; Gitlin & Corcoran, 2005; Gitlin et al., 2003; Graff et al., 2007; Samia, Hepburn, & Nichols, 2012; Schulz et al., 2003; Sorensen, Pinquart, & Duberstein, 2002).

Driving

As a result of changes in personal well-being and environment, older adults may experience unpredictable transitions in IADLs, such as driving. Many older adults drive safely, but practitioners should be aware of how aging and age-related diagnoses may affect older clients' motor and praxis skills, sensory-perceptual skills, emotional regulation skills, and cognitive skills when driving (Stav, 2015). Impairments of skills that may affect the client's ability to drive may not be mentioned by the client or family for fear of losing independence or because of denial or other concerns and uncertainty.

Not all occupational therapists are specialists in driving, but all should be able to screen for driving goals, history, and foundational skills and should be able to refer to the appropriate specialist when necessary. **Driving rehabilitation specialists (DRSs)** are occupational therapy and other practitioners who have met the requirements for certification and education, which vary state to state (McGuire & Schold Davis, 2012; Stav, 2015). See Appendix 7.B for resources on driving rehabilitation.

A **comprehensive driving evaluation** includes a clinical off-road evaluation and an in-vehicle on-road assessment (Stav, 2015; Unsworth, Pallant, Russell, & Odell, 2011). Some decisions about

driving cessation can be guided by clinical evaluation by a health care provider and are made on the basis of state licensing standards. For example, an occupational therapy evaluation may detect severe dementia or a visual field cut that does not meet minimal state standards for driving.

The Occupational Therapy Driver Off-Road Assessment (OT–DORA; Unsworth et al., 2011) is an off-road evaluation battery that may be used by generalist and specialist occupational therapists and DRSs to evaluate the skills needed for driving (Redepenning, 2006). It includes a medical history, medication screen, sensory assessments, physical assessments, cognitive assessments, and additional assessments. An off-road evaluation such as the OT–DORA may determine presence or absence of skills needed to drive, but an on-the-road assessment by a DRS may be justified to assess safety and ability on the road (Redepenning, 2006).

If adaptive equipment for a vehicle is needed, suggestions should be made by a DRS and the equipment should be installed by a vendor certified by the National Mobility Equipment Dealer Association for proper installation. Other resources for driving safety are available to practitioners and older adults through AOTA, AARP, and AAA and are listed in Appendix 7.B. Also see Chapter 10, “Supportive Environments for Transition,” for the potential role for occupational therapy in driving rehabilitation.

Community mobility

Community mobility is “planning and moving around in the community and using public or private transportation” (AOTA, 2014, p. S19) and contributes to one’s independence, spontaneity, and identity. People who lack safe and effective community mobility are at risk of loss of occupational participation (Stav, 2015). Older adults who cease driving may need intervention to transition to the use of alternate means of transportation. Transitional planning for transportation options includes gathering information about the person’s desire and necessity for community mobility, identity as it relates to driving, and lifestyle redesign to use transportation options in the person’s community (Clark et al., 1997; Liddle, Carlson, & McKenna, 2003).

Practitioners can contact local agencies for aging to find out about transportation options in their

area. The World Health Organization (2007) described ideal conditions for transportation options for **age-friendly cities**, which address cost, reliability, connections, maintenance, accessibility, location, clarity of information, lighting, hazards, and safety (see Exhibit 7.1).

Early exploration of transportation options can provide options for community access as driver or as passenger. Ideally, one would gradually limit driving and increase other transportation options as skills decrease and risk increases. This self-limiting requires awareness of limitations and readiness for change to use public transportation or to accept the more passive role as passenger.

Occupational Participation

Meaningful occupation within an enabling environment is key in transitions to restored health. People learn to adapt to changing needs and conditions through occupations. The desire to participate in occupation and the desire for mastery result in a response to occupational challenges and thereby adaptation (Schkade & Schultz, 1992). Blair (2000) described life transitions as periods of disequilibrium and emphasized the centrality of occupation to well-being. Blair identified means used by people to negotiate recent transitions and strive for equilibrium, including support systems, personalized activities, and engagement in familiar occupations.

Humans of all ages are occupational beings who need to use time in a purposeful way and engage in occupation (Wilcock, 1993; Yerxa, 1998). Engagement in meaningful and purposeful occupations can positively influence physical, mental, spiritual, and social health and well-being. Times of transition challenge a person to examine his or her routines and activities and the purpose and meaning attributed to them. Occupational deprivation can be detrimental to health and well-being (Whiteford, 2000).

Practitioners are experts in occupation, ensuring activity is purposeful, individualized, and integrated within contexts. Addressing older clients’ interests and values, habits, roles, routines, and capacity to improve skills for performance and participation in purposeful and meaningful occupations is empowering (Kielhofner, 1989, 2008). Several tools are available to assess occupational performance of older adults (see Appendix 7.A; Asher, 2014).

Collaboration between clients and occupational therapists to set goals for coaching and education to attain goals related to occupation, as well as to enable self-advocacy to change policy and political structure within the local and larger environment, can empower occupational participation (Flemming-Castaldy & Orentlicher, 2010).

Occupational adaptation is a normative process that occurs across the life course in response to occupational challenges. When a client is disrupted by disability, it is the role of the practitioner to facilitate the client's ability to generate, assess, and integrate adaptive responses and relative mastery to occupational challenges (Schultz & Schkade, 1992). Practitioners have an important role in promoting wellness to prepare older adults for predictable transitions in occupation and in restorative interventions when disability leads to occupational disengagement.

Occupational Engagement: Emma

Emma incorporated regular healthy and enjoyable habits into her life. She had defined, daily, and regular routines, such as eating three square meals each day, regular card-playing days, favorite television shows, and a regular bedtime. Her daughter, aware of Emma's propensity for routine, designated Thursdays as the day she would be available to Emma for whatever she wanted or needed her to do. By creating that regularity, she was able to balance Emma's needs with the other demands of her busy life.

Emma made many adaptations in significant occupations. Modifying but continuing engagement in meaningful activities and socialization despite age-related changes in health contributed to her subjective sense of well-being. When Emma moved to a more metropolitan area to be nearer to family, she recognized her limitations in the new environment and relinquished driving and adapted to the role of passenger.

Emma transitioned multiple times within the health care system from a series of inpatient hospitalizations, subacute rehabilitation, and back to home. Rehabilitation helped her maximize her potential for successful transitions. She received intervention to promote personal well-being, harmonious context, and occupational participation.

According to Emma's daughter, the interventions of particular significance in promoting a healthy occupational transition included

- Education to Emma and her caregivers on healthy activity and exercise;
- Fall risk reduction measures, including education on proper footwear and removal of tripping hazards in her home;
- Education on energy conservation to enable Emma to assist with cooking tasks;
- Provision of a long-handled shoe horn and reacher;
- Use of a leg lifter, long-handled sponge, hand-held shower, and tub bench to enable Emma to shower;
- Use of a bedside commode and night light;
- Use of adaptive devices and positioning to enable reading and card playing;
- Education on functional mobility and safe transportation of food items from the kitchen to the eating area;
- Methods for reduction of spillage of food during self-feeding; and
- Addressing community access (e.g., installation and use of a stair lift).

Emma's lifestyle was active, healthy, and social to the extent she was able at every chapter of her life.

Occupational Engagement: Mae

Mae's environment provided a poor medium through which to engage in occupation; thus, her health and occupations were not maintained and eventually declined. Mae stayed in bed most days and watched television. A Hoyer lift was used when she did get out of bed. She used an incontinence pad and received sponge baths in bed. Her shower chair sat, symbolic of Mae's occupational status, unused, with the tag still on, with clothing piled on top, in the corner of her bedroom. In the living room, the power wheelchair sat in the same state of disuse.

Mae's occupational deprivation and inactivity due to the environment caused further decline in health and ability, including signs of depression and severe left upper extremity and lower extremity contractures and pain. The centrality of occupation

in facilitating health, well-being, and transitional ease (Blair, 2000) was evident.

Mae feared leaving her bed, using her power wheelchair, and using the ramp. She tearfully expressed a desire to prepare a simple meal, which was used as an occupational challenge to facilitate occupational adaptation and relative mastery. Mae was motivated to leave her bed and sit in her wheelchair to engage in simple meal preparation. Education on her visual field deficit was initiated with her, her family, and the caregiver through the medium of simple meal preparation.

Mae had abruptly lost the ability to drive and access to the community at the onset of her disability. Her transportation needs were addressed with the occupational therapist. A ramp was installed to allow Mae to exit her home independently. The practitioner explored community transportation options for people with disabilities. Mae began to experience a sense of mastery and satisfaction with her steps toward independence. She gained interest in her appearance and considered accessible bathroom modifications.

Questions

- What are the predictable and unpredictable transitions of Emma and Mae in occupation?
- What is the role of occupational therapy in facilitating transitions through promotion and restoration of occupational participation?
- What aspects of Emma's or Mae's occupational participation are facilitators or barriers to successful transition?
- How might aspects of Mae's or Emma's support systems, personalized activities, and engagement in familiar activities (Blair, 2000) facilitate transition?
- What was the role of occupational therapy with Emma and Mae in facilitating successful transitions through healthy occupational participation?

Summary

Older adulthood is a period of profound transition. Some transitions are predictable, and preparation is possible and preferable to facilitate readiness for the change. Examples of predictable transitions include health-related transitions in older adulthood, occupational transitions, and transitions in environmental needs.

Emma and Mae experienced predictable transitions, such as age-related changes in body functions, retirement, and changes in the environmental fit of their homes. Other transitions are unpredictable and require acceptance of the change and readiness to transition to meet the demands of the new circumstances. Examples of unpredictable transitions faced by Emma and Mae include the onset on illness, injury, and disability, with the resultant changes in environment and the increased potential for change in occupational performance.

Practitioners can help ease clients' transition into roles and routines that include engagement in meaningful and purposeful occupations by addressing the person, occupations, and environments or contexts. Interventions focusing on education, wellness, prevention, and health promotion assist with preparing older adults for successful transitions. In the face of unexpected transitions, such as the impairments and disabilities experienced by Emma and Mae, restorative occupational therapy enabled participation in meaningful and purposeful occupations in a supportive environment.

Questions

Consider one older adult client who has received occupational therapy services and with whom you are familiar. Create a treatment plan that includes facilitators of successful transition to productive aging, including personal well-being, contextual harmony, and occupational participation.

- Identify the predictable and unpredictable transitions encountered by the client in health, environment or context, or occupation. How might you help the client prepare to successfully navigate these transitions?
- Identify the occupational therapy interventions that were used. How were they facilitators of transitional ease?
- How might occupational therapy interventions be expanded or modified to include personal well-being, environmental harmony, and occupational participation as facilitators of transitional ease?
- Consider where the client will be living and whether the client will live alone or with family. Consider how the client will engage socially. Are there any contextual barriers to participation? What are realistic methods of addressing barriers

and facilitators in the environment to which the client will transition upon discharge from an inpatient setting? How will you help prepare this client for his or her current and future living spaces? Can the client safely navigate the bathroom, bedroom, and kitchen? What can be predicted and anticipated for safe, independent living?

- How does the current health care system support or prevent practitioners addressing personal, environmental, and occupational transitions of older adult clients? What factors require change to adequately address transitions in older adulthood and are within your control to change?
- Design interventions with an emphasis on health promotion to facilitate successful navigation of predictable transitions of older adulthood and interventions with a restorative approach, often required for navigation of unpredictable transitions. Can the client take his or her medications independently? Does the client know signs of heart attack and stroke? Is the client at risk for falls? What are the client's driving and mobility needs?

References

- American Occupational Therapy Association. (2014). Occupational therapy practice framework: Domain and process (3rd ed.). *American Journal of Occupational Therapy*, 68(Suppl. 1), S1–S48. <http://dx.doi.org/10.5014/ajot.2014.682006>
- American Optometric Association. (2014). *Adult vision: Over 60 years of age*. Retrieved from <http://www.aoa.org/patients-and-public/good-vision-throughout-life/adult-vision-19-to-40-years-of-age/adult-vision-over-60-years-of-age?ssos=y>
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA: American Psychiatric Publishing.
- Asher, I. E. (Ed.). (2014). *Asher's occupational therapy assessment tools: An annotated index* (4th ed.). Bethesda, MD: AOTA Press.
- Blair, S. (2000). The centrality of occupation during life transitions. *British Journal of Occupational Therapy*, 63, 231–237.
- Bonder, B., & Bello-Haas, V. (Eds.). (2009). *Functional performance in older adults*. Philadelphia: F. A. Davis.
- Centers for Disease Control and Prevention. (2011). *New data on older drivers*. Retrieved from <http://www.cdc.gov/Features/dsOlderDrivers/>
- Centers for Disease Control and Prevention. (2014). *Falls among older adults*. Retrieved from <http://www.cdc.gov/homeandrecreationsafety/Falls/adulfalls.html>
- Christiansen, C., & Baum, C. (2005). *Occupational therapy: Performance, participation, and well-being* (3rd ed.). Thorofare, NJ: Slack.
- Clark, F., Azen, S., Zemke, R., Jackson, J., Carlson, M., Mandel, D., . . . Lipson, L. (1997). Occupational therapy for independent-living older adults: A randomized controlled trial. *JAMA*, 278, 1321–1326.
- Cohn, D., & Taylor, P. (2010). Survey findings about America's largest generation. *Pew Research Center Publications*. Retrieved from <http://pewresearch.org/pubs/1834/baby-boomers-old-age-downbeat-pessimism>
- Coleman, E. (2003). Falling through the cracks: Challenges and opportunities for improving transitional care for persons with continuous complex care needs. *Journal of the American Geriatric Society*, 51, 549–555.
- Coleman, E., & Berenson, R. (2004). Lost in transition: Challenges and opportunities for improving the quality of transitional care. *Annals of Internal Medicine*, 140, 553–536.
- Coleman, E., Smith, J., Frank, J., Min, S. J., Parry, C., & Kramer, A. (2004). Preparing patients and caregivers to participate in care delivered across settings: The care transitions intervention. *Journal of the American Geriatric Society*, 53, 1817–1825.
- Dean, E., & DeAndrade, A. D. (2009). Cardiovascular and pulmonary function. In B. Bonder & V. Bello-Haas (Eds.), *Functional performance in older adults* (pp. 65–94). Philadelphia: F. A. Davis.
- Dewey, J., & Bentley, A. (1949). *Knowing and the known*. Boston: Beacon Press.
- Dickie, V., Cutchin, M. P., & Humphry, R. (2006). Occupation as transactional experience: A critique of individualism in occupational science. *Journal of Occupational Science*, 13, 83–93.
- Dooley, N., & Hinojosa, J. (2004). Improving quality of life for persons with Alzheimer's disease and their family caregivers: Brief occupational therapy intervention. *American Journal of Occupational Therapy*, 58, 561–569. <http://dx.doi.org/10.5014/ajot.58.5.561>
- Elgin, J., Owsley, C., & Classen, S. (2012). Vision and driving. In M. McGuire & E. Schold Davis (Eds.), *Driving and community mobility: Occupational therapy strategies across the lifespan* (pp. 173–219). Bethesda, MD: AOTA Press.
- Flemming-Castaldy, R., & Orentlicher, M. L. (2010, November). *Whose life is it anyway? Empowerment, transition from school to adult life and occupational therapy*. Paper presented at the annual New York State Occupational Therapy Association Conference, New York.

- Gitlin, L., & Corcoran, M. (2005). *Occupational therapy and dementia care: The home environmental skill-building program for individuals and families*. Bethesda, MD: AOTA Press.
- Gitlin, L., Winter, L., Corcoran, M., Dennis, M., Schinfeld, S., & Hauck, W. (2003). Effects of the home environmental skill-building program on the caregiver–care recipient dyad: 6-month outcomes from the Philadelphia REACH initiative. *The Gerontologist*, 43, 532–546.
- Graff, M., Vernooij-Dassen, L., Thijssen, M., Dekker, M., Hoefnagels, J., OldeRikkert, W., & Marcel, G. M. (2007). Effects of community occupational therapy on quality of life, mood, and health status in dementia patients and their caregivers: A randomized controlled trial. *Journal of Gerontology*, 62A, 1002–1009.
- Hayase, D., Mosenteen, D., Thimmaiah, D., Zemke, S., Alter, K., & Fisher, A. (2004). Age related changes in activities of daily living ability. *Australian Occupational Therapy Journal*, 51, 192–198.
- Heatwole, K., & Cutchin, M. (2010). Transactional occupations of older women aging in place: Negotiating change and meaning. *Journal of Occupational Science*, 17, 4–13.
- Hickman, J., Rogers, W., & Fisk, A. (2007). Training older adults to use new technology. *Journal of Gerontology*, 62B, 77–84.
- Hooper, C. R., & Bello-Haas, V. (2009). Sensory function. In B. Bonder & V. Bello-Haas (Eds.), *Functional performance in older adults* (pp. 101–121). Philadelphia: F. A. Davis.
- Howden, L., & Meyer, J. (2011). Age and sex composition: 2010. *2010 Census Briefs*. Retrieved from <http://www.census.gov/prod/cen2010/briefs/c2010br-03.pdf>
- Kielhofner, G. (1989). The Model of Human Occupation: Developing a conceptual tool for clinicians. *British Journal of Occupational Therapy*, 52, 210–214.
- Kielhofner, G. (2008). *Model of Human Occupation: Theory and application* (4th ed.). Philadelphia: Lippincott Williams & Wilkins.
- Lavela, S. L., & Ather, N. (2009). Psychological health in older adult spousal caregivers of older adults. *Chronic Illness*, 6, 67–80.
- Law, M., Cooper, B., Strong, S., Stewart, D., Rigby, P., & Letts, L. (1996). The Person–Environment–Occupation Model: A transactive approach to occupational performance. *Canadian Journal of Occupational Therapy*, 63, 9–23.
- Letts, L., Moreland, J., Richardson, J., Coman, L., Edwards, M. M., Ginis, K.,... Wishart, L. (2010). The physical environment as a fall risk factor in older adults: Systematic review and meta-analysis of cross-sectional and cohort studies. *American Journal of Occupational Therapy*, 57, 51–64. <http://dx.doi.org/10.1111/j.1440-1630.2009.00787.x>
- Liddle, J., Carlson, G., & McKenna, K. (2003). Older drivers and driving cessation. *British Journal of Occupational Therapy*, 66, 125–132.
- Liddle, J., Carlson, G., & McKenna, K. (2004). Using a matrix in life transition research. *Quantitative Health*, 14, 1396–1417.
- Liu, J., & Richardson, P. (2012). Successful aging in older adults with disability. *Occupational Therapy Journal of Research*, 32, 126–134.
- McGuire, M., & Schold Davis, E. (Eds.). (2012). *Driving and community mobility: Occupational therapy strategies across the lifespan*. Bethesda, MD: AOTA Press.
- Mernar, J. (2011). How well do you know your onions? Transactionalism can be your guide. *Gerontology Special Interest Section Quarterly*, 34, 1–4.
- Moody, H. R. (2010, September 15). Urban legends of aging. *Teaching Gerontology E-Newsletter*, pp. 14–16.
- National Association of Home Builders. (2007). *Design/build solutions for aging and accessibility*. Washington, DC: Author.
- National Institute of Mental Health. (2007). *Older adults: Depression and suicide facts*. Retrieved from <http://www.nimh.nih.gov/health/publications/older-adults-and-depression/index.shtml#pub10>
- Orentlicher, M. L. (2011, January 24). Person-centered planning: An innovative approach for transition planning. *OT Practice*, 16, CE1–CE8.
- Pascale, R., Primavera, L. H., & Roach, R. (2012). *The retirement maze: What you should know before you retire*. Lanham, MD: Rowman & Littlefield.
- Pinto, S., & Schub, B. (2010). *Quick lessons about elder abuse*. Glendale, CA: Cinahl Information Systems.
- Prochaska, J. O., DiClemente, C. C., & Norcross, J. C. (1992). In search of how people change: Applications to addictive behaviors. *American Psychologist*, 47, 1102–1114.
- Redepenning, S. (2006). *An occupational therapy guide: Driver rehabilitation across age and disability*. Bethesda, MD: AOTA Press.
- Riley, K. (2009). Mental function. In B. Bonder & V. Dal Bello-Haas (Eds.), *Functional performance in older adults* (pp. 177–188). Philadelphia: F. A. Davis.
- Rossen, E., Knaf, K., & Flood, M. (2008). Older women's perceptions of successful aging. *Activities, Adaptation, and Aging*, 32, 73–88.
- Roth, D. L., Perkins, M., Wadley, V. G., Temple, E. M., & Haley, W. E. (2009). Family caregiving and emotional strain: Associations with quality of life in a large national sample of middle-aged and older adults. *Quality Life Research*, 18, 679–688.
- Samia, L., Hepburn, K., & Nichols, L. (2012). "Flying by the seat of our pants": What dementia family caregivers want in an advanced caregiver training program. *Research in Nursing and Health*, 35, 598–609.

- Schkade, J., & Schultz, S. (1992). Occupational adaptation: Toward a holistic approach for contemporary practice, Part 1. *American Journal of Occupational Therapy*, 46, 829–837. <http://dx.doi.org/10.5014/ajot.46.9.829>
- Schulz, R., Burgio, L., Burns, R., Eisdorfer, C., Gallagher-Thompson, D., Gitlin, L., & Mahoney, D. (2003). Resources for Enhancing Alzheimer's Caregiver Health (REACH): Overview, site-specific outcomes, and future directions. *The Gerontologist*, 43, 514–531.
- Schultz, S., & Schkade, J. (1992). Occupational adaptation: Towards a holistic approach for contemporary practice, Part 2. *American Journal of Occupational Therapy*, 46, 917–925. <http://dx.doi.org/10.5014/ajot.46.10.917>
- Siebert, C., Smallfield, S., & Stark, S. (2014). *Occupational therapy practice guidelines for home modifications*. Bethesda, MD: AOTA Press.
- Sorensen, S., Pinquart, M., & Duberstein, P. (2002). How effective are interventions with caregivers? An updated meta-analysis. *The Gerontologist*, 42, 356–372.
- Spencer, J., Davidson, H., & White, V. (1996). Continuity and change: Past experience as adaptive repertoire in occupational adaptation. *American Journal of Occupational Therapy*, 50, 526–534. <http://dx.doi.org/10.5014/ajot.50.7.526>
- Stav, W. (2015). *Occupational therapy practice guidelines for driving and community mobility for older adults*. Bethesda, MD: AOTA Press.
- Tornstam, L. (1997). Gerotranscendence: The contemplative dimension of aging. *Journal of Aging Studies*, 11, 143–155.
- Unsworth, C., Pallant, J., Russell, K., & Odell, M. (2011). *OT-DORA: Occupational Therapy Driver Off-Road Assessment battery*. Bethesda, MD: AOTA Press.
- U.S. National Library of Medicine. (2015). Dementia: Summary. *Medline Plus*. Retrieved from <http://www.nlm.nih.gov/medlineplus/dementia.html>
- Vrkljan, B. (2010). Facilitating technology use in older adulthood: The Person–Environment–Occupation model revisited. *British Journal of Occupational Therapy*, 73, 396–404.
- Walker, C. (2002). Transformative aging: How mature adults respond to growing older. *Journal of Theory Construction and Testing*, 6, 109–116.
- Werner, C. (2011). *The older population: 2010*. Retrieved from <http://www.census.gov/prod/cen2010/briefs/c2010br-09.pdf>
- Whiteford, G. (2000). Occupational deprivation: Global challenge in the new millennium. *British Journal of Occupational Therapy*, 63, 200–204.
- Wilcock, A. (1993). A theory of the human need for occupation. *Occupational Science: Australia*, 1, 17–24.
- Wiseman, L., & Whiteford, G. (2009). Understanding occupational transitions: A study of older rural men's retirement experiences. *Journal of Occupational Science*, 16, 104–109.
- World Health Organization. (2007). *Global age-friendly cities: A guide*. Geneva: Author.
- Yerxa, E. (1998). Health and the human spirit for occupation. *American Journal of Occupational Therapy*, 52, 412–418. <http://dx.doi.org/10.5014/ajot.52.6.412>

Appendix 7.A. Matrix of Assessments Appropriate for Older Adult Populations

Assessment Title	Assessment of		
	Performance skills and client factors	Environment/ Context	Occupational participation
Activities of Daily Living Index (Kazim et al., 1979)			x
Allen Cognitive Level Test (Allen, Earhart, & Blue, 1992)	x		
Arnadottir OT–ADL Neurobehavioral Evaluation (Arnadottir, 1990)	x		x
Arthritis Hand Function Test (Beckman, Mackie, & Harris, 1991)	x		
Assessment for Persons Profoundly or Severely Impaired (Connard & Bradley-Johnson, 1998)	x		
Assessment of Motor and Process Skills (Fisher, 2005)	x		x
Autobiographical Memory Interview (Kopelman, Wilson, & Baddeley, 1990)	x		
Barthel Index of ADL (Mahoney & Barthel, 1965)			x
Bayer Activities of Daily Living Scale (Hindmarch, Lehfeld, Jongh, & Erzigkeit, 1998)			x
Beck Depression Inventory (Beck, Steer, & Brown, 1996)	x		
Beck Hopelessness Scale (Beck, 1978)	x		
Behavioral Inattention Test (Wilson, Cockburn, & Halligan, 1987)	x		
Benton Visual Retention Test (Sivan, 1991)	x		
Berg Balance Scale (Berg, Wood-Dauphinee, Williams, & Maki, 1992)	x		
Blessed Dementia Rating Scale (Blessed, Tomlinson, & Roth, 1968)	x		
Box and Block Test (Desrosiers, Bravo, Jebert, Dutil, & Mercier, 1994)	x		
Brain Injury Visual Assessment Battery for Adults (Warren, 1999)	x		
Brief Neuropsychological Cognitive Examination (Tonkonogy, 1997)	x		
Brief Pain Inventory (Cleeland, 1991)	x		
Brief Test of Attention (Schretlen, Bobholz, & Brandt, 1996)	x		
Brief Visuospatial Memory Test–Revised (Benedict, 1997)	x		
Bristol Activities of Daily Living Scale (Romola, Ashworth, Wilcock, & Siegfried, 1996)	x		x
Canadian Occupational Performance Measure (Law et al., 2005)			x

(Continued)

Appendix 7.A. Matrix of Assessments Appropriate for Older Adult Populations (Cont.)

Assessment Title	Assessment of		
	Performance skills and client factors	Environment/Context	Occupational participation
Caregiver Strain Index (Robinson, 1983)	x	x	
Cleveland Scale for Activities of Daily Living (Patterson et al., 1992)			x
Cognitive Capacity Screening Exam (Jacobs, Bernhard, Delgado, & Strain, 1997)	x		
Cognitive Linguistics Quick Test (Helm-Estabrooks, 2001)	x		
Cognitive Performance Test (Burns, Mortimer, & Merchak, 1994)	x		x
Contextual Memory Test (Toglia, 1993)	x		
Daily Activities Questionnaire (Oakley et al., 1990)			x
Direct Assessment of Functional Status (Loewenstein et al., 1989)			x
Dysphagia Evaluation Protocol (Avery-Smith, Rosen, & Dellarosa, 1997)	x		x
Elemental Driving Simulator and Driving Assessment System (Rosamond & Beattie, 2004)	x		x
Falls Efficacy Scale (Tinetti, Richman, & Powell, 1990)			x
FROMAJE Mental Status Guide (Libow, 1981)	x		
Functional Assessment Scale (Breines, 1983)			x
Functional Autonomy Measurement System (Hebert, 2001)			x
Functional Behavioral Profile (Baum, Edwards, & Morrow-Howell, 1993)			x
Functional Evaluation of Assistive Technology (Raskind & Bryant, 2002)		x	x
Functional Rating Scale (Crockett, Tuokko, Koch, & Parks, 1989).			x
Health Assessment Questionnaire (Fries, Spits, Kraines, & Holman, 1980)	x		x
Home Environmental Assessment Protocol (Gitlin, Schinfeld, et al., 2002)		x	
Housing Enabler (Iwarsson & Isacsson, 1996)		x	
Idyll Arbor Leisure Battery (Hawkins, Ardovino, Rodgers, Foose, & Ohlsen, 2001)			x
Independent Living Scales (Loeb, 1996)	x		x
Instrumental Activities of Daily Living Scale (Lawton & Brody, 1969)			x
Katz Adjustment Scales Relative Report Form (Katz & Warren, 1998)	x		x

(Continued)

Appendix 7.A. Matrix of Assessments Appropriate for Older Adult Populations (Cont.)

Assessment Title	Assessment of		
	Performance skills and client factors	Environment/Context	Occupational participation
Katz Index of ADL (Katz, Ford, Moskowitz, Jackson, & Jaffe, 1963)			x
Kitchen Task Assessment (Baum & Edwards, 1993)			x
Klein–Bell Activities of Daily Living Scale (Klein & Bell, 1982)			x
Kohlman Evaluation of Living Skills (Thomson, 1992)			x
Life Satisfaction Index–Z (Neugarten, Havinghurst, & Tobin, 1961)			x
Loewenstein Occupational Therapy Cognitive Assessment: Geriatric Version (Itzkovich, Elazar, & Katz, 1996)	x		
Melbourne Low Vision ADL Index (Haymes, Johnston, & Heyes, 2001)	x		x
Melville–Nelson Self-Care Assessment (Nelson et al., 2002)			x
Middlesex Elderly Assessment of Mental State (Golding, 1989)	x		
Mini-Mental State Examination (Folstein, Folstein, & McHugh, 1975)	x		
Model of Human Occupation Screening Tool (Parkinson, Forsyth, & Kielhofner, 2006)			x
Montreal Cognitive Assessment (Nasreddine et al., 2005)	x		
Motor Assessment Scale (Carr, Shepherd, Nordholm, & Lynne, 1985)	x		
Motor-Free Visual Perception Test (Colarusso, Hammill, Mercier, & Herbert, 1995)	x		
Neurobehavioral Cognitive Status Exam (Keirnan, Mueller, & Langston, 1987)	x		
Occupational Circumstances Assessment Interview Rating Scale (Forsyth et al., 2005)			x
Occupational Performance History Interview—II (Kielhofner et al., 2005)			x
Occupational Questionnaire (Riopel & Kielhofner, 1986)			x
OT–DORA: Occupational Therapy Off-Road Driver Assessment Battery (Unsworth, Pallant, Russell, & Odell, 2011)	x		x
Paracheck Geriatric Behavior Rating Scale (Paracheck & King, 1986)	x		x
Participation Scale (Van Brakel et al., 2006)	x	x	x
Performance Assessment of Self-Care Skills (Rogers & Holm, 1989)	x		x
Performance Test of ADL (Kuriansky & Gurland, 1976)			x
Physical Performance Test (Reuben & Siu, 1990)	x		
Present Functioning Questionnaire (Crockett et al., 1989)			x

(Continued)

Appendix 7.A. Matrix of Assessments Appropriate for Older Adult Populations (Cont.)

Assessment Title	Assessment of		
	Performance skills and client factors	Environment/Context	Occupational participation
Psychosocial Impact of Assistive Devices Scale (Day & Jutai, 1996)	x		x
Refined ADL Assessment Scale (Tappen, 1994)			x
Rivermead Behavioral Memory Test (Wilson, Cockburn, & Baddeley, 2003)	x		
Rivermead Perceptual Assessment Battery (Whiting, Lincoln, Bhavnani, & Cockburn, 1985)	x		
Role Change Assessment (Rogers & Holm, 1999)			x
Role Checklist (Dickerson, 1999)			
Ross Information Processing Assessment—Geriatric (Ross-Swain & Fogle, 1996)	x		
Safety Assessment of Function and the Environment for Rehabilitation (SAFER) Health Outcome Measurement Evaluation (HOME; Oliver, Blath, Brackley, & Tamaki, 1993)		x	x
Safety Assessment Scale (Poulin de Courval et al., 2006)		x	
Severe Impairment Battery (Saxton, McGonigle-Gibson, Swihart, & Boller, 1993)	x		
SHORT—CARE (Comprehensive Assessment and Referral Evaluation) (Gurland, Golden, Teresi, & Challop, 1984)	x		
Short Category Test (Wetzel & Boll, 2000)	x		
Short Form—36 Health Survey (RAND Corporation & Ware, 2002)	x		
Short Portable Mental Status Questionnaire (Pfeiffer, 1975)	x		
Sickness Impact Profile (Bergner, Bobbitt, Carter, & Gilson, 1981)	x		
Slosson Visual—Motor Performance Test for Children and Adults (Slosson & Nicholson, 1996)	x		
Structure Assessment of Independent Living Skills (Mahurin, Debettignies, & Pirozzolo, 1991)	x		x
Swallowing Ability and Function Evaluation (Kipping, Ross-Swain, & Yee, 2003)	x		x
Task Management Strategies Index (Gitlin, Winter, et al., 2002)		x	x
Tinetti Performance Oriented Mobility Assessment (Tinetti, 1986)	x		
Toglia Category Assessment (Toglia, 1994)	x		
Visual Motor Assessment (Fuller, 2006)	x		
Volitional Questionnaire (Gloria de las Heras et al., 2003).		x	x
Westmead Home Safety Assessment (Cooper, Letts, Rigby, Stewart, & Strong, 2005)		x	x

Note. Adapted from *Asher's Occupational Therapy Assessment Tools: An Annotated Index* (4th ed.), by I. E. Asher (Ed.), 2014, Bethesda, MD: AOTA Press. Copyright © 2014 by the American Occupational Therapy Association. Adapted with permission.

References

- Allen, C., Earhart, C., & Blue, T. (1992). *Occupational therapy treatment goals for the physically and cognitively disabled*. Rockville, MD: American Occupational Therapy Association.
- Arnadottir, G. (1990). *The brain and behavior: Assessing cortical dysfunction through activities of daily living*. Philadelphia: Mosby.
- Avery-Smith, W., Rosen, A., & Dellarosa, D. (1997). *Dysphagia Evaluation Protocol*. San Antonio: Harcourt Assessment.
- Baum, C., & Edwards, D. (1993). Cognitive performance in senile dementia of the Alzheimer's type: The Kitchen Task Assessment. *American Journal of Occupational Therapy*, 47, 431–436. <http://dx.doi.org/10.5014/ajot.47.5.431>
- Baum, C., Edwards, D., & Morrow-Howell, N. (1993). Identification and measurement of productive behaviors in senile dementia of the Alzheimer type. *The Gerontologist*, 33, 403–408.
- Beck, A. (1978). *Beck Hopelessness Scale*. San Antonio: Psychological Corporation.
- Beck, A., Steer, R., & Brown, G. (1996). *Beck Depression Inventory*. San Antonio: Psychological Corporation.
- Beckman, C., Mackie, H., & Harris, J. (1991). Arthritis Hand Function Test: Development of a standardized assessment tool. *Occupational Therapy Journal of Research*, 11, 245–256.
- Benedict, R. (1997). *Brief Visuospatial Memory Test-Revised*. Lutz, FL: Psychological Assessment Resources.
- Berg, K., Wood-Dauphinee, S., Williams, J., & Maki, B. (1992). Measuring balance in the elderly: Validation of an instrument. *Canadian Journal of Public Health*, 2(Suppl.), S7–S11.
- Bergner, M., Bobbitt, R., Carter, W., & Gilson, B. (1981). The Sickness Impact Profile: Development and final revision of a health status measure. *Medical Care*, 19, 787–805.
- Blessed, G., Tomlinson, B., & Roth, M. (1968). The association between quantitative measures of dementia and of senile change in the cerebral grey matter of elderly subjects. *British Journal of Psychiatry*, 114, 797–811.
- Breines, E. (1983). *Functional Assessment Scale*. Lebanon, NJ: Geri-Rehab.
- Burns, T., Mortimer, J., & Merchak, P. (1994). Cognitive Performance Test: A new approach to functional assessment in Alzheimer's disease. *Journal of Geriatric Psychiatry and Neurology*, 7, 46–54.
- Carr, J., Shepherd, R., Nordholm, L., & Lynne, D. (1985). Investigation of a new motor assessment scale for stroke patients. *Physical Therapy*, 65, 175–180.
- Cleeland, C. (1991). *Brief Pain Inventory*. Madison, WI: WHO Collaborating Center for Symptom Evaluation in Cancer Care.
- Colarusso, R., Hammill, D., Mercier, L., & Herbert, R. (1995). *Motor-Free Visual Perception Test* (3rd ed.). Novato, CA: Academic Therapy Publications.
- Connard, P., & Bradley-Johnson, S. (1998). *Assessment for Persons Profoundly or Severely Impaired*. Austin, TX: Pro-Ed.
- Cooper, B., Letts, L., Rigby, P., Stewart, D., & Strong, S. (2005). Measuring environmental factors. In M. Law, C. Baum, & W. Dunn (Eds.), *Measuring occupational performance: Supporting best practice in occupational therapy* (2nd ed., pp. 326–327). Thorofare, NJ: Slack.
- Crockett, T., Tuokko, H., Koch, W., & Parks, R. (1989). The assessment of everyday functioning using the Present Functioning Questionnaire and the Functional Rating Scale in elderly samples. *Clinical Gerontologist*, 8, 3–25.
- Day, H., & Jutai, J. (1996). Measuring the psychosocial impact of assistive devices: The PIADS. *Canadian Journal of Rehabilitation*, 9, 159–168.
- Desrosiers, J., Bravo, G., Jebert, R., Dutil, E., & Mercier, L. (1994). Validation of the Box and Block Test as a measure of dexterity of elderly people: Reliability, validity, and norm studies. *Archives of Physical Medicine and Rehabilitation*, 75, 751–755.
- Dickerson, A. (1999). The Role Checklist. In B. J. Hemphill-Pearson (Ed.), *Assessment in occupational therapy mental health* (pp. 175–191). Thorofare, NJ: Slack.
- Fisher, A. (2005). *Assessment of Motor and Process Skills*. Hampton Falls, NH: AMPS International.
- Folstein, M., Folstein, S., & McHugh, P. (1975). Mini-Mental State: A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research*, 12, 189–198.
- Forsyth, K., Deshpande, S., Kielhofner, G., Henriksson, C., Haglund, L., Olson, L.,...Kulkarni, S. (2005). *Occupational Circumstances Assessment Interview Rating Scale* (Version 4). Chicago: Model of Human Occupation Clearinghouse.
- Fries, J., Spits, P., Kraines, R. G., & Holman, H. (1980). Measurement of patient outcomes in arthritis. *Arthritis and Rheumatism*, 23, 137–145.
- Fuller, G. (2006). *Visual Motor Assessment*. Toronto: Multi-Health Systems.
- Gitlin, L., Schinfeld, S., Winter, L., Corcoran, M., Boyce, A., & Hauck, W. (2002). Evaluating home environments of persons with dementia: Interrater reliability and validity of the Home Environmental Assessment Protocol. *Disability and Rehabilitation*, 24, 59–71.
- Gitlin, L., Winter, L., Dennis, M., Corcoran, M., Schinfeld, S., & Hauck, W. (2002). Strategies used by families to simplify tasks for individuals with Alzheimer's disease and related disorders: Psychometric analysis of the Task Management Strategies Index. *The Gerontologist*, 42, 61–69.
- Gloria de las Heras, C., Geist, R., Keilhofner, G., Li, Y., Basu, S., Kafkes, A., & Geist, R. (2003). *Volitional Questionnaire* (Version 2.0). Chicago: Model of Human Occupation Clearinghouse.

- Golding, E. (1989). *Middlesex Elderly Assessment of Mental State*. Suffolk, England: Thames Valley Test Company.
- Gurland, B., Golden, R., Teresi, J., & Challop, J. (1984). The SHORT-CARE: An efficient instrument for the assessment of depression, dementia, and disability. *Journal of Gerontology*, 39, 166–169.
- Hawkins, B., Ardvino, P., Rodgers, N., Foose, A., & Ohlsen, N. (2001). *Idyll Arbor Leisure Battery Leisure Assessment Inventory*. Enumclaw, WA: Idyll Arbor.
- Haymes, S., Johnston, A., & Heyes, A. (2001). Preliminary investigation of the responsiveness of the Melbourne Low Vision ADL Index to low vision rehabilitation. *Optometry and Vision Science*, 78, 565–579.
- Hebert, R. (2001). *Functional Autonomy Measurement System*. Sherbrooke, Quebec: Institut universitaire de geriatrie de Sherbrooke.
- Helm-Estabrooks, N. (2001). *Cognitive Linguistic Quick Test*. San Antonio: Harcourt Assessment.
- Hindmarch, I., Lehfeld, H., Jongh, P., & Erzigkeit, H. (1998). The Bayer Activities of Daily Living Scale. *Dementia and Geriatric Cognitive Disorders*, 9(Suppl. 2), 20–26.
- Itzkovich, M., Elazar, B., & Katz, N. (1996). *Loewenstein Occupational Therapy Cognitive Assessment (LOTCA-G) battery: Geriatric version*. Pequannock, NJ: Maddak.
- Iwarsson, S., & Isacsson, A. (1996). Development of a novel instrument for occupational therapy of assessment of the physical environment in the home: A methodological study on “the enabler.” *Occupational Therapy Journal of Research*, 16, 227–244.
- Jacobs, J., Bernhard, M., Delgado, A., & Strain, J. (1997). Screening for organic mental syndromes in the medically ill. *Annals of Internal Medicine*, 86, 40–46.
- Katz, M. M., & Warren, W. L. (1998). *Katz Adjustment Scales Relative Report Form*. Los Angeles: Western Psychological Services.
- Katz, S., Ford, A., Moskowitz, R., Jackson, B., & Jaffe, M. (1963). The Index of ADL: A standard measure of biological and psychosocial function. *Journal of the American Medical Association*, 185, 914–919.
- Kazim, S., Smith, D., Meade, T., Goldenberg, E., Brennan, P. J., & Kinsella, G. (1979). Repeatability and validity of a modified Activities of Daily Living Index in studies of chronic disability. *International Rehabilitation Medicine*, 1, 51–58.
- Keirnan, R., Mueller, J., & Langston, W. (1987). *Neurobehavioral Cognitive Status Exam*. Fairfax, CA: Northern California Neurobehavioral Group.
- Kielhofner, G., Mallinson, T., Crawford, C., Nowak, M., Rigby, M., Henry, A., & Walens, D. (2005). *Occupational Performance History Interview-II* (Version 2.1). Chicago: Model of Human Occupation Clearinghouse.
- Kipping, P., Ross-Swain, D., & Yee, P. (2003). *Swallowing Ability and Function Evaluation*. Austin, TX: Pro-Ed.
- Klein, R. M., & Bell, B. (1982). Self-care skills: Behavioral measurement with Klein-Bell ADL scale. *Archives of Physical Medicine and Rehabilitation*, 63, 335–338.
- Kopelman, M., Wilson, B., & Baddeley, A. (1990). *Autobiographical Memory Interview*. Gaylord, MI: Northern Speech Services.
- Kuriansky, J., & Gurland, B. (1976). The Performance Test of Activities of Daily Living. *International Journal of Aging and Human Development*, 7, 343–352.
- Law, M., Baptiste, S., Carswell, A., McColl, M., Polatajko, H., & Pollock, N. (2005). *Canadian Occupational Performance Measure* (4th ed.). Ottawa: Canadian Association of Occupational Therapy.
- Lawton, M., & Brody, E. (1969). Assessment of older people: Self-maintaining and instrumental activities of daily living. *The Gerontologist*, 9, 179–186.
- Libow, L. (1981). A rapidly administered, easily remembered mental status evaluation: FROMAJE. In L. S. Libow & F. T. Sjeram (Eds.), *The core of geriatric medicine* (pp. 85–91). St. Louis: Mosby.
- Loeb, P. (1996). *Independent Living Scales*. San Antonio: Harcourt Assessment.
- Loewenstein, D., Amigo, E., Duara, R., Guterman, A., Hurwitz, D., Berkowitz, N., . . . Gittleman, B. (1989). A new scale for the assessment of functional status in Alzheimer’s disease and related disorders. *Journal of Gerontology*, 44, 114–121.
- Mahoney, F., & Barthel, D. (1965). Functional evaluation: The Barthel Index of ADL. *Maryland State Medical Journal*, 14, 61–65.
- Mahurin, R., DeBettignies, B., & Pirozzolo, F. (1991). Structured Assessment of Independent Living Skills: Preliminary report of a performance measure of functional abilities in dementia. *Journal of Gerontology*, 46, 58–66.
- Nasreddine, Z., Phillips, N., Bedirian, V., Charbonneau, S., Whitehead, V., Colin, I., . . . Chertkow, H. (2005). The Montreal Cognitive Assessment, MoCA: A brief screening test for mild cognitive impairment. *Journal of the American Geriatrics Society*, 53, 695–699.
- Nelson, D., Melville, L., Wilkerson, J., Magness, R., Grech, J., & Rosenberg, J. (2002). Interrater reliability, concurrent validity, responsiveness, and predictive validity of the Melville-Nelson Self-Care Assessment. *American Journal of Occupational Therapy*, 56, 51–59. <http://dx.doi.org/10.5014/ajot.56.1.51>
- Neugarten, B., Havinghurst, R., & Tobin, S. (1961). The measurement of life satisfaction. *Journal of Gerontology*, 16, 124–143.
- Oakley, F., Sunderland, T., Hill, J., Phillips, S., Makahon, R., & Ebner, J. (1990). The Daily Activities Questionnaire: A functional assessment for people with Alzheimer’s disease. *Physical and Occupational Therapy in Geriatrics*, 10, 67–81.

- Oliver, R., Blath, J., Brackley, C., & Tamaki, T. (1993). Development of the Safety Assessment of Function and the Environment for Rehabilitation (SAFER) tool. *Canadian Journal of Occupational Therapy*, 60, 78–82.
- Paracheck, J., & King, L. (1986). *Paracheck Geriatric Behavior Rating Scale* (3rd ed.). Glendale, AZ: Children's Center for Neurodevelopmental Studies.
- Parkinson, S., Forsyth, K., & Kielhofner, G. (2006). *Model of Human Occupation Screening Tool* (Version 2.0). Chicago: Model of Human Occupation Clearinghouse.
- Patterson, M. B., Mack, J., Neundorfer, M., Martin, R., Smyth, K., & Whitehouse, P. (1992). Assessment of functional ability in Alzheimer disease: A review and preliminary report in the Cleveland Scale for Activities of Daily Living. *Alzheimer Disease and Associated Disorders*, 6, 145–163.
- Pfeiffer, E. (1975). A Short Portable Mental Status Questionnaire for the assessment of organic brain deficit in elderly patients. *Journal of the American Geriatrics Society*, 23, 433–441.
- Poulin de Courval, L., Gelinas, I., Gauthier, S., Gayton, D., Liu, L., Rossignol, M.,...Dastoor, D. (2006). Reliability and validity of the Safety Assessment Scale for people with dementia living at home. *Canadian Journal of Occupational Therapy*, 73, 67–75.
- RAND Corporation, & Ware, J. (2002). *Short Form-36 Health Survey* (Version 2). Lincoln, RI: Quality Metric.
- Raskind, M., & Bryant, B. (2002). *Functional Evaluation for Assistive Technology*. Austin, TX: Psycho-Educational Services.
- Reuben, D., & Siu, A. (1990). An objective measure of physical function of elderly outpatients: The Physical Performance Test. *Journal of the American Geriatrics Society*, 38, 1105–1112.
- Riopel, N., & Kielhofner, G. (1986). *Occupational Questionnaire*. Chicago: Model of Human Occupation Clearinghouse.
- Robinson, B. (1983). Validation of a Caregiver Strain Index. *Journal of Gerontology*, 38, 344–348.
- Rogers, J., & Holm, M. (1989). *Performance Assessment of Self-Care Skills*. Unpublished test, University of Pittsburgh.
- Rogers, J., & Holm, M. (1999). Role Change Assessment: An interview tool for evaluating older adults. In B. J. Hemphill-Pearson (Ed.), *Assessments in occupational therapy mental health: An integrative approach* (pp. 73–82). Thorofare, NJ: Slack.
- Romola, S., Ashworth, D., Wilcock, G., & Siegfried, K. (1996). Assessment of daily living in dementia: Development of the Bristol Activities of Daily Living Scale. *Age and Ageing*, 25, 113–120.
- Rosamond, G., & Beattie, A. (2004). *Elemental Driving Simulator and Driving Assessment System* (2nd ed.). Bayport, NY: Life Sciences Associates.
- Ross-Swain, D., & Fogle, P. (1996). *Ross Information Processing Assessment and Ross Information Processing Assessment-Geriatric*. Austin, TX: Pro-Ed.
- Saxton, J., McGonigle-Gibson, K., Swihart, A., & Boller, F. (1993). *Severe Impairment Battery (SIB) manual*. San Antonio: Harcourt Assessment.
- Schretlen, D., Bobholz, J., & Brandt, J. (1996). Development and psychometric properties of the Brief Test of Attention. *Clinical Neuropsychologist*, 10, 80–89.
- Sivan, A. (1991). *Benton Visual Retention Test* (5th ed.). San Antonio: Harcourt Assessment.
- Slosson, R., & Nicholson, C. (1996). *Slosson Visual-Motor Performance Test for Children and Adults*. East Aurora, NY: Slosson Educational.
- Tappen, R. (1994). Development of the Refined ADL Assessment Scale for patients with Alzheimer's disease and related disorders. *Journal of Gerontological Nursing*, 20, 36–42.
- Thomson, L. (1992). *Kohlman Evaluation of Living Skills* (3rd ed.). Bethesda, MD: American Occupational Therapy Association.
- Tinetti, M. (1986). Performance-oriented assessment of mobility problems in elderly patients. *Journal of the American Geriatric Society*, 34, 119–126.
- Tinetti, M., Richman, D., & Powell, L. (1990). Falls efficacy as a measure of fear of falling. *Journal of Gerontology*, 45, 239–243.
- Toglia, J. (1993). *Contextual Memory Test*. San Antonio: Harcourt Assessment.
- Toglia, J. (1994). *Toglia Category Assessment*. San Antonio: Harcourt Assessment.
- Tonkonogy, J. (1997). *Brief Neuropsychological Cognitive Examination*. Los Angeles: Western Psychological Services.
- Unsworth, C., Pallant, J., Russell, K., & Odell, M. (2011). *OT-DORA: Driver Off-Road Assessment battery*. Bethesda, MD: AOTA Press.
- Van Brakel, W., Anderson, A., Mutatkar, R., Bakirtzieff, Z., Nicholls, P. G., Raju, M. S., & Das-Pattanayak, R. K. (2006). The Participation Scale: Measuring a key concept in public health. *Disability and Rehabilitation*, 28, 193–203.
- Warren, M. (1999). *Brain Injury Visual Assessment Battery for Adults*. Lenexa, KS: visABILITIES Rehab Services.
- Wetzel, L., & Boll, T. (2000). *Short Category Test*. Los Angeles: Western Psychological Services.
- Whiting, S. E., Lincoln, N. B., Bhavnani, G., & Cockburn, J. (1985). *The Rivermead Perceptual Assessment Battery*. Windsor, England: NFER-Nelson.
- Wilson, B., Cockburn, J., & Baddeley, A. (2003). *Rivermead Behavioral Memory Test* (2nd ed.). San Antonio: Harcourt Assessment.
- Wilson, B., Cockburn, J., & Halligan, P. (1987). *Behavioral Inattention Test*. San Antonio: Harcourt Assessment.

Appendix 7.B. Resources for Practitioners and Older Adult Clients

American Occupational Therapy Association (AOTA) Resources

- **Evidence-Based Practice:** <http://www.aota.org/Practice/Productive-Aging/Evidence-based.aspx>
Evidence to support practice on the topics of productive aging, home modifications and falls prevention, driving and community mobility, low vision, and Alzheimer's and related dementias.
- **Productive Aging:** <http://www.aota.org/About-Occupational-Therapy/Professionals/PA.aspx>
Fact sheets that explain the role and scope of occupational therapy for occupational therapy practitioners and other professionals. Fact sheets are available on productive aging, including community mobility and older drivers, chronic conditions, dementia, falls prevention, home modification, mental health, stroke, and occupational therapy's role with older adults.
- **Aging:** <http://www.aota.org/About-Occupational-Therapy/Patients-Clients/Adults.aspx>
Information and tips for people who may receive occupational therapy.
- **Emerging Niche in Productive Aging:** <http://www.aota.org/Practice/Productive-Aging/Emerging-Niche.aspx>
Information on emerging areas of occupational therapy practice related to aging.
- **Apps for Productive Aging:** (AOTA members) <http://www.aota.org/Practice/Productive-Aging/PA-Apps.aspx>
A list of apps that may be assistive to occupational therapy practitioners, their older adult clients, and caregivers.

Other Resources

- Christensen, M., & Chase, C. (Eds.). (2011). *Occupational therapy and home modification: Promoting safety and supporting participation*. Bethesda, MD: AOTA Press.
Addresses environmental modifications to support occupational participation.

- **National Center for Elder Abuse:** <http://www.ncea.aoa.gov>
A resource for prevention of mistreatment of older adults.
- McGuire, M. & Schold Davis, E. (Eds.). (2012). *Driving and community mobility: Occupational therapy strategies across the lifespan*. Bethesda, MD: AOTA Press.
Addresses occupational therapy evaluation, intervention, and consultation on driving and community mobility.
- **Find a certified aging in place specialist:** <http://www.nahb.org/en/consumers/homeownership/aging-in-place-vs-universal-design/aging-in-place-remodeling.aspx>
In association with AOTA and AARP, National Association of Home Builders (NAHB) trains Certified Aging in Place Specialists (CAPS). A directory of CAPS-trained professionals is available through NAHB.
- **Fall Stop...Move Strong Program—A Fall Prevention Program:** <http://www.fallstop.net/>
A fall prevention and strengthening program.
- **Exercise and Physical Activity:** https://www.nia.nih.gov/sites/default/files/nia_exercise_and_physical_activity.pdf
The National Institute on Aging's guide to exercise and activity for the health and well-being of older adults.
- **Rebuilding Together:** www.rebuildingtogether.org
AOTA has an alliance with Rebuilding Together, a national organization that remodels and rehabilitates homes of low-income people, older adults, and people with disabilities in their community. The mission of Rebuilding Together, is to "bring volunteers and communities together to improve the homes and lives of homeowners in need."
- Siebert, C., Smallfield, S., & Stark, S. (2014). *Occupational therapy practice guidelines for home modifications*. Bethesda, MD: AOTA Press.
Provides guidelines for addressing home modifications for people whose environments are incompatible with the abilities.

- Stav, W. (2015). *Occupational therapy practice guidelines for driving and community mobility for older adults*. Bethesda, MD: AOTA Press.
An overview of the occupational therapy process for addressing driving and community mobility in adults.
- **World Health Organization's Global Age-Friendly Cities:**
- *Guide:* http://www.who.int/ageing/publications/Global_age-friendly_cities_Guide_English.pdf
- *Checklist:* http://www.who.int/ageing/publications/Age_friendly_cities_checklist.pdf
A guide and checklist to promote active aging in communities by addressing outdoor spaces and building, transportation, housing, social participation, respect and social inclusion, civic participation and employment, communication and information, community support, and health services.

Part III.

UNIVERSAL CONSIDERATIONS

IN TRANSITION

CHAPTER 8.

HEALTH CARE TRANSITION

Robert W. Gibson, PhD, OTR/L

Chapter Objectives

After reading this chapter, readers will be able to

- ❖ Describe the policies and barriers that affect health care transition,
- ❖ Understand the role of occupational therapy in health care transition, and
- ❖ Incorporate health care transition into treatment planning and support patients and families in their transition experiences.

Key Terms and Concepts

- ❖ Age of responsibility
- ❖ Age of transition
- ❖ Clinician-related barriers
- ❖ Delivery system–related barriers
- ❖ Envisioning a future
- ❖ Functional independence
- ❖ Health care transition
- ❖ Health Insurance Portability and Accountability Act of 1996
- ❖ Interpersonal dynamics
- ❖ Patient Protection and Affordable Care Act of 2010
- ❖ Patient-related barriers
- ❖ Personal preferences
- ❖ Primary care
- ❖ Service needs
- ❖ Structural issues
- ❖ Transition coordinator
- ❖ Transition health record
- ❖ Transition plan
- ❖ Transition readiness
- ❖ Transitional care

The complexity and compartmentalization of medical systems have made it extremely difficult for people with complex health needs to transition to and receive health care in a high-quality, efficient, or holistic way. This chapter explores health care transition (HCT) policy and

barriers to successful HCT. Next, it reviews pertinent HCT research, which provides a framework for discussion of how occupational therapy practitioners can play a significant role in addressing and alleviating some HCT difficulties that patients and families face.

Although this chapter focuses on HCT, such transitions do not occur in isolation from other life transitions, many of which are described throughout this book. HCT is much more successful when it is incorporated in a holistic understanding of other life transitions, including education, development, decreases in cognitive abilities, and life progression.

Defining Health Care Transition

An often-quoted definition put forward by Blum et al. (1993) states that *HCT* is the

purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health-care systems. Transitions from such child-centered to adult health care systems is important for *all* teenagers, healthy or ill.... The optimal goal of transition is to provide health care that is uninterrupted, coordinated, developmentally appropriate, psychosocially sound, and comprehensive. (p. 570)

This definition, included in a position paper from the Society for Adolescent Medicine, was part of early efforts to alert the medical community to the necessity of appropriately planning for and assisting the growing wave of young people with special health care needs and disabilities who, as a result of the successes of modern pediatric medicine, were living into adulthood and would be seeking health care from the adult-oriented health system.

Although recognition of HCT may have started with a focus on adolescents, it soon became apparent that there were many other instances of HCT within Western biomedicine. As medical systems have become more complex and compartmentalized, and as more people with complex care needs, in addition to temporary or permanent decreases in cognitive ability, move through the health system, it has been observed that the need for HCT is not limited to only young people.

Coleman and Boult (2003) expressed the need to expand the scope of HCT to adult patients. In a position statement, the American Geriatrics Society Health Care Systems Committee defined *transitional care* as "a set of actions designed to ensure

the coordination and continuity of health care as patients transfer between different locations levels of care within the same location" (Coleman & Boult, 2003, p. 556). As conceptualized by Coleman and Boult, HCT is not only a developmental process for young people, but it also includes the continuity of care in the health system throughout the life course. This chapter examines HCT from both perspectives and the role occupational therapists can play in facilitating and supporting successful HCT.

Joey's Story: Young Adult Perspective

Joey, age 8 years, was born with spina bifida (SB). He received excellent neurological and surgical care, as well as developmental services, including outpatient rehabilitation and early intervention from birth. He and his family have been receiving routine follow-up care in a specialty clinic at the local children's hospital. Joey's mom has developed a close relationship with the staff and physicians at the clinic. She even has Joey's neurologist's cell phone number following a series of critical incidents when a shunt blockage was misdiagnosed in the emergency department.

Although Joey's mom would never think of calling the number except in cases of emergency, she sees it as a sign of trust between her and Joey's doctor that shows she is respected as a member of Joey's health care team. Joey's mom and dad have actively participated in developing Joey's care plan and are actively engaged in Joey's health care.

Because of the excellent care that Joey received and his parents' advocacy and support, he will graduate high school in a few months, will turn 18, and will head off to a college 3 hours away from home. Joey has been a good patient and has done what the doctors and his parents have told him regarding his health. However, he has rarely had to solve any health problems on his own because his parents and supportive health care providers have done their best to take care of these issues.

For example, if Joey had difficulty with his bowel and bladder program at school that resulted in an accident, his mom would drive to the school with clean clothes. He has limited understanding of the medications he takes, because his parents have always maintained his prescriptions. He does not

have the phone number for his pediatrician or pharmacist in his cell phone. Recently, when there was a question about a possible shunt blockage while he was away at camp, he had to call his parents so they could speak with the camp nurse to clarify the symptoms. He is dependent on others to address his health care needs and does not know what to do in a medical emergency.

Joey also frequently forgets to charge the battery on his electric wheelchair, so his dad had purchased additional batteries and is frequently called to replace the battery whenever Joey has a problem.

The SB clinic at the children's hospital informed Joey's mother during the most recent clinic visit that their next visit would be Joey's last, because Joey turns age 18 years the following month and hospital policy states that young adults older than age 18 years cannot receive care in the children's hospital. The clinic suggested that Joey might receive ongoing care from his family physician. However, Joey had only received care in the specialty clinic and did not have a family physician. Joey's mom is now actively seeking an adult primary care provider who has experience treating adults with SB.

During a recent visit to the college that Joey plans to attend, Joey and his parents spoke to the nurse practitioner (NP) at the campus health center. During the conversation, the NP initially directed his questions to Joey regarding his health history, current medications, and any health needs that will need to be addressed while he is on campus. Joey deferred to his mom by looking over to her to provide answers.

The NP did not want to embarrass Joey but informed the family that it was important for Joey to know or have his health information written down by the time he arrives on campus. Once Joey turns age 18 years, if there was a need for health care, the ***Health Insurance Portability and Accountability Act of 1996 (HIPAA)*** privacy rules make it very difficult to include family members in the process of providing health care and health decisions without written waivers.

Joey and his parents realized at that moment that he was unprepared to go to college and to independently manage his health care needs. The drive home began a 3-month process of rapidly completing HCT preparation, finding new health providers, and battling the frustration that there just was not enough time to get everything ready before Joey's departure for college and impending adulthood.

Renzo's Story: Young Adult Perspective

The "Prologue" described the transition experiences of Renzo and his family. This young man's development was typical of most healthy young people. It was expected that his HCT would also be typical and similar to other healthy young adults: Because of few health needs, he would have left pediatric health care and would, most likely, receive only episodic health care in emergent or acute situations, such as a broken bone or an infection, until well into adulthood.

Lack of immediate health care needs results in most young adults not regularly engaging the adult-oriented health system until later in life. Only then do they turn to the adult-oriented health care system to address health conditions related to aging, such as elevated blood pressure, diabetes, or other infirmities of aging. By this time, they are established and independent adults (Reiss, Gibson, & Walker, 2005).

This was not the case for Renzo. Following his cardiac arrest, he received emergent care in the pediatric health system, but once he became an adult, it was necessary to transfer care to the adult-oriented health care system. This transition, just as the one described for Joey, can be challenging, frustrating, and fraught with problems for all concerned. Whereas Joey's family had 18 years to address HCT, Renzo's family had a much shorter time period to accomplish the same tasks along with addressing significant medical and social needs.

Esther: Older Adult Perspective

Esther, age 75 years, has just been admitted to the hospital following a fall and possible hip fracture. Her adult children have been conscious of recent subtle cognitive changes but, in general, have respected their mother's wishes to live independently. Her fall and hospitalization have brought the family to her bedside to hear the result of the x-rays and the proposed treatment process. Esther is to have hip replacement surgery in the next few days, which will be followed by rehabilitation and then discharge home with home health services, if they are required. Esther's children left the hospital feeling comfortable with the proposed plan of care.

Following surgery, Esther did not respond as expected. She seemed more confused and had difficulty taking care of her needs. The plan of care was therefore modified to send Esther to a skilled nursing facility to recover from the surgery and begin her rehabilitation there. The transfer occurred the next day. Because of lack of communication regarding the transfer, the pain medication she had been receiving was changed, which resulted in an allergic reaction. This allergy had been documented in her hospital electronic medical record, but this information was lost in the conversion to a different charting system at the skilled care facility.

During the transfer, Esther also lost her glasses, which made it very difficult for her to see the forms she was asked to sign. Prior to the transfer, the records failed to include Esther's glasses among her list of belongings, and her children's suspicion of her increasing confusion, which they had observed and had shared with the hospital staff.

Esther became very frustrated with the imposition of the hospital routine on her life and started yelling at the staff to leave her alone. For example, Esther was frustrated when staff woke her early for routine checks. The nurses on the unit requested an order for a sedative. After a few days, Esther began to feel better and could participate in therapy. Her glasses still had not been found, and her children were in the process of getting a new pair made. Esther made significant progress in both occupational and physical therapy.

At the time of discharge, the family was informed that Esther was still experiencing some cognitive difficulties, and it was recommended that she receive an evaluation at a geriatric clinic as an outpatient. Occupational and physical therapy home services were also ordered but would not start immediately because it would take a few days to arrange for the therapists to come to the home. The exercises and activities that Esther had been performing were explained to Esther's children that afternoon, and they were encouraged to continue these at home until home health services began.

Esther went to stay with her son; however, this move was not communicated to the home health agency, and the occupational therapist and home health aide both went to Esther's home address. It took a couple of days and a number of phone calls to straighten out the confusion. Esther had not had more than a modest sponge bath since she left the

nursing facility because both she and her son were uncomfortable with him helping her in the shower.

It took 2 months to schedule a comprehensive evaluation by a geriatrician. The geriatrician determined that the confusion that Esther's children had observed was an uncommon side effect of a new medication that had been prescribed by her family physician for a rash following some work in her garden. It took a long time, but Esther was now back happily at her own home, stating she would never go back to the hospital. Everything they did seemed to make her feel worse.

Questions

- What happens to the clients who leave your care?
- Are you aware of their future transitions?
- Have your treatment services included interventions designed for success in future environments and anticipated transitions?
- Can you think of clients with whom you have worked who experienced both successful and unsuccessful transitions?
- When you think about these three examples and your own treatment experiences, what are things that you might have done to facilitate a smoother transition?
- How can occupational therapy facilitate or support successful HCT?

Developing Guidelines

HCT has been a growing concern over the past 30 years, when it was initially documented that the success of pediatric medicine has enabled more than 90% of children born with disabilities and special health care needs to survive to adulthood (Gortmaker & Sappenfield, 1984). As these children aged out of pediatric care, it was discovered that many of the young people and their families were unprepared for the transition to adulthood and independence, and there were few or no adult providers with expertise for many of their health problems and disabilities. Family medicine practitioners and internists were often reluctant to take on these young adults as patients, and the health care system as a whole was unprepared for this wave of new and sometimes challenging patients (Reiss et al., 2005). Additionally, the pediatric system was

required by hospital or clinic policy or other guidelines to discharge these young adults.

Transition From Youth to Adulthood

Various pediatric medical associations and federal agencies have developed guidelines and policy statements regarding the necessity, process, and goals of HCT. (See Reiss & Gibson, 2002, for a history of this process.) The American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians–American Society of Internal Medicine (2002) described critical initial steps that need to be taken to support HCT for young people, including

- Ensuring young people with special health care needs had an identified health professional who assumed responsibility for their transition needs;
- Identifying core provider knowledge and skills needed to provide HCT services;
- Creating and maintaining a portable ***transition health record***, which is a written HCT plan;
- Applying guidelines for primary and preventive care to all adolescents; and
- Ensuring affordable and accessible insurance coverage for young people with special health care needs.

Rosen, Blum, Britto, Sawyer, and Siegle (2003) built on these objectives by highlighting the need for transition programs to address the full range of health concerns experienced by transition-age young people, “including growth and development, sexuality, mood and other mental health disorders, substance use, and other health promoting and damaging behaviors” (p. 309).

The American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians Transitions Clinical Report Authoring Group (Clinical Authoring Group; 2011) detailed an age-based algorithm to establish the timing and development of appropriate transition plans and guide young people, their families, and providers through the transition process within the context of the medical and health care systems. ***Transition plans*** outline goals and steps to be taken to establish and secure necessary medical care throughout one’s adult life.

The American Academy of Pediatrics, American Academy of Family Physicians, and American

College of Physicians–American Society of Internal Medicine (2002) developed the concept of ***medical home*** as a model of providing ***primary care*** (i.e., the delivery of integrated health care services) that is accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective. Current policy statements about transition from medical professional associations mention the transition process, but they do not address what actually needs to be included in a health care transition plan, who is responsible for seeing that the plan is accomplished, or the necessary skills training that young people and their families may require.

Transition plans are important and necessary, and they should document the ability of young people to successfully carry out the skills and tasks necessary to manage their own health care and the health care system at large. A more complete discussion of the role of occupational therapists in transition planning is found at the end of this chapter.

Adult Transitions

Similar to the transition guidelines for adolescents and young adults, Coleman and Boult (2003) set out five principles to improve transition for adult patients with complex and continuous care:

1. Health care professionals must prepare clients and their caregivers to receive care in the next setting and involve them in the development and execution of a transition care plan.
2. Good, mutual communication among clinical professionals is essential to ensuring high-quality transitional care; involvement of a ***transition coordinator***, a person with specialized knowledge of transition policies and who oversees the process, may enhance the care provided.
3. Clinical guidelines and specific instructions on how to care for the person should be developed by providers and health care settings that promote high-quality transitional care.
4. All health care professionals involved in transferring patients across settings should receive education in transitional care.
5. Research should take place to improve the transitional care process.

Similarities can be seen across the policy statements from the American Academy of Pediatrics,

American Academy of Family Physicians, and American College of Physicians–American Society of Internal Medicine. Such principles generally address institutional policy, goals and the roles of providers, and inclusion of patients and families, but they do not address important aspects of what actually has to occur to make HCT a reality.

Structural and System Barriers

An extensive literature review (While et al., 2004) has identified through various means, including observational, survey, and qualitative research, the structural and system barriers to HCT. Similarities exist between adolescent and adult transitional care. Many of these barriers are outside the scope of practice of occupational therapy but are important to recognize, because clients will often have to address these issues.

Youth Transitions

A wide range of barriers have been identified that can impede the transition of young people to adult-oriented care. Reiss and Gibson (2002) and Reiss et al. (2005) proposed the following categorization of barriers: service needs, structural issues, and personal preferences and interpersonal dynamics.

Service needs

Service needs refer to both health care providers with expertise to provide age-appropriate care to individuals with special health care needs across the life course and specific transition supports or services that facilitate a smooth transition. Some service needs barriers include

- Lack of interested or knowledgeable adult-oriented health care providers and health care services,
- Lack of adult-oriented primary and preventive services in pediatric settings (adult-oriented settings often overlook these needs and focus on the disability),
- Lack of transition services or programs to assist with the process of HCT, and
- Life-sustaining treatments or approaches to the disease are not available in the adult-oriented practice setting.

Structural issues

Structural issues are health system-wide practices and policies that tend to segment health care by age or specialty practice area and therefore make transitions necessary. The following are some examples of structural issues that are often difficult to change and often need to be accommodated through advance planning:

- Education and training of many health care providers are age segregated (e.g., pediatrics, internal medicine, gerontology), which can result in different styles and standards of practice and distrust between pediatric and adult-oriented providers.
- Transfer or discharge out of pediatric service can sometimes be abrupt when it is precipitated by the young person's pregnancy or involvement with drugs or the criminal justice system.
- Age rather than maturity is the prompt for transition because of system rules and facility or clinic age policies.
- Missions of facilities or charities are designated for children under certain ages (e.g., 18 or 21 years). Health care systems for children are expected to send their young adult patients to adult-oriented facilities to make room for new younger patients.
- Health insurance and federal programs for children with special health care needs end at age 18 or 21 years despite the fact that the special health care need continues.
- Licensing of some health care providers limits the age range in which they can legally practice.
- Lack of or inadequate health insurance limits the health services available to the young adult.
- Absence of referral networks across age practice groups.
- A difference in style exists for practice and availability of support or ancillary personnel or support services between pediatric and adult-oriented care.
- Family involvement is greatly encouraged in pediatric care but not in adult-oriented care. This is related to federal privacy regulations such as HIPAA. This shift in focus changes the role of family members from active and respected members of the treatment team to outsiders or only the source of transportation for the young person.

Personal preferences and interpersonal dynamics

Personal preferences and interpersonal dynamics involve the important human element in the transition process. The intimate acts of health care can create strong and lasting relationships that are difficult to end or replace. Trust and respect built over years with pediatric providers can make relationships with new providers challenging and unfulfilling. Some personal preference and interpersonal dynamics barriers include

- The intensity and trust relationships between families and pediatric providers and the difficulty terminating these relationships at the end of pediatric care,
- The emotional and intellectual challenges of building new therapeutic relationship, and
- Lack of respect toward the young persons and their families for their knowledge and experience about special health care needs.

Two other issues that affect transition are (1) the cognitive ability of the young person and (2) the progressive nature of the illness. Young people who, as a result of cognitive challenges, will not be able to independently make decisions for themselves or direct and manage their care will require additional supports and protections, including various types of guardianships, while at the same time desiring as much self-determination and independence as possible.

Tragically, some pediatric illnesses shorten young people's lifespan to their early 20s. In these instances, it is important that, when desired by the young person and his or her family, adult responsibility be transferred to the young person and as many opportunities and responsibilities of adulthood be made available, including adult-oriented health care services.

Transition in Adult Care

Transition for adult and geriatric patients often involves moving between different levels and location of care, from intensive care to subacute, to various aspects of rehabilitation, and then to home with outpatient or home care. Through this process,

health information is shared, instructions are provided, providers change with location, the plan of care is not always forwarded with the patient or is revised without consultation with the family, and consistency seems very limited.

The patient and family members are the only consistent elements in the transition process. With health care delivered through fragmented and independent service, transition is fraught with problems and dangers related to poor communication, missing information, and lack of anticipation of problems.

For example, an older patient may be disoriented upon arrival in a new facility (Coleman, 2003; Coleman, Min, Chomiak, & Kramer, 2004; Coleman, Smith, et al., 2004). Patients and their families are required to reorient to new systems and processes of care. Medication errors can occur, and possessions, including eyeglasses, dentures, and assistive devices, along with the consistency of care, get lost in the shuffle.

In adult care, Coleman (2003) identified three areas of problems that impede transition:

1. Delivery system
2. Clinician
3. Patient.

Delivery system-related barriers

Coleman's (2003) list of delivery systems is similar to the previously described "service needs" and "structural issues." **Delivery system-related barriers** in HCT include

- Organization and fragmentation,
- Lack of formal relationships among health care settings,
- Lack of financial incentives promoting transitional care and accountability,
- Individual facility contractual relationships with pharmaceutical companies that influence available medication and prompt changes in the medications used to treat the patient,
- Breakdown in communication and a lack of informational systems designed to facilitate the timely transfer of essential information, and
- Lack preparation of the patient and caregiver for the transition or transfer.

Clinician-related barriers

Clinician-related barriers are related to health services and providers. They include

- Change in practice patterns that make it less likely that a provider would take care of patients across multiple treatment settings,
- Staffing shortages and lack of care providers who are concerned with long-term outcomes,
- Lack of training in cross-setting communication to facilitate transition,
- Lack of reconciliation of medication regimens between treatment sites,
- Lack of communication of advanced directive between treatment sites,
- Problems with transportation and follow-up care, and
- Problems with the communication of advanced directive between treatment sites.

Patient-related barriers

Similar to patient preferences previously discussed, **patient-related barriers** are related to patient choices and behaviors. Patient-related barriers to HCT include

- Limited expectation that transition could be better and an expectation or demand for better services.
- Patients and caregivers are not prepared to benefit from care in subsequent settings. They may be suspicious and mistrusting of the new providers and resist building relationships that would help their care.

Health Insurance

Recent changes in health care reimbursement as a result of the **Patient Protection and Affordable Care Act of 2010** have made it more affordable for some young adults to get improved access to health insurance. This improvement is not universal; because of adoption of parts of the law on a state-by-state basis, many young adults with special health care needs do not have affordable health insurance (Goudie & Carle, 2011). Despite the importance of health insurance, its presence does not cure the problem of transition. This can be seen in countries

where universal access to health care exists, yet difficulties with transition for young adults continue (Forbes et al., 2001; McDonagh, 2005).

Transition Supports

Parallel to the exploration of barriers to HCT, supports for transition have been proposed to address HCT in the short term, as broader system changes would take significantly longer. Reiss and Gibson (2002) detailed five recommendations:

1. Use a future orientation when working with children with disabilities and special health care needs.
2. Anticipate change, and develop a flexible plan for the future.
3. Foster personal and medical independence and creative problem solving.
4. Develop a specific transition plan.
5. Celebrate transitions as they occur.

Coleman (2003) also presented a list of components of effective care transitions, which included

- Communicating between the sending and receiving clinicians around a common plan of care;
- Receiving a summary of care;
- Establishing goal preferences and advanced directives;
- Updating problem lists, baseline physical and cognitive status, medicine, and allergies;
- Preparing the patient and caregiver for what to expect at the next site;
- Reconciling medication at the new site; and
- Creating a follow-up plan for how outstanding tests and appointments will be completed and discussing in detail with patients and caregivers warning symptoms or signs that may indicate a worsening condition.

Since publication of Reiss and Gibson (2002) and Coleman (2003), many health systems, children's hospitals, and health providers have initiated more formal transition programs. Descriptions of these programs can be found throughout the health care literature (e.g., Evans, McDougall, & Baldwin, 2006; Gall, Kingsnorth, & Healy, 2006; Treadwell, Telfair, Gibson, Johnson, & Osunkwo, 2011).

A review of transition programs is beyond the scope of this chapter, but recommendations for practitioners to support transition at the end of this chapter can help define the role occupational therapy can play in HCT programs and improve outcomes for transitioning clients.

Evidence and Expert Opinion

Despite numerous calls for research to discern best practices in HCT (Coleman, 2003; Reiss & Gibson, 2002; Reiss et al., 2005; Rosen et al., 2003), few published studies have addressed what approaches or timing of intervention will result in the desired outcomes of HCT. Much of the published research in HCT addresses satisfaction surveys of programs, qualitative studies of experiences or barriers to HCT, and program descriptions.

Current Research

Two systematic reviews have examined the transition research literature. Betz (2004) conducted a detailed review of 43 transition studies focused on adolescents and young adults and emphasized the importance and need for clear criteria to determine transition readiness and documentation of the effectiveness of interventions. *Transition readiness* means that the young adult acquired skills in the areas of self-care, health care decision making, and self-advocacy that will prepare him or her to take more responsibility for his or her own health care (Reiss et al., 2005).

While et al. (2004), in a systematic appraisal of 126 articles on adolescent and young adult transition, identified the components that supported good transition practice and preparation. Components relevant to occupational therapy focused on young people's "development of skills of self-management and self-determination, support for psychosocial development, involvement of young people, peer involvement, support for changed relationships with parent/carers, provision of choice, provision of information and focus on young person's strengths for future development" (p. 445).

The need for transition readiness and the necessary skills for independence could be an important area addressed by occupational therapists. Many of the features that focus on skills support for change

and self-management are also relevant to clients transitioning across the age spectrum.

Increasing focus has been in the area of transition readiness assessment. A recent systematic review (Stinson et al., 2014) of transition readiness measures for adolescents with chronic illness determined that of the 14 measures examined, none had well-established reliability or validity.

Investigator-developed instruments that have not been validated were also cited in the occupational transition literature. For example, Abel et al. (2015) discussed the use of an author-adapted 100-question transition checklist for young adults with sickle cell disease. The checklist, derived from the Adolescent Autonomy Checklist (Goodwyn, 1990), was modified and implemented without established psychometric properties for the checklist. Despite good intention, the use of an instrument that has not been adequately validated inhibits the development of evidence to support the implementation of transition services.

Treadwell et al. (2015a, 2015b) discussed the development and establishment of reliability and validity of a transition readiness assessment for youth and young adults with sickle cell disease. The scale focuses on knowledge, health practices, and behaviors necessary to independently address one's health care needs. This scale is an initial effort to develop valid and reliable measurements. It is important to recognize that these efforts rely largely on self-report.

The addition of criterion-related observational skill assessments would greatly increase the validity and predictive ability of these assessments. The perspective of functional assessment provided by occupational therapists could be invaluable in this process.

Expert Opinion

The absence of research evidence regarding best practices in HCT is not necessarily a failure of effort or desire but rather because of the difficulty in addressing a truly complex process.

Research challenges

The first challenge is defining and establishing consensus about the end goal of HCT. When is it achieved? With the new understanding of adolescent and young adulthood neurological and cognitive development continuing into the mid-20s (U.S. Department of Health and Human Services, 2011), is it plausible

to arbitrarily decide that HCT should be measured at a chronological age of 18 years or 21 years? Also, the source of care for the young adult changes over time. HCT should begin during childhood. Pediatric providers will most likely be overseeing these preparatory health care services. However, success in preparing for and achieving independence will most likely be observed once the young adult is receiving care from adult providers. Clear linkages and cooperation across age-related health systems will improve intervention and the ability to measure the successes or failures of HCT once the young adult transitions to the adult-oriented health care system.

Keeping up with research participants who no longer are in practitioners' care requires extensive financial support and research personnel to allow accurate measurement of outcomes. While research studies wait for this evidence about best practices, young adults continue to age out of the pediatric health care system; something must be done to assist the young people and their families to transition successfully.

In the absence of empirical evidence, it is valuable to turn to the experiences of young people and their families who have transitioned successfully and to their health care providers. Reiss et al. (2005), in their qualitative study of 143 participants that included transitioning young adults with disabilities and special health care needs, their families and providers described several important elements of transition that are relevant to the discussion of occupational therapy involvement in transition in the final section of this chapter, "Supporting Health Care Transition."

Stages of transition

In Reiss et al.'s (2005) study, three stages of transition were identified:

1. Envisioning a future
2. Age of responsibility
3. Age of transition.

Envisioning a future. Although many transition policies describe the need for transition to begin by ages 12–14 years (Clinical Authoring Group, 2011), family members in Reiss et al.'s (2005) study recognized the need for transition to begin very early in the child's life.

The first stage of transition was identified as **envisioning a future**. Participants who had personal

experience with HCT stated that this stage began when their child was first identified with a disability or special health care need. This stage is best typified by the realization that the child has a future, but that future will take extra planning and effort than it might for a typically developing child. Additionally, anticipating the health care needs of the child would play an important role in his or her overall development and ultimate independence.

Parents acknowledged that although it was not clear what the full potential of their child might be, it was nonetheless important to ask questions about future education, employment, and independent living and begin to initiate activities that would foster and support independence. As one parent stated, the child's pediatrician

looked at the kids developmentally. So when Bobby was 3 or 4 months old, he said to me, "Where do you want Bobby to be in 20 years?" And because of that, I began to think about where it was that I wanted him to be in 20 years. (Reiss et al., 2005, p. 115)

Although most formal transition plans begin during the young person's teen years, there was consensus among participants about the necessity to start the HCT process as early as possible by fostering independence.

Age of responsibility. The second stage that was identified was the **age of responsibility**, during which the young people were actively engaged in their care and took on increasing responsibility for carrying out all aspects of their medical self-care, including interacting with providers and managing medications. Participants believed activities of this stage were best completed prior to the onset of adolescence.

Age of transition. The last stage, **age of transition**, was divided into two time periods, ages 12–17 years (i.e., adolescence) and ages 18–23 years (i.e., young adulthood). During the first time period, the focus was on supported practice and increasing independent responsibility for medical management. Also, the preparation for transition to new adult-oriented providers, including exploring ways to acquire or maintain health insurance, was put into place. Around the legal age of emancipation (age 18 years), the focus shifted to solidifying and supporting independence.

Supporting transition

Stewart, Stavness, King, Antle, and Law (2006) concluded, in their critical review of the transition literature, that there are numerous factors that support transition, including “self-determination, self-advocacy, choice making, and problem solving” (p. 22) and environmental supports such as peer mentors and family support. Additionally, communication and an individualized approach are important in planning transition services. Although their review focused on transition in general, their findings are very relevant to HCT because of the reinforcement of individual skills system supports and the acknowledgment of the importance of an individual approach.

Transition plans

One area that has been suggested in the policy literature, but that has not been empirically evaluated, is the development and implementation of transition plans. As defined earlier, an HCT plan is a way to anticipate the changes in accessing and paying for health care and interacting with adult-oriented providers.

A young person’s participation in the development and execution of an HCT plan provides opportunities for the young person to demonstrate independence and readiness to manage his or her disability or special health care needs. Reiss and Gibson (2007) described an HCT planning process that, although begun in childhood, is formally documented and evaluated through adolescence and young adulthood. The planning process is organized around three age groupings (12–14 years, 15–17 years, and 18 years or older). (For specifics about the development and use of the planning workbook, see Reiss & Gibson, 2005.)

Health Care Transition and Occupational Therapy

Occupational Therapy’s Role

Occupational therapy practitioners can play an important role in supporting youth and families prepare for and successfully accomplish HCT by helping them identify and become proficient at important health occupations that support independence.

This support was made very clear through interaction with one family in the development of family center transition material and the collection of data in the study of HCT documented in Reiss et al. (2005). The following comments are from family interviews regarding HCT:

- “His [occupational and physical therapists] were very instrumental in planning for transition.”
- “They were marvelous in identifying services for Bill.”
- “[The occupational therapist] looked at what will he need to be successful? What modifications will he need in college to be successful?”
- “These two women [the occupational and physical therapists] really were influential in his success.”
- “His [occupational] therapist was the first one to say we’ve gotta get him an electric wheelchair to go off to college.”
- “What will he need, and what training does he need to manage his care? And so both the [occupational and physical therapists] worked together. For instance they started with him in his freshman year [of high school] about how you gotta do things. And they actually had him transition to other students caring for him. So that he could get used to explaining [his care]. They came out and worked with him as his personal care attendants, would come to the home, so I could go to work. They had him work. They were the first ones to get him a job. They worked with him on developing a résumé. They worked with him on developing life skills.”

Not every therapeutic experience is this successful, but these parents’ comments show how occupational therapy practitioners play a significant role in HCT.

Occupational Therapy Philosophy

Practitioners’ focus on function, task completion, and occupations creates a unique and important role for occupational therapy in HCT. One of occupational therapy’s principal goals is achieving ***functional independence***, the capacity to manage and take care of one’s self. Functional

independence can include all aspects of taking care of one's medical needs.

Occupational therapy recognizes that independence is developed or achieved incrementally over a lifetime and that skills, abilities, or functional capacity can diminish as a result of disease or the aging process. Occupational therapy's developmental or life span perspective, involvement in treatment across the life course, and focus on function are ideal for supporting successful HCT.

Applying clinical reasoning, practitioners can incorporate relevant HCT activities such as assertiveness and communication with providers, use of portable health records, and specific health self-care activities. Practitioners can also advise families and caregivers on how to provide support to improve performance abilities and provide opportunities to practice maximal independence and function within future health contexts.

Occupational therapy's philosophical base guides practitioners to view HCT as a series of defined health care self-management tasks that can be learned, practiced, and used as signs of independence in preparation for adulthood and independent living.

Supporting Health Care Transition

Because empirical research evidence is limited in HCT and occupational therapy, it is necessary to rely on clinical experience, proven occupational therapy tenets, and client feedback. Occupational therapy can contribute in two broad areas of HCT: (1) health systems and (2) patients and their families or caregivers.

Health Systems

Occupational therapy practitioners can promote HCT by participating in policy-setting groups. Insight into supportive environments, adaptation, and anticipatory planning to maximize independence can help design transition programs that are patient centric and effective. Within the education-based transition system, practitioners can seek ways to incorporate HCT into individualized education

program (IEP) planning and inclusion in curriculums on the basis of the premise that health and the maintenance of health support success in other areas of life. Integrating HCT into the IEP can extend into treatment and the opportunity to look for corollaries between the traditional task of independence and health care management task.

Patient and Families

Working with families is another area where practitioners can affect HCT outcomes. Practitioners can encourage families to think about and plan for a future and start early in fostering independence in health care tasks. They can support families in the development of transition plans and anticipate environments and ways that the young patients will need to rely on themselves to carry out medical tasks.

Questions to guide these plans include

- Where can I expect to get medical care when I am an adult? and
- What skills will I need to be successful in taking care of my medical needs?

Practitioners can support the change in role of responsibility for the completion of medical task while assisting families in determining their comfort level through client-demonstrated independence.

Assessment and Intervention

When evaluating a client, practitioners must determine what medical tasks the client—whether child, young adult, and independent adult—will need to complete.

Youth

For young people, understanding the medical care needs can be achieved by using an assessment tool such as the transition workbook (Reiss & Gibson, 2005) or readiness assessment (Treadwell et al., 2015a, 2015b). These planning workbooks ask the young adult to think about current and future medical and health care needs and the specific tasks that person will need to do to address those needs.

The person is also guided to think about needs that may develop as life progresses. Once deficits have been determined, these medical self-management tasks can then be incorporated into treatment.

In a school setting, medical corollaries to school tasks can be incorporated into treatment by allowing the young person to be responsible for in-school medical tasks or completing the task themselves as the therapeutic goal. Strategies to help students learn to address their medical needs can include

- Scheduling and using calendars to document daily treatments and doctor's visits;
- Being responsible for medication knowledge, purchasing, and using the telephone to renew prescriptions at a pharmacy;
- Learning how to appropriately work with support personnel and aides and learning how to hire, direct, and even fire health care aides;
- Learning how to teach or direct others to carry out health care tasks that are necessary but beyond the person's capacity;
- Completing tasks that involve health insurance, money management, and the collection and review of health information;
- Learning assertiveness training that uses examples of getting or understanding medical advice, working with a health care provider, making decisions, providing assent or consent, and directing support personnel and aides; and
- Developing life maps, creating a medical journal, or arranging transportation.

Adults

For adult clients in situations in which their functional or cognitive ability may be in flux or deteriorating, practitioners can assess the clients' ability to manage their environment and health care tasks and inform caregivers and providers of the clients' new functional status. Practitioners can also support families in assuming new roles as the clients' decreasing function start to limit their ability to manage their health care needs.

- Assess performance of health-related tasks and document needed assistance.
- Teach family to provide assistance in ways that support and preserve independence.

- Encourage families to document the use of aids and glasses and work with nursing and other staff to ensure their use and upkeep.
- Encourage families to proactively monitor transitions through the health care system, verifying and validating the transfer of instructions, medication regimes, and possessions or aids.

Summary

Clients in the three case examples discussed in this chapter, and their families, faced HCT. Joey and Renzo were progressing along the developmental continuum learning and acquiring life skills to support adult independence. Esther was functioning independently, but age and declining health exposed her to a fragmented health care system and demanded of her competencies or skills that she was not able to perform successfully because of her injury.

How could occupational therapy services have supported or planned for HCTs in each of these cases? For Joey, the focus could have been on helping his parents recognize the importance of allowing Joey opportunities to make choices and experience the outcomes of those choices regarding his health in a supportive environment. It would also have been important for Joey to develop his own relationships with health care providers to learn how to negotiate and manage his care.

Renzo experienced a mix of both developmentally focused HCT and the type of HCT experienced more frequently by adults. Practitioners needed to focus not only on helping Renzo restore skills and foster healthy self-management but also on helping Renzo and his family adjust to the differing intensity and health care environments in his recovery journey and planning for his future.

Esther and her family demonstrated the need for a detailed transition plan, assessments of her functional performance, and how it affected her ability to participate in her care and awareness of support and adaptations that were necessary to maintain and improve her ability and that of her caregivers to participate in and manage her care. These general goals can be achieved only with a thorough assessment process, detailed treatment plans, and use of meaningful and functional tasks that support the achievement of independence in medical self-management.

References

- Abel, R. A., Cho, E., Chadwick-Mansker, K. R., D'Souza, N., Houston, A. J., & King, A. A. (2015). Transition needs of adolescents with sickle cell disease. *American Journal of Occupational Therapy*, 69, 6902350030p1–6902350030p5. <http://dx.doi.org/10.5014/ajot.2015.013730>
- American Academy of Pediatrics. (2002). The medical home. *Pediatrics*, 110(1, Pt. 1), 184–186.
- American Academy of Pediatrics, American Academy of Family Physicians, & American College of Physicians—American Society of Internal Medicine. (2002). A consensus statement on health care transition for young adults with special health care needs. *Pediatrics*, 110, 1304–1306.
- American Academy of Pediatrics, American Academy of Family Physicians, & American College of Physicians Transitions Clinical Report Authoring Group. (2011). Critical Report—Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics*, 128, 182–200.
- Betz, C. L. (2004). Transitions of adolescents with special health care needs: Review and analysis of the literature. *Issues in Comprehensive Pediatric Nursing*, 27, 179–241.
- Blum, R., Garell, D., Hodgman, C., Jorissen, T., Okinow, N., Orr, D., & Slap, G. B. (1993). Transition from child-centered to adult health-care systems for adolescents with chronic conditions: A position paper of the Society for Adolescent Medicine. *Journal of Adolescent Health*, 14, 570–576.
- Coleman, E. (2003). Falling through the crack: Challenges and opportunities for improving transitional care for persons with continuous complex care needs. *Journal of the American Geriatrics Society*, 51, 549–555.
- Coleman, E., & Boult, C. (2003). Improving the quality of transitional care for persons with complex care needs: Position statement of the American Geriatrics Society Health Care Systems Committee. *Journal of the American Geriatrics Society*, 51, 556–557.
- Coleman, E., Min, S., Chomiak, A., & Kramer, A. (2004). Posthospital care transitions: Pattern, complications, and risk identification. *Health Services Research*, 39, 1449–1465.
- Coleman, E., Smith, J., Frank, J., Min, S., Parry, C., & Kramer, A. (2004). Preparing patients and caregivers to participate in care delivered across settings: The care transition intervention. *Journal of the American Geriatrics Society*, 52, 1817–1825.
- Evans, J., McDougall, J., & Baldwin, P. (2006). An evaluation of the "Youth En Route" program. *Physical and Occupational Therapy in Pediatrics*, 26, 63–87.
- Forbes, A., While, A., Ullman, R., Lewis, S., Mathes, L., & Griffiths, P. (2001). *A multi-method review to identify components of practice which may promote continuity in the transition from child to adult care for young people with chronic illness or disability* (Report for the National Coordination Centre for National Health Service, Service Delivery and Organization R & D). London: Kings College, Florence Nightingale School of Nursing and Midwifery.
- Gall, C., Kingsnorth, S., & Healy, H. (2006). Growing up ready: A shared management approach. *Physical and Occupational Therapy in Pediatrics*, 26, 47–62.
- Goodwyn, M. A. (1990). *A study of the biomedical and psychosocial factors that predict independence in activities of daily living, academic success, and self-perception of children with myelomeningocele* (Unpublished doctoral dissertation). University of Washington, Seattle.
- Gortmaker, S., & Sappenfield, W. (1984). Chronic childhood disorders: Prevalence and impact. *Pediatric Clinics of North America*, 31, 3–18.
- Goudie, A., & Carle, A. C. (2011). Ohio study shows that insurance coverage is critical for children with special health care needs as they transition to adulthood. *Health Affairs*, 30, 2382–2390. <http://dx.doi.org/10.1377/hlthaff.2011.0641>
- Health Insurance Portability and Accountability Act of 1996 (HIPAA), Pub. L. 104–191, 110 Stat. 1936.
- McDonagh, J. (2005). Growing up and moving on: Transition from pediatric to adult care. *Pediatric Transplantation*, 9, 364–372.
- Patient Protection and Affordable Care Act of 2010, Pub. L. 111–148, § 3502, 124 Stat. 119, 124.
- Reiss, J., & Gibson, R. (2002). Health care transition: Destinations unknown. *Pediatrics*, 110, 1307–1314.
- Reiss, J., & Gibson, R. (2005). *Health care transition workbooks series*. Gainesville: University of Florida, Institute for Child Health Policy.
- Reiss, J., & Gibson, R. (2007). Developing transition health care plans. In C. L. Betz & W. M. Nehring (Eds.), *Promoting health care transitions for adolescents with special health care needs and disabilities* (pp. 137–154). Baltimore: Paul H. Brooks.
- Reiss, J., Gibson, R., & Walker, L. (2005). Health care transition: Youth family and providers perspectives. *Pediatrics*, 115, 112–120.
- Rosen, D., Blum, R., Britto, M., Sawyer, S., & Siegle, D. (2003). Transition to adult health care for adolescents and young adult with chronic conditions. *Journal of Adolescent Health*, 33, 309–311.
- Stewart, D., Stavness, C., King, G., Antle, B., & Law, M. A. (2006). Critical appraisal of literature reviews about the transition to adulthood for youth with disabilities. *Physical & Occupational Therapy in Pediatrics*, 26, 6–24.
- Stinson, J., Kohut, S., Spiegel, L., White, M., Gill, N., Colbourne, G.,... Kaufman, M. (2014). A systematic review of transition readiness and transfer satisfaction measures

- for adolescents with chronic illness. *International Journal of Adolescent Medicine and Health*, 26(2), 159–174. <http://dx.doi.org/10.1515/ijamh-2013-0512>
- Treadwell, M., Johnson, S., Sisler, I., Bitsko, M., Gildengorin, G., Medina, R.,...Smith, W. (2015a). Development of a sickle cell disease readiness for transition assessment International. *Journal of Adolescent Medicine and Health* [Epub ahead of print]. <http://dx.doi.org/10.1515/ijamh-2015-0010>
- Treadwell, M., Johnson, S., Sisler, I., Bitsko, M., Gildengorin, G., Medina, R.,...Smith, W. (2015b). Self-efficacy and readiness for transition from pediatric to adult care in sickle cell disease. *International Journal of Adolescent Medicine and Health* [Epub ahead of print]. <http://dx.doi.org/10.1515/ijamh-2015-0014>
- Treadwell, M., Telfair, J., Gibson, R., Johnson, S., & Osunkwo, I. (2011). Transition from pediatric to adult care in sickle cell disease: Establishing evidence-based practice and directions for research. *American Journal of Hematology*, 86, 116–120.
- U.S. Department of Health and Human Services. (2011). *The teen brain: Still under construction* (NIH Publication No. 11-4929). Retrieved from http://www.nimh.nih.gov/health/publications/the-teen-brain-still-under-construction/teen-brain_141903.pdf
- While, A., Forbes, A., Ullman, R., Lewis, S., Mathes, L., & Griffiths, P. (2004). Good practices that address continuity during transition from child to adult care: Synthesis of the evidence. *Child: Care, Health and Development*, 30, 439–452.

CHAPTER 9.

MENTAL HEALTH AND EMOTIONAL NEEDS IN TRANSITION

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Chapter Objectives

After reading this chapter, readers will be able to

- ❖ Develop awareness of mental health and emotional needs of people with disabilities and their family members during transitions;
- ❖ Discuss emotional aspects of change and transition, including individual factors and environmental contexts; and
- ❖ Identify roles for occupational therapy practitioners in supporting mental health and emotional needs during transition, including individual-, family-, and system-level interventions.

Key Terms and Concepts

- ❖ Advocacy
- ❖ Communitas
- ❖ Disability-related supports
- ❖ Emotional well-being
- ❖ Extrafamilial supports
- ❖ Family protective factors
- ❖ Family quality of life
- ❖ Family-level needs
- ❖ Health realization
- ❖ Horizontal stressors
- ❖ Incorporation
- ❖ Individual choice
- ❖ Individual needs
- ❖ Interdependence
- ❖ Life course perspective theory
- ❖ Life cycle system perspective
- ❖ Mental health
- ❖ Midlife crises
- ❖ Personal protective factors
- ❖ Protective factors
- ❖ Quality of life
- ❖ Resilience
- ❖ Rite-of-passage theory
- ❖ Role confusion
- ❖ Self-determination
- ❖ Separation
- ❖ System perspective
- ❖ Transition
- ❖ Vertical stressors
- ❖ Waiting

This chapter focuses on the emotional aspects of transitions across the lifespan and across families and systems to promote emotional well-being and mental health for all people. For the purpose of this chapter, *emotional well-being* is conceptualized as an outcome of occupational therapy intervention that reflects contentment across multiple life domains (American Occupational Therapy Association [AOTA], 2014). *Mental health* is “a state of well-being in which every individual realizes his or her own potential, can cope with the normal stresses of daily life, can work productively and fruitfully, and is able to make a contribution to his or her community” (World Health Organization, 2011, para. 1).

Sara and Melissa's Story: The Beginning

In Sara and Melissa's story, their family navigates emotional transitions, both expected and unexpected. Provided from the mother's point of view, this case example highlights theoretical concepts, such as contextual factors that affect transition, stages in the life cycle system perspective theory, family quality of life (FQoL), and resilience. A broad perspective is shared to inform professionals providing services, such as occupational therapy, of the family's emotional journey.

Sara is a 63-year-old married woman with two adult children and three grandchildren. She has two graduate degrees and a career as a special educator in the public school system, which she pursued after her children were grown and left the nest. Sara's husband, Gerry, was diagnosed with multiple sclerosis (MS) 15 years ago. Together, they raised one typically developing child, Gabe, and one child with disabilities, Melissa. Melissa was diagnosed with cerebral palsy (CP) and an intellectual disability.

Sharing anecdotes about facing transitions and the particular challenges related to raising a child with disabilities, Sara demonstrates real-life transitions related to emotional and mental health. These anecdotes are shared throughout the chapter.

Sara became a stay-at-home mom after her older child, Gabe, was born. After the birth of Melissa, Sara felt something “wasn't quite right” but was assured by everyone—her husband, the grandparents, the pediatrician—that Melissa was fine. Eventually, Sara took Melissa to a neurologist, and

she was diagnosed with CP and intellectual disability. Sara describes her emotions when she realized that her vision of a perfectly planned life was shattered and her fear of the unknown:

Had child number one, a little boy; absolutely perfect...the best baby....I was better than anybody else in the world...I was a stay-at-home mom, everything was wonderful. You know, the plan was in 3 years we'd have child number two. Plan was to have a boy, have a girl, have a dog, everything was put in place. Child number two came; it was a little girl, perfect. She was a beautiful child. Not quite as active as child number one, but she was still perfect in her mom's eyes.

By the time she was 2 months old, I thought I saw something that wasn't quite right. I'm not sure what it was; just a feeling, and, of course, the response from the pediatrician was, “You're comparing the children.” We know, we should never compare children, and I didn't think that I was, [but] something wasn't right....To know there's something wrong with your child and not be able to say what it is was very difficult, you know, it's that unknown....So we go to the neurologist, and, again, I guess this was the beginning of the change....I was right that there was something developmentally wrong with her...and that's when my world came crashing down.

When Melissa was age 22 months, Sara was told that Melissa would be better served at a full-day preschool for children with CP, which offered therapeutic services such as occupational, physical, and speech and language. Sara described the day Melissa transitioned to school as “one of the toughest days of my life ... putting her on the bus, diaper bag and all.” She was not prepared to put her baby on a bus to school, because that is not a typical transition for a parent of a child this age.

Questions

As you read this chapter, consider the following factors and questions:

- Melissa's diagnosis presented the first unexpected transition for the family. What were the emotional needs of Melissa's family members when she was

diagnosed? How could they have been supported by an occupational therapy practitioner?

- Identify future transitions that Melissa and her family will go through as Melissa grows older. What supports can be provided by occupational therapy to address their emotional needs during these transitions?

Emotional Aspects of Transitions

A *transition* is moving from one state to another, which sometimes can result in disequilibrium. For example, when a baby learns to walk, until the sense of balance is recalibrated to standing, he or she wobbles, falls, and reaches for objects to maintain stability. This physical activity also has emotional components. Suddenly, the child can separate from the adult, and the roles and responsibilities must shift for both. Such shifts in identity and independence may evoke positive emotions such as pride or may lead to feelings of fear or anxiety.

Transitions include cognitive and psychosocial aspects of coping and adaptation, such as

- Becoming aware of a need,
- Defining the challenge,
- Exploring alternatives,
- Choosing and acting on the decision, and
- Evaluating an outcome.

Resilience, defined as “competence to achieve well-being despite life problems” (Ghimbult & Opre, 2013, p. 311), is a necessary part of achieving competence and well-being during transitions and is explored throughout this chapter. It encapsulates how a person processes information, copes with challenges, and regains balance.

Transition events are a normal part of life and can be viewed through systems and lifespan developmental perspectives. Moving from one life stage to another, such as a child entering school, a young adult marrying, or an older adult moving from the family home to assisted living, means change. Such transitions demand new skills, shift expectations, and affect role performance. For example, starting school requires a child to enter a classroom and appropriately make his or her needs known, exercise self-control, follow rules, and perform tasks at a certain time in a certain

way. A child needs to have the requisite skills to successfully function during the school day.

Approaches to Transition

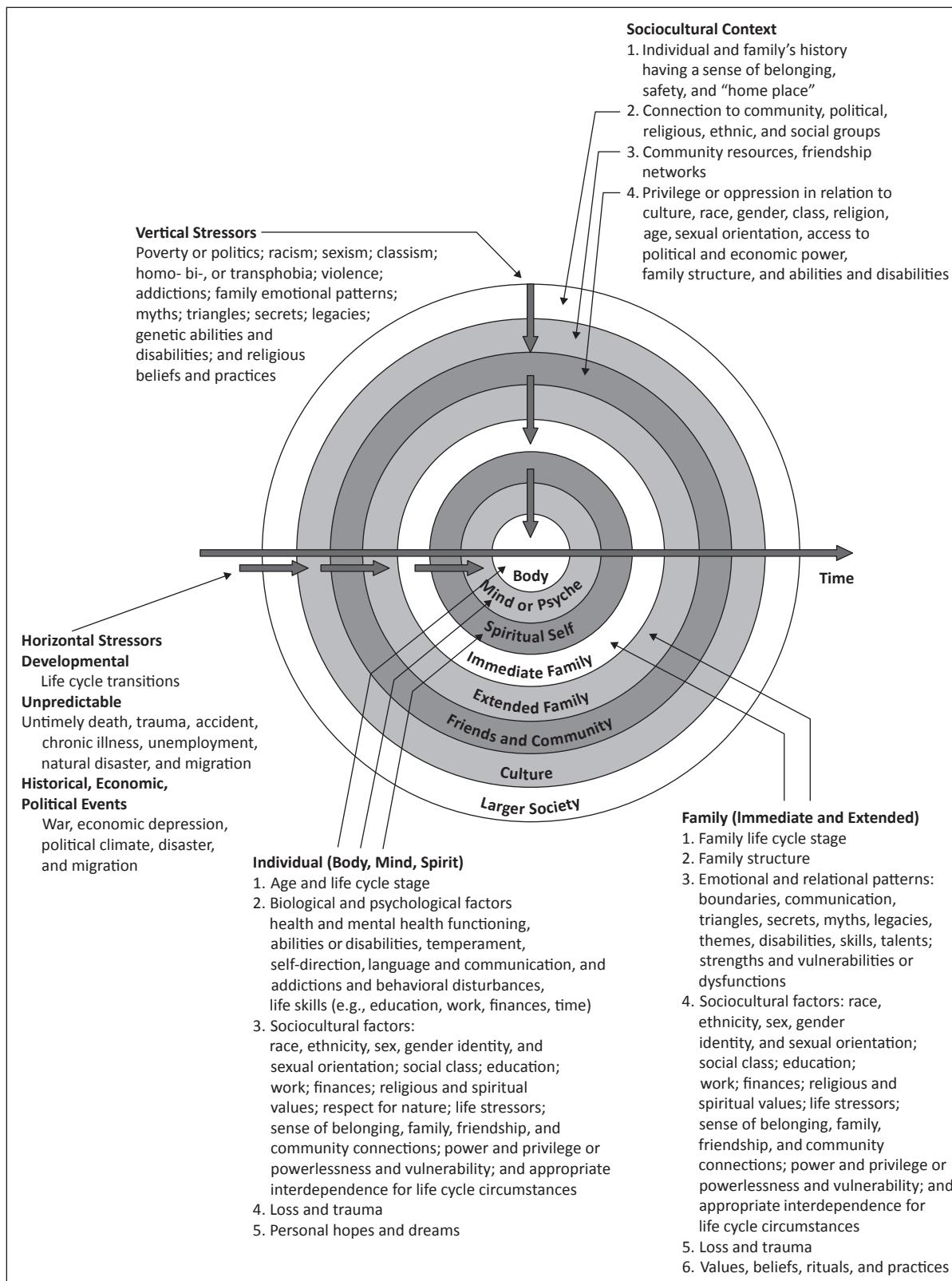
Review of the literature reveals several approaches to understanding emotional responses to change, or transitions, across the lifespan. Most are derived from developmental, social learning, and systems perspectives. This chapter discusses five approaches related to the complexity of the effects of transition on the family system: (1) life cycle system perspective, (2) life course perspective theory, (3) family quality of-life-perspective, (4) rite-of-passage theory, and (5) resilience theory.

Life Cycle System Perspective

The *life cycle system perspective* (McGoldrick, Carter, & Garcia-Preto, 2011), based on previous work by Bronfenbrenner (1979) and Carter and McGoldrick (2005), provides a context for understanding transition. From this perspective, transitions rarely occur in isolation; rather, each event affects and is affected by the immediate family system (i.e., microsystem), cultural values (i.e., macrosystem), and the systems in between. A *system perspective* suggests that a change in one element of a system will, in some way, affect and be affected by each layer in that system.

The life cycle system perspective includes systems that are nested circles (Carter & McGoldrick, 2005; McGoldrick et al., 2011) and parallels Bronfenbrenner’s (1979) extensive work in this area (see Figure 9.1; for more on Bronfenbrenner’s work, see Chapter 3, “Early Childhood Transitions”). Context is depicted through concentric circles, with three inner circles representing the individual at the core; four outer circles that represent the immediate family, extended family, friends and community, and culture; and the outermost circle that represents the larger society. Settings that provide health care, education, and general human services (e.g., vocational, residential) are part of the larger society, but they almost always interface with communities.

How people deal with transition is often affected by families, communities, and cultures. For example, a person who chooses to divorce may belong to a family and a cultural group in which divorce is not

Figure 9.1. Contexts of the life cycle system perspective.

Source. From *Individual, Family, and Social Perspectives: The Expanded Family Life Cycle*, by M. McGoldrick, B. Carter, & N. Garcia-Preto, 2011. New York: Allyn & Baker. Copyright © 2011 by Pearson Education. Used with permission.

acceptable and divorced people are looked down upon. That person may feel very stressed and worried about the outcomes of the transition in terms of dealing with the emotions and attitudes of people in his or her social circle.

Occupational therapy practitioners understand the system perspective. The *Occupational Therapy Practice Framework: Domain and Practice* (3rd ed.; *Framework*; AOTA, 2014) grounds occupational engagement within contexts, which is a similar concept to the system perspective. When supporting a client during transition, occupational therapy practitioners should also be mindful about the needs of the family and consider occupational engagement within the context of the client's community.

Types of stressors

McGoldrick et al. (2011) further discussed family, community, and societal systems as they are affected by horizontal and vertical stressors. **Horizontal stressors** include typical transitions and unexpected events that require unanticipated transitions, such as surviving a debilitating injury. **Vertical stressors** are based on a person's personal history and add dimension to how the person manages transitions. Vertical stressors may include family emotional patterns, religious practices, genetic abilities, and cultural belief systems.

Transitions capture family, community, and social systems moving through time. Emotional and mental health processes, including coping, adaptation, and resilience, are core to successfully navigating through ongoing periods of change and stressors.

Family unit in transition

The family, home, community, and work environments affect and are affected by the family unit in transition. For example, Sara described the period when she had to wait 3 months until she could schedule an appointment with a neurologist to diagnose Melissa. Such bureaucracy, which is part of the larger social system, affects family members and, in turn, valued family routines, such as Melissa's grandmother helping to babysit her. Sara said,

So we try to make the appointment at [a diagnostic center], and of course, it's like a 3-month waiting period. In the meantime, I can't go back to the family. My husband's

not quite sure what to do with this whole thing. My mother-in-law now will no longer babysit for this child, because there's something wrong, and my mother had the attitude of "woe is me."

Consider a similar impact during the natural transition of youth graduating from high school. This graduation has a different meaning for each member of the family and for different families, which is particularly evident in families with a child with a disability. Specifically, the family with a typical graduate usually anticipates an "empty nest," whereas the family with a graduate with disabilities often experiences a "forever nest." The expectation for the typically developing young adult is that of independence, with family members serving as consultants or support. However, for young adults with disabilities, the family members may need to remain involved in a sustained capacity, which often influences their own ability to participate in valued occupations (Eskow, Pinelis, & Summers, 2011).

Community in transition

The community to which the youth is transitioning is also affected by transitions such as high school graduation. For example, a typically developing young adult may transition to college and usually considers finances and an institution's location and overall goodness of fit. The young adult with a developmental disability must draw on even more resources and funding to meet his or her needs compared with the typical graduate.

Larger social systems

When helping people with disabilities and their families manage stress during transitions, it is important to prepare them for imposed changes in the larger social system (e.g., decreased access to care, loss of eligibility for education or health benefits) because of new legal status or changed financial criteria. Specifically, when children age out of the education system they lose eligibility for education, medical, and therapeutic services provided by education regulations mandated by the Individuals With Disabilities Education Improvement Act (2004; Pub. L. 108–446). Occupational therapy practitioners must prepare clients and their families

to advocate for their own needs and for social policies that positively affect them.

Families may perceive social policy as irrelevant to their daily lives, but practitioners can educate families about the implications of social policies on their life choices. The *Framework* (AOTA, 2014) designates **advocacy** as an occupational therapy intervention and points to the importance of helping clients locate and get the resources they need. Families who receive necessary resources often report enhanced quality of life and well-being (Eskow et al., 2011).

Stages of life cycle development

McGoldrick et al. (2011) recognized the variability in transitions as a result of multiple factors such as history, culture, and person and family context. To illustrate life cycle development with a system focus, they discussed seven flexible stages:

1. Leaving home (emerging young adults)
2. Joining of families through marriage or union
3. Families with young children
4. Families with adolescents
5. Launching children and moving on at midlife
6. Families in late middle age
7. Families nearing the end of life.

They examined how family structures affect and are affected by emotional health and used examples of single parents, blended families of previously divorced parents, and couples who live together but are not married.

Stage 1. Leaving home (emerging young adults). This stage involves emerging young adults separating from their family of origin and gaining financial and emotional independence. Although this stage is traditionally seen as a time for celebration, it may also create feelings of uncertainty. The young adult may have mixed feelings, that is, a sense of pride that comes with appreciating one's achievements and anxiety about the future.

Stage 2. Joining of families through marriage or union. This stage occurs when two people form a committed relationship. Through this relationship, a new family system is created involving the dyad and each person's family group.

This stage is happy for most couples because they are hopeful about their future together. However, stress and feelings of disappointment may

arise when the couple is required to negotiate personal issues and learn to adapt to each other's values and expectations. They also must realign their relationships with their extended families and friends so that the marriage becomes a priority. This change may be accompanied by feelings of loss.

Stage 3. Families with young children. This stage often requires an expansion of the family system to include significant others, such as grandparents, neighbors, and friends. The social-emotional work associated with a young couple coming together, such as compromising on how to spend money, must expand and develop "roots." These roots require responsibilities beyond each individual's focus. Tasks include decision making and performing activities associated with child rearing, expanding financial responsibility, and managing the household.

In addition, with a first child, the new parents must revise roles with their own parents, who are now grandparents. For example, Sara discussed the role adjustments that occurred when her children were born. She became a stay-at-home mother and worked part-time when the baby was asleep. Later, this change allowed her to have the time needed to care for a child with disabilities.

The first day of school is a noteworthy transition for many parents. Sara's description of that moment in time was particularly poignant. When Sara was told that her daughter would be better served at a preschool for children with CP, she had to transition from her role as stay-at-home mother to mother of a child in school before she was ready to do so.

For many families, the first day of school means having to adjust to regulated routines and plan schedules around school and extracurricular activities. A daily process of children separating from and reuniting with parents occurs, which requires emotional adjustment for both parents and children.

Stage 4. Families with adolescents. This stage recognizes the importance of flexible boundaries between parents and teens to allow for independence of the emerging adult. It also recognizes that the grandparents are aging and the family system may need to begin to adjust to the changed role of an aging parent. In addition, many religions mark the entrance into adulthood with a special ceremony during the teen years. For example, Sara described a conversation about Melissa's bat mitzvah that she

had with her rabbi after her son's bar mitzvah. This ritual was important to her because so many other rites of passage would probably not be possible for her daughter. She said,

At age 13, my son Gabe had a bar mitzvah. The day after that, I called the rabbi and said, "Now we need to plan for my Melissa's bat mitzvah. She is going to be 13 in 2 years." He wanted to know why, and I explained that as she grows and turns 16, she's not going to drive. When she's 18, she's not going to graduate from high school. When she's 21, she's not going to go with her friends to the bar and drink, and I don't know if she'll ever get married. But one thing she can do in the normal scale is to have a bat mitzvah at the age of 13. Jewish religion gives her that.

Parenting adolescents can be stressful. The adolescent's need for autonomy can trigger relationship conflicts with parents. For example, parents and adolescents may disagree on choices (e.g., clothing) or privileges (e.g., curfew time). For parents, reaching middle age can also trigger a sense of loss—losing their growing kids, having fewer possibilities in older age, or losing their parents.

Stage 5. Launching children and moving at midlife and Stage 6. Families in late middle age. Stages 5 and 6 are closely related. Stage 5 begins when the first child leaves home and ends when the last child leaves home. Stage 6 begins with the empty nest, when all children leave home. These two stages are marked in almost every culture by the marriage or union of children and the return to each parent's individual identity, which can include, for example, identity as part of a union with a significant other, as an adult without children, and so forth. The parent begins to deal with his or her own aging and creating new relationships with in-laws and grandchildren. The death of a person's parents often occurs in midlife.

The emotional adjustments during this time period are typically referred to as **midlife crises**. A midlife crisis is experienced by some people as they realize they have reached a midpoint in their lifespan and face their mortality. They may experience conflicts or dissatisfaction within themselves because of unrealized goals, physical changes, or health issues. They may feel loneliness after the death of a parent or their children have left home.

Sara discussed this stage when parents typically have more freedom because their young adult children become independent, nurturing friendships and working and learning away from their family. Although Gabe experienced typical life transitions, such as getting married and having children, it was clear that Melissa would have a different life path because of her disability.

After high school, Melissa attended a specialized program for young adults with developmental and intellectual disabilities at a local university. Sara started the program, for students requiring special education services through age 21 years to complete high school on a college campus, and was the special education teacher who taught Melissa's group. In addition, to address two of her main concerns for Melissa—lack of social opportunities and isolation and lack of opportunities for productive work—Sara began the Best Buddies program. This program paired young adults with disabilities with typical college students for social events and programs. The program also assisted young adults in obtaining work experiences. Sara said,

And then we started the Best Buddies...and that's when the social piece was able to kick in. I think the biggest challenge for children with disabilities, particularly with intellectual disabilities, is that social piece. You know, they just don't have a lot of friends. We were very, very lucky that she had this one girlfriend that was just very, very special. [When it comes to work], my goal was to find out what else these young adults [can] do. [We found a job in child care for Melissa], and it was because so many people right here on campus gave her the option.

When Melissa was age 28 years, she began having seizures and Sara's husband was diagnosed with MS. Because he was not comfortable looking after Melissa, particularly as they tried to find the right medications for him, the family decided to explore living arrangements for Melissa to ensure her care. Melissa moved out of the family home and into a community-based group home. Sara described the emotional shift that often happens when an adult child with disabilities moves from the parent's home to the care of others: "When you make this kind of move, you're putting an awful lot of faith into people."

When Sara's son Gabe got engaged, she had other concerns. She wanted to ensure that his wife (Karen) would accept and care for Melissa. She said,

Gabe got older and sort of changed gears, and I needed to look at the future. I would say to him, "You know, will this girl be okay with Melissa?" And he said, "Mom, I would never marry anybody who wasn't willing to embrace Melissa." [Melissa met Karen before I did,] and [with Gabe] they did a lot of things [together] because Gabe's feeling was Karen needed to get to know Melissa. Melissa loves everybody... but Gabe gauged whether there was a comfort level.

As Sara has reached late middle age, she described taking care of Melissa's needs that may arise as she ages and Sara is no longer there to care for her. She described feeling sad but accepting of the fact that Melissa will not get married or have children. She also described making end-of-life and funeral plans to relieve Gabe of having to be financially responsible for his sister.

The importance of communities such as religious organizations in these life transitions is evident in holiday celebrations and traditions that bring people together and continue from one generation to the other. Even when children leave home, they often return home to celebrate holidays and other traditions. They also choose which traditions to continue in their own independent lives away from home.

Sara related that during Yom Kippur services, Melissa received a public honor for adults, that is, being called to the stage to participate in the service. She said,

There's Melissa up there on Yom Kippur, and you could hear people that knew her say, "Wow, there's Melissa." I was crying. ... we try to [make life as] normal for her as possible, knowing full well that she's a little bit outside of the box. And that's okay.

As children leave their parents' home, the parents often face myriad feelings. They may be excited to establish a new kind of relationship with their adult children, find new ways to occupy their free time, and reconnect with each other. However, they may feel a loss of purpose, or worry, stress, and anxiety over their young adult children's well-being.

Stage 7: Families nearing the end of life.

During this stage, people often find opportunities to share acquired wisdom and skills. However, relationships may be affected by transitional stressors such as physical and cognitive decline. Of particular stress during this stage is navigating the fragile line from an independent life to dependency in late life. Many issues arise related to maintaining one's integrity, independence, and safety.

Creating a life that allows a person to accept needed help without losing autonomy becomes some of the emotional work of this life stage. (For more information on this state, see Chapter 7, "Transition and Aging"). Sara grapples with multiple roles as a spouse, parent, and grandparent. She discussed the emotional process of making decisions that sustain her roles, including continuing to care for Melissa, and maintaining independence for the next stage of life. In this stage, Sara looks back and recognizes both loss and success. She summarized her life cycle development as a constant journey, involving many transitions and adjustments:

You have to allow yourself to cry. Sometimes you cry for the good things. I cry for the loss of my parents at not seeing [Melissa] today. There are losses, you know. Would I like to be a grandmother to her children? You bet. I'd be lying if I said differently, but I know that's not reality. [But] while you're crying, you need to also look at what we've gained from her... and she's just happy. So, yeah, you need to cry.... You have to accept that's a part of it.

Many of Sara's responses reflect her resilience throughout life transitions. Resilience, which is discussed later, is a major ingredient required for emotional well-being and mental health.

Life Course Perspective Theory

In the *life course perspective theory*, interdependence is the norm for daily life, occurring in the context of relationships (Elder, 1998). *Interdependence* is the relationship between two or more people in which all members of the group are mutually dependent on the others. The life course perspective theory views major life events (e.g., changes in family structure) as key times of change that are strongly influenced by the context in which those events occur (Ravanera, Rajulton, & Burch, 2004).

Close social relationships may influence how stressful a person finds a life event to be. Recently, life course theory has been used to explore the health and social needs of children with special health care needs across the lifespan (Bethell et al., 2014). Bethell and colleagues argued that health and well-being in early ages predict health and well-being later in life.

In addition, to improve children's health and promote well-being throughout the lifespan, optimal services must include family and community involvement. This theory emphasizes the importance of considering a longitudinal, functional perspective when planning and providing services for people with chronic or long-term disabilities. It is also in line with the client- or family-centered perspective embraced by occupational therapy practitioners.

Family Quality-of-Life Perspective

Transitions affect the person making the transition and his or her family, so it is useful to examine the construct **FQoL**. FQoL theories define **quality of life (QoL)** as a sense of well-being that is felt by the family, both collectively and subjectively by its members (Zuna, Summers, Turnbull, Hu, & Xu, 2011). *FQoL* includes conditions in which the family's "needs are met, and family members enjoy their life together and have the chance to do things that are important to them" (Park et al., 2003, p. 368).

Turnbull and Turnbull (2000) theorized that FQoL changes as each member and the family unit experiences life. When one family member experiences a transition, the family unit also experiences the transition; therefore, during transitions, the individual member must recalibrate to a state of equilibrium and so must the family unit. The family serves as the foundational unit that engages with key external systems and settings that support the person with a disability to successfully participate in meaningful life roles.

FQoL is dynamic and fluid, changing over time; it influences and is influenced by transitions. It includes individual and family domains. Domains with an individual orientation involve how the QoL of individual family members influences the QoL of other family members and the family as a whole. Each family member has his or her own unique QoL across the individual domains. Family-oriented domains occur at the family level and provide a context in which members live their lives collectively (Poston et al., 2003).

Hoffman, Marquis, Poston, Summers, and Turnbull (2006) conceptualized FQoL with a scale, the Beach Center Family Quality of Life Scale, which examines individual and family domains and extra-familial support. It is a useful tool for practitioners who work with families, particularly those with a child with a disability, because QoL is an outcome of occupational therapy (AOTA, 2014). When FQoL is satisfactory, each family member is more likely to be emotionally healthier and to participate in activities at home and at work (Zuna et al., 2011).

Individual needs

Individual needs include emotional well-being and physical and material well-being. Emotional well-being includes identity, respect, choice, stress management, and social support. Physical and material well-being includes physical and mental health; access to health care and the home, school, work, and community environments; and financial security (Poston et al., 2003).

Family-level needs

Family-level needs include parenting and family interaction. Parenting includes teaching, guiding, supervising, and disciplining. Family interaction includes relationships, communication, support of each other, and the interaction environment (Poston et al., 2003).

Extrafamilial supports

Extrafamilial supports are services originating outside of the family. It is generally recognized that when a family has a member with a disability, **disability-related supports** are essential contributors to the QoL of the family. These supports include both services specifically designed for people with disabilities and informal supports from family and friends. They are important because for people with disabilities and their families, the environment needs to be reinforced with various opportunities and resources to attain QoL (Brown & Brown, 2005). These supports are not only for people with disabilities. Families need to be the beneficiaries of services because they are affected by their family member's disability. In addition, family support appears to be critical for the most effective outcomes for the family member with a disability (Zuna et al., 2011).

Disability-related supports may include respite care, which relieves parents of their caregiving duties; a home aide who provides direct services to enhance the skills of the family member with a disability; and transportation to take the family member with a disability to a specific program or activity. Occupational therapy practitioners are important in determining the types of disability-related supports that are most critical for successful occupational performance. In turn, occupational performance is essential to enhancing QoL and well-being.

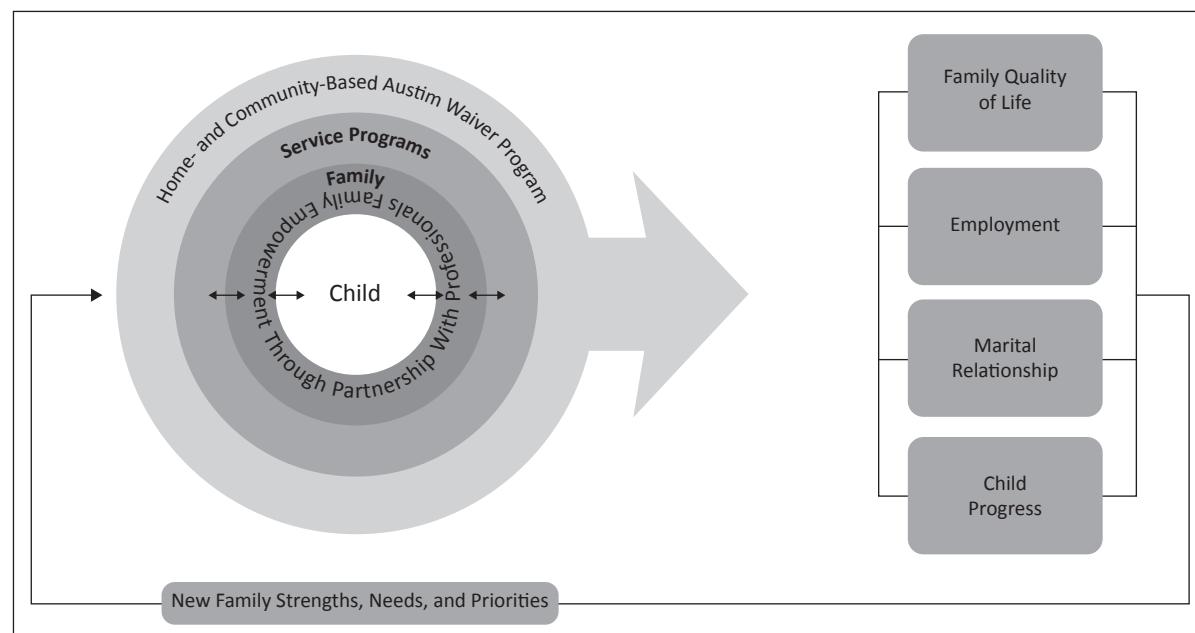
Receiving disability-related supports contributes to the family's ability to make day-to-day living easier and enables people with disabilities and their family members to participate in activities within their communities. The benefit of such supports is evident in Renzo's story (see "Prologue"). The family received donations of time, food, labor, and other critical resources that contributed to their QoL by allowing them much needed rest and time away from Renzo and reducing financial burden. The caretakers who assist Renzo every day to get to his classes and job not only enable him to live his desired life but also enhance the lives of his family. Renzo and his family, who are all productive members of their community, demonstrate that these supports give them the ability to cope with the stressors of daily life and achieve positive mental health.

The contribution of disability-related supports to family QoL is also illustrated in Sara's story. Because Melissa has assistance to live away from her parents and to maintain a job in child care, the entire family can focus on their own individual meaningful occupations. For example, Sara is able to continue to engage in her own work and community activities. As a result of these supports, Sara and her family demonstrate positive mental health.

Failure to receive disability-related supports can negatively affect both the person with the disability and family members (Dunst & Trivette, 2009) as reflected in self-ratings of FQoL (Brown, Anand, Fung, Isaacs, & Baum, 2003; Eskow et al., 2011; Graetz, 2010; Renty & Royers, 2006). For example, in a survey study examining a Medicaid waiver program for children and youth on the autism spectrum, families receiving waiver services reported enhanced emotional well-being and overall QoL compared with families on the waiver registry, or waiting list, for services (Eskow et al., 2011). Figure 9.2 shows FQoL as both part of a system and is both an outcome variable and a factor influencing the family system. It demonstrates the relationship between the life cycle system perspective and FQoL models.

The needs of people with disabilities and their families usually increase at times of transition; therefore, disability-related supports may also need to increase.

Figure 9.2. Life cycle system perspective and family quality of life.



Source. K. Eskow. Used with permission.

However, when young adults with disabilities age out of the school system, for example, they transition from school-based comprehensive services to adult services, which may offer fewer supports (Hendricks & Wehman, 2009). Therefore, to achieve the best outcomes during transition from secondary education, broad community participation must be part of the transition planning process.

In addition, although community participation includes productive engagement in activities, Hendricks and Wehman stressed that community participation must also include the desired goals of integrating youth with disabilities into social networks and fostering relationship development (see Chapter 5, "Transition From School to Adult Life"). As discussed later in this chapter, having a social network enhances overall emotional well-being.

Rite-of-Passage Theory

In *rite-of-passage theory*, first described by Turner (1972), community rituals enable people to transition from one role to another. The theory has been used to describe the experiences of people with unexpected changes in social status as a result of illness or disability (Murphy, Scheer, Murphy, & Mack, 1988; Willett & Deegan, 2001). According to the theory, a person experiences a change in social status through the following three-phase series of transitions, or rites of passage:

1. **Separation.** This phase involves the person separating from prior social roles.
2. **Waiting.** This *liminal* phase is when the person is between roles.
3. **Incorporation.** This phase involves the resolution of the liminal status, in which a new role is incorporated into the person's identity.

Separation

The first phase of rite-of-passage theory involves a separation from current social roles and status as a result of the onset of a chronic illness or disability, such as that of a student. Unlike with chronic illness or disability, a person with an acute illness is afforded time to get well by society and receives community support such as providing meals and employment sick leave. The person's social roles and status are not adversely affected, and he or she relatively quickly resumes prior roles without experiencing *role confusion* (i.e., being

unsure of one's role or place in society) or isolation. For people with chronic conditions, separation isolates the person or family from important supports and participation in valued life roles and they often experience role confusion.

Waiting

After separation, the person with a chronic illness or disability or the family loses prior social roles and status and enters the second phase, the waiting phase. This phase typically involves struggles with and confusion about identity because the person no longer fits into prescribed roles or expectations of himself or herself or by others. This phase is characterized by the person waiting for a change or transformation from unclear or confusing roles and status to clarity in identity.

In acute cases, the waiting phase is usually relatively short. However, in the case of a chronic condition, this phase tends to be longer and more complicated. The confusion can extend to family and friends and may lead to marginalization or loss of needed supports. For example, during a long recovery, because a particular "sick role" is not afforded through hospitalization, supports from the broader community may drop off and sick leave may end. The person or family is often left to fend for themselves in navigating changes to their personal identity, family experience, and social roles and status.

Incorporation

The third phase is incorporation, where the person or family resolves the liminal status and resumes daily life, transformed by the experience. Entering this phase requires the person or family to apply resilience to the situation, because they use various means of coping and adaptation to integrate the experience into daily life. For example, Cohn's (2001) study of experiences of parents in an occupational therapy clinic detailed the positive community feeling that emerged from the weekly ritual of being together in the waiting room. In this example, parents were able to use this setting as an opportunity for support and social interaction.

Resilience Theory

The concept of *resilience* has been of interest to researchers studying what protects people from negative

outcomes during stressful times (Garmezy, 1993; Lin, Sandler, Ayers, Wolchik, & Luecken, 2004). For example, people react differently to the same or similar stressors. Among the findings are that most people adapt to stressful situations, despite the degree of challenge. Resilience studies can inform occupational therapy practice by enabling clients to emerge from liminal status and incorporate their illness experience into the daily fabric of their lives in a personally meaningful way.

Resilience involves use of **protective factors**, or strengths, by people during times of vulnerability, such as during transition (Garmezy, 1993). Hjemdal, Friberg, Stiles, Martinussen, and Rosenvinge (2006) described *resilience* as “the protective factors, processes, and mechanisms that, despite experiences with stressors shown to carry significant risk for developing psychopathology, contribute to a good outcome” (p. 84).

Protective factors may be internal (i.e., characteristics of the person) or external (i.e., characteristics of the environment) and contribute to a person's ability to deal with adverse situations. According to Masten and Reed (2002), protective factors exist in the person, family, and community. Protective factors also exist in school (Murray, 2003). It is recognized that resilience interventions are most effective when started early in multiple contexts (Richaud, 2013).

Personal protective factors

Among the **personal protective factors** that contribute to resilience's protective factors are cognitive abilities and problem-solving skills, easy temperament in infancy and adaptability in childhood, positive self-concept, self-efficacy, a sense of meaning or purpose to life, optimism, self-regulation abilities, sense of humor, and talents that are recognized by others (Reivich & Gillham, 2010). These personal protective factors develop in childhood and continue through adulthood.

Self-determination. Development of **self-determination**, or a person's ability to set goals, act on the basis of these goals, evaluate performance, and adjust goals, is a protective factor that fosters resilience and is related to self-efficacy and self-esteem (Wehmeyer & Abery, 2013; Wehmeyer & Schwartz, 1997).

Individual choice. **Individual choice**, or one's decisions about what to do and what not to do, is a fundamental principle of QoL and strongly

influences self-determination and resilience (Brown & Brown, 2005). Choice is related to the developmental skills of the person and should be viewed within the contexts of needs, goals, activities, place, and personnel working with those with disabilities. In Sara and Melissa's story, having choices and exerting self-determination by setting their goals and having a say in how they lived their lives affected their individual and family QoL.

Evidence indicates that for people with developmental disabilities with and without autism, an important relationship exists among personal control, social participation, and relationships (Mehling & Tasse, 2015). Increasing choice making in areas that exert control over a person's life may improve social outcomes and should be included in occupational therapy interventions.

Social skills and social-cognitive problem solving. Students who can sustain social relationships with others are more resilient and more likely to have positive postschool outcomes than those without social competence (Kohler, 1993; Leake, 2012). For example, in Renzo's story, Cheryl described how Renzo's relationship with his friends has been important in his recovery. In school-aged youth, strong cognitive and academic skills have also been associated with long-term adjustment (Benz, Yovanoff, & Doren, 1997; McDonnell & Crudden, 2009).

Family protective factors

Family protective factors include strong relationships among family members; low levels of discord between parents; and a parenting style that is warm, structured, and sets appropriate expectations. In addition, socioeconomic resources, parents' involvement in their children's education, and parents having personal factors of self-regulation and optimism are protective factors.

Effective parents can promote a variety of academic, social, behavioral, and emotional skills and competencies in children and youth (Masten, Best, & Garmezy, 1990; Khanlou & Wray, 2014). Parenting style can be positively influenced by training, such as that provided by occupational therapy practitioners. Training might include strategies for play, supporting the development of children's independent living skills, and understanding behavior through a sensory integration perspective.

In Renzo's story, Cheryl described their resilience through the use of the family protective factors of parental optimism, involvement in their child's daily life, and warm and supportive parental style. She described how Renzo's dad reacted to Renzo's new disability by emphasizing that their job as parents is to help Renzo achieve his potential. Renzo's potential may have changed, but their job as parents remained the same—offering support and promoting his optimal potential.

Community factors

Community factors that promote participation and inclusion can instill resilience. Wagner (1995) demonstrated that youth diagnosed with serious emotional disturbance who participated in extracurricular activities such as sports teams, church groups, or other community activities showed better school adjustment than those who did not participate. Similarly, Hass and Graydon (2009) found that successful youth in foster care who were most resilient were engaged in community service activities.

An analysis of policy recommendations relative to strengthening resilience emphasized a supportive school environment, family interventions, and community socioeconomic development, among others (Ager, 2013). However, resilience may be diminished because of a lack of these community factors, placing many people with disabilities in an unending liminal state in which they are isolated and marginalized (Willett & Deegan, 2001).

Liminal status can restrict community participation when it fails to end with incorporation of the person or family into valued roles or meaningful activities. This failure relegates the person to permanent outsider status. For example, incorporation failure may occur to transition-aged youth with disabilities when, upon leaving school, they lose access to valued supports and experience underemployment or unemployment, limited postsecondary education participation, lower rates of independent living status, and lower social status than their typical peers (Hennessey, Roessler, Cook, Unger, & Rumrill, 2006).

Incorporation failure may also occur after acquired disability through illness or accident. Immediately after acquired disability, a person's entire social network may rally to support him or her. However, once the permanence and irreversibility of the condition becomes clear, the person may no longer be classified as sick, but he or she cannot

be called well either. His or her state of being is indeterminate. Those around the person may deal with this "indefinite" role status by social distance or avoidance (Murphy et al., 1988).

Physical isolation and noncommunication are seen all too frequently in people with disabilities. The separation of people with disabilities from mainstream society is often the result of deliberate exclusion by others, not lack of accessibility. Despite the passage of the Americans With Disabilities Act of 1990 (ADA; Pub. L. 101–336) and the subsequent ADA Amendments Act of 2008 (Pub. L. 110–325), many Americans with disabilities still function in the margins of society. They are less likely to be employed and have lower levels of social interaction than the typical population. However, although society may limit opportunities for people with a wide range of impairments (Willett & Deegan, 2001), occupational therapy practitioners work to enhance community participation of people with disabilities and therefore increase their resilience.

Role of occupational therapy in promoting resilience

The occupational therapy literature provides several examples in which key occupational therapy interventions aimed at establishing routines and participating in daily activities within one's community enabled people to develop resilience through needed supports, advocacy skills, and engagement and work toward resolution of liminal status.

Schultz-Krohn (2004) found that developing meaningful routines despite the challenge of illness or disability facilitated resumption of social roles. Koome, Hocking, and Sutton (2012) documented that families found new meaning in routines that were changed because of the mental illness of an adolescent in the family. Specifically, routines helped establish a sense of well-being and gave the family stability and continuity in family life during times of stress.

Cohn (2001), as described previously, observed families in an occupational therapy clinic waiting room. She found that parents developed important coping and adaptive routines while waiting for their children receiving therapy. They shared strategies for raising their children with disabilities with each other, offered emotional support, and looked forward to their weekly unofficial support meetings in the waiting room. The shared experience with and

exposure to other parents of children in therapy promoted ***communitas***, or shared social support. Keough, Pierce, and Thomas (2005) argued that incorporating the patient's future daily rituals into his or her home and community during discharge planning aided in increasing confidence and reducing anxiety for people transitioning to a community setting after hospitalization, contributing to resilience. For youth in school, practitioners can promote resilience by

- Developing and practicing work and activities of daily living skills through repetition and rehearsal in school;
- Providing important learning experiences (e.g., learning how to interact with people on the street or in the workplace);
- Developing relationships with students that foster individual protective factors of self-esteem through participation in valued activities;
- Providing opportunities for children and youth with disabilities to make choices (e.g., choice of activity, steps within an activity, scheduling sessions) and develop self-determination (Murray, 2003);
- Actively teaching and modeling appropriate behavior and social skills;
- Fostering school and home involvement;
- Engaging children and youth in activities that increase physical health, improve social skills with peers and adults, and support opportunities to help others (Bell, 2001); and
- Addressing social and interpersonal assertiveness skills in brief focused group intervention to enable participation in normative experiences such as Scouts or community summer day camp.

When any person loses his or her ability to participate in valued occupations through injury or disability, his or her purpose and meaning are compromised. Occupational therapy's unique contribution to mental health can support resilience and adaptation and promote engagement in meaningful occupations (AOTA, 2007).

Occupational Therapy's Role in Enhancing Mental Health During Transition Evaluation

Recommended methods of occupational therapy evaluation of emotional health and well-being during transitions include surveys and interviews, observation,

and formal instruments. Survey and interview questions might ask the clients or family members whether they have questions about the condition and how they are coping with the changes it brings. Observation of the client or family may include the following guiding questions:

- Do the person and family members attend education or teaching sessions?
- Do they engage with the person, equipment, or procedure?
- Do they ask questions?
- Do they seem familiar with the family member's routines, preferences, and social supports?

Some instances require a formal instrument to provide important information about individual factors relative to emotion and coping with transitions. These instruments might include assessments for differential diagnosis, such as depression or anxiety; for a particular problem or need such as self-regulation or risk behavior; or for data collection as part of a research study. Some common instruments are provided in Table 9.1.

Regardless of which method is used, it is important for occupational therapy practitioners to respect the client's individual and cultural differences in experience, coping, and self-disclosure when addressing emotional response to transition.

Occupational Therapy's Role in Enhancing Mental Health During Transition Intervention

Intervention should support the emotional aspects of transitions by resolving liminal status, improving resilience, and supporting FQoL. Occupational therapy practitioners use a variety of emotional and mental health intervention strategies to support successful transitions. For instance, for a youth transitioning from school to adulthood, the practitioner may modify environments and tasks to enhance successful work performance or help the client establish productive routines and habits that support successful job performance and that enhance mental health (AOTA, 2012).

Similarly, practitioners may support a child's transition from one grade or school to another by providing positive behavior supports and facilitating social skills important for successful school

Table 9.1. Tools to Evaluate Emotional and Mental Health Needs During Transition

Evaluation Tool	Purpose
Adolescent Coping Orientation for Problem Experiences (Patterson & McCubbin, 1996)	Self-rating coping scale for adolescents to identify behaviors they find helpful in managing problems or difficult situations
Assessment Scale for Positive Character Traits for Developmental Disabilities (Woodard, 2009)	Measures presence and strength of selected strengths-based traits in people with developmental disabilities considered to be associated with level of happiness, quality of life, or both
Child Health Questionnaire (Landgraf, Abetz, & Ware, 1996)	Measures functional health status and health outcomes of children (ages 0–18 yr) in 12 domains of health, such as Behavior, Bodily Pain, General Health, and Mental Health
Children's Coping Strategies Checklist (Sandler, Tein, & West, 1994)	Self-report survey to describe coping efforts (ages 9–13 yr); two versions: one for coping with a specific situation and one for the usual style of coping when facing a problem; assesses coping across three domains: Active Coping, Support Seeking, and Distraction
Coping Responses Inventory (CRI; Moos, 1993a) and CRI-Youth Form (Moos, 1993b)	Self-report checklist or interview for adults (ages ≥ 18 yr, CRI) and adolescents (ages 12–18 yr, CRI-Youth Form); can be administered to individuals or groups; both forms identify individual approaches to coping and the person's methods of coping and describe the person's coping responses to specific stressful life circumstances
General Self-Efficacy Scale (Jerusalem & Schwarzer, 1992)	Self-rating scale for adults and adolescents (age ≥ 12 yr); assesses a person's perceived personal competence to deal effectively with a variety of stressful situations and predicts ability to cope with daily hassles and adaptation after stressful life events
Infant-Toddler Social Emotional Assessment (ITSEA) and Brief Infant-Toddler Social-Emotional Assessment (BITSEA; Carter & Briggs-Gowan, 2005)	ITSEA: Screen for social-emotional problems BITSEA: In-depth analysis of emerging social-emotional development and intervention guidance; 17 subscales in 4 domains; parent form and child care provider form
Life Satisfaction Index-Z (Neugarten, Havinghurst, & Tobin, 1961)	Self-report questionnaire for older adults (ages > 65 yr); is administered orally and in writing; assesses life satisfaction and well-being
Occupational Self-Assessment (OSA; version 2.2; Baron, Kielhofner, Iyengar, Goldhammer, & Wolenski, 2006) and Child Occupational Self-Assessment (COSA; Kramer et al., 2014)	Self-report questionnaire for people (ages > 12 yr, OSA) or children (ages 8–13 yr, COSA); administered individually or in a small group; assessment and outcome measures based on the Model of Human Occupation to collect data on a person's self-perception of occupational competence, the importance of occupational functioning, and environmental adaptation
Perceived Efficacy and Goal Setting System (Missuna, Pollock, & Law, 2004)	Self-report questionnaire for children (ages 5–10 yr) with a variety of diagnoses; includes pictures and additional questionnaire for parents and teachers; assesses child's perceived abilities in 24 daily activities in the home, school, and community and in collaborating in setting goals for intervention

(Continued)

Table 9.1. Tools to Evaluate Emotional and Mental Health Needs During Transition (Cont.)

Evaluation Tool	Purpose
Resilience Scale (RS; Wagnild & Young, 1993)	Self-report survey that assesses resilience (ages ≥ 13 yr); two versions: RS (25 items) or Short RS (14 items)
Resiliency Scales for Adolescents: A Profile of Personal Strengths (Prince-Embury, 2006)	Self-report checklist or interview for adolescents (ages 15–18 yr); measures areas of perceived strength or vulnerability in managing adverse experiences by quantifying core personal qualities of resiliency
Youth Quality of Life Instrument—Research Version (Topolski et al., 2001)	Self-administered questionnaire assessing quality of life in youth (ages 11–18 yr) with and without disabilities; easy to administer
Youth Self-Report (Achenbach & Edelbrock, 1991)	Screening tool for emotional challenges (ages 11–18 yr) that includes a self-report survey with 20 problem items paralleling the Child Behavior Checklist (Achenbach & Edelbrock, 1991).
Ways of Coping Questionnaire (Folkman & Lazarus, 1988)	Interview or self-report checklist to assess coping processes people use to deal with specific stressful encounters and analyze practical coping skills

performance. In addition, practitioners may also use a strengths-based approach to enhance a child's occupational performance, for instance, by providing interventions that offer the just-right challenge to promote successful performance in activities in which the child is interested and to increase self-confidence (AOTA, 2012).

For transitions throughout the lifespan, practitioners may provide environmental modifications that enable an older adult to remain safely in his or her home and continue to engage in desired occupations. By doing so, the practitioner not only helps this client maintain physical skills and abilities but also positive mental health.

The remainder of this section describes specific intervention strategies that are directed toward increasing individuals' and families' resiliency and emotional well-being. Interventions include shared experiences, skills-based training, health realization, advocacy, family–professional relationships, and mental health professional framework.

Shared Experiences

According to Murphy (1987), people in a liminal state find strength in their shared experiences. Occupational therapy interventions that would

support the resolution of liminal status may include providing group interventions, family and sibling interventions, information through newsletters or other vehicles, online peer support links, and organizing equipment swap events and speaker series chosen by clients or families. It is also crucial to respect individual family preferences and socio-cultural norms. Therefore, the practitioner may provide written resources (including in languages other than English); online resources; in-person professional and peer support; and informal opportunities for natural group interactions, such as an annual reunion of clients treated at the center or graduation and transition celebrations.

Skill-Based Training

One of the underlying constructs of resilience theories is that protective factors can be enhanced through skill-based training. Among the protective factors amenable to training are self-efficacy, self-regulation, optimism, and self-determination. Occupational therapy skill-based training programs to enhance resiliency should focus on developing social and problem-solving skills to enable participation in typical youth social group experiences, such as recreational team sports, Boy or Girl Scouts, or youth activities in a faith community.

An example of such a program is the Penn Resiliency Program, a school-based prevention program that focuses on teaching youth at risk key resilience skills through cognitive and social problem solving (Reivich & Gillham, 2010). A meta-analysis of controlled studies of this program revealed that participating youth had fewer symptoms of depression than those in control groups (Brunwasser, Gillham, & Kim, 2009) and had less anxiety and conduct problems (Gillham et al., 2006).

Family involvement is also essential to the development of a child's protective factors. Interactions between parents and their children may provide opportunities and reinforcement for the development of these skills. For example, practitioners can teach parents concrete advocacy skills and strategies. When parents engage in advocacy efforts on behalf of their children, the advocacy skills that they model can help their children with disabilities acquire these skills. Additional research shows that resiliency is associated with positive parent-child relationships, parental monitoring, and parental structure, all of which can be taught and demonstrated by occupational therapists (Dutra et al., 2000; Pedro-Carroll, 2001).

Health Realization

Resilient adults have an innate ability to manage stresses of daily life, including extreme challenges such as loss and trauma (Bonanno, 2004). This belief is reflected in a prevention model known as *health realization*, which has been taught to many at-risk populations as a means of empowerment (Kelley, 2005).

Health realization is a community-delivered, mental health intervention that focuses on resilience rather than psychopathology. This intervention uses a strengths-based approach for gaining perspective in the present (Halcón, Robertson, & Monsen, 2010).

Among strategies used is reframing a situation to enable acceptance. Reframing could happen through interactions with others or by analyzing and interpreting social situations. For example, Sara offered an example of reframing a situation with Melissa. Melissa had to wear a helmet for protection while she explored the community. Sara's neighbor viewed the helmet as identifying Melissa as disabled and different; however, through the interaction with the neighbor, Sara was able to see the

helmet as a positive enabler that allowed Melissa to participate more fully. Sara said,

[What] flipped my thinking about where you begin to really look at ability versus disability was the day [Melissa] came home wearing a helmet. We were all waiting for the school buses, and my neighbor became very upset when she saw Melissa get off the bus with the helmet. And I said, "No, no, no, no—it's because she needs the helmet." [Melissa also] walked up and down the street with everybody else with her helmet. And we have pictures of her—trying to keep things as normal as possible—at Halloween, [when she wore a] costume with her helmet so she could go. [The helmet] became an enabler rather than a sign that [she] was disabled. The helmet was ... in my mind ... her first enabler that Melissa was able to deal with.

Advocacy

Advocacy on behalf of a family member with a disability is another important skill that reflects positive problem solving and resilience. Parents in particular find themselves having to advocate on behalf of their son or daughter with a disability, often to secure needed services or opportunities. According to Wang, Mannan, Poston, Turnbull, and Summers (2004), some parents find advocating for a child with a disability to be a source of stress; others consider it a positive coping strategy.

Practitioners should develop collaborative partnerships with families to assist in developing advocacy skills (AOTA, 2014). They can assist families by teaching concrete advocacy skills and by offering resources and information on community agencies that can provide services and support for advocacy.

Some advocacy is more simple; it means teaching the person with disabilities to make simple choices and ask for what they prefer. In Sara and Melissa's story, this kind of advocacy is a central part of their family dynamic. Although Melissa is now an adult, she often asks her mother for advice on how to deal with certain situations. Sara said,

Your advocacy as a parent doesn't end; it's ongoing...even in her mid-twenties...[as an] adult, she is her own guardian; we've never taken over

Table 9.2. Three Tiers of Occupational Therapy Interventions

Tier	Individual or Small Group	Family	System
Tier 1: Universal	Promote mental health literacy through newsletters, school paper column, after-school club, assemblies, and in-services	Provide school in-service programs for families Develop a resource booklet for families	In the school, identify a range of inclusive resources, promote structured leisure, and advocate for mental health services
Tier 2: Targeted at risk	Provide skill-based training in self-regulation and self-efficacy	Consult on mental health and its effects on learning and on effective environments by providing education for families, assisting families in developing advocacy skills, and encouraging positive parent-professional collaborations	In the school, identify a range of inclusive resources, promote structured leisure, and advocate for mental health services
Tier 3: Intensive	Provide positive behavioral support to improve social skills Develop environmental modifications at school, home, and work Teach advocacy skills Provide activities for the just-right challenge for children and youth for structured leisure and positive routine development		

Note. Material adapted from "Occupational Therapy Process: A Public Health Approach to Promoting Mental Health in Children and Youth" by S. Bazyk, 2011a, in S. Bazyk (Ed.), *Mental Health Promotion, Prevention, and Intervention With Children and Youth*. Bethesda, MD: AOTA Press, p. 21–44. Copyright © 2011 by the American Occupational Therapy Association. Used with permission.

her guardianship. She makes her own decisions, but she will say, "I have to ask my mommy."

Family–Professional Partnerships

Positive family–professional partnerships can enhance FQoL and help to produce effective outcomes (Blue-Banning, Summers, Frankland, Nelson, & Beegle, 2004). Blue-Banning et al. provide examples for positive partnership that is supportive to families, including communicating in a manner that is positive, understandable, and respectful; showing commitment to help the families achieve their goals; involving families in decision making; demonstrating competence; being dependable and truthful; and showing respect to one another.

Mental Health Promotion Framework

Bazyk (2011b) articulated an occupational therapy mental health promotion framework based on a public health model, Response to Intervention, and tenets of occupation-based practice. In this model, three tiers of intervention were identified, with a role for occupational therapy at each. Tier 1 addresses universal, or population, needs relative to health promotion, such as educating the school community about mental health and its effect on academic and social success.

Tier 2 addresses the needs of targeted, at-risk groups. For example, for people preparing for transition, interventions may include small-group sessions focused on their skill development in time management, self-regulation, and self-efficacy. Family interventions may include small-group sessions on the value of structured leisure for social competence, aspects of the environment that support social participation, and time management for healthy living. System-level interventions may include developing a booklet of inclusive community resources and advocating in policy-making forums for increased inclusive social opportunities.

Tier 3 interventions are those reflective of intensive traditional occupational therapy interventions for youth diagnosed with mental health conditions. Table 9.2 includes examples of interventions in the three tiers of intervention. All three levels include interventions for individuals, small groups, families, and systems.

Summary

Addressing emotional aspects of transition across the lifespan and across systems is important for successful transitions. Several key system and life developmental perspectives on transition inform occupational therapy practice, including the life cycle system

perspective (Carter & McGoldrick, 2005), FQoL (Zuna et al., 2011), rite-of-passage theory (Turner, 1972), and resilience (Garmezy, 1993) theories. In addition, evidence-based occupational therapy interventions enhance and support people's capacities to cope with transition.

To support emotional aspects of transition, occupational therapy practitioners intervene on the individual, family, or system levels of intervention (Jackson & Arbesman, 2005). A broad-based community approach emphasizing early intervention, multiple contexts, and population health is supported in the literature (Khanlou & Wray, 2014).

References

- Achenbach, T. M., & Edelbrock, C. (1991). *The Child Behavior Checklist and Revised Child Behavior Profile*. Burlington, VT: University Associates in Psychiatry.
- ADA Amendments Act of 2008, Pub. L. 110–325, 122 Stat. 3553.
- Ager, A. (2013). Annual research review: Resilience and child well-being—Public policy implications. *Journal of Child Psychology and Psychiatry*, 55, 488–500.
- American Occupational Therapy Association. (2007). AOTA's statement on stress and stress disorders. *American Journal of Occupational Therapy*, 61, 711. <http://dx.doi.org/10.5014/ajot.61.6.711>
- American Occupational Therapy Association. (2012). *Promoting strengths in children and youth*. Retrieved from <http://www.aota.org/-/media/Corporate/Files/Practice/Children/SchoolMH Toolkit/Promoting%20Strengths%20REVISED.pdf>
- American Occupational Therapy Association. (2014). Occupational therapy practice framework: Domain and process (3rd ed.). *American Journal of Occupational Therapy*, 68(Suppl. 1), S1–S48. <http://dx.doi.org/10.5014/ajot.2014.6820066>
- Americans With Disabilities Act of 1990, Pub. L. 101–336, 42 U.S.C. §§ 12101–12213.
- Baron, K., Kielhofner, G., Iyenger, A., Goldhammer, V., & Wolenski, J. (2006). *Occupational Self-Assessment (OSA)*, version 2.2. Retrieved from <http://www.cade.uic.edu/moho/productDetails.aspx?aid=2>
- Bazylk, S. (2011a). Occupational therapy process: A public health approach to promoting mental health in children and youth. In S. Bazylk (Ed.), *Mental health promotion, prevention, and intervention with children and youth: A guiding framework for occupational therapy* (pp. 21–44). Bethesda, MD: AOTA Press.
- Bazylk, S. (2011b). Promotion of positive mental health in children and youth: A guiding framework for occupational therapy. In S. Bazylk (Ed.), *Mental health promotion, prevention, and intervention with children and youth: A guiding framework for occupational therapy* (pp. 3–20). Bethesda, MD: AOTA Press.
- Bell, C. C. (2001). Cultivating resiliency in youth. *Journal of Adolescent Health*, 29, 375–381.
- Benz, M. R., Yovanoff, P., & Doren, B. (1997). School-to-work components that predict post school success for students with and without disabilities. *Exceptional Children*, 63, 151–165.
- Bethell, C., Newacheck, P., Fine, A., Strickland, B., Antonelli, R., Wilhelm, C.,...Wells, N. (2014). Optimizing health and health care systems for children with special health care needs using the life course perspective. *Maternal and Child Health Journal*, 18, 467–477.
- Blue-Banning, M., Summers, J. A., Frankland, H. C., Nelson, L. L., & Beegle, G. (2004). Dimensions of family and professional partnerships: Constructive guidelines for collaboration. *Exceptional Children*, 70, 167–184.
- Bonanno, G. A. (2004). Loss, trauma, and human resilience: Have we underestimated the human capacity to thrive after extremely aversive events? *American Psychologist*, 59, 20–28.
- Bronfenbrenner, U. (1979). *The ecology of human development: Experiments by nature and design*. Cambridge, MA: Harvard University Press.
- Brown, I., Anand, S., Fung, W. L. A., Isaacs, B., & Baum, N. (2003). Family quality of life: Canadian results from an international study. *Journal of Developmental and Physical Disabilities*, 15, 207–230.
- Brown, R. I., & Brown, I. (2005). The application of quality of life. *Journal of Intellectual Disability Research*, 49, 718–727.
- Brunwasser, S., Gillham, J., & Kim, E. (2009). A meta-analytic review of the Penn Resiliency Program's effect on depressive symptoms. *Journal of Consulting and Clinical Psychology*, 77, 1042–1054.
- Carter, A. S., & Briggs-Gowan, M. (2005). *ITSEA BITSEA: The Infant-Toddler and Brief Infant-Toddler Social-Emotional Assessment*. San Antonio, TX: PsychCorp.
- Carter, B., & McGoldrick, M. (2005). *The expanded family life cycle: Individual, family, and social perspectives* (3rd ed.). Boston: Allyn & Bacon.
- Cohn, E. S. (2001). From waiting to relating: Parents' experiences in the waiting room of an occupational therapy clinic. *American Journal of Occupational Therapy*, 55, 167–174. <http://dx.doi.org/10.5014/ajot.55.2.167>
- Dunst, C., & Trivette, C. (2009). Capacity-building family systems intervention practices. *Journal of Family Social Work*, 12, 119–143.
- Dutra, R., Forehand, R., Armistead, L., Brody, G., Morse, E., Morse, P. S., & Clark, L. (2000). Child resiliency in inner-city families affected by HIV: The role of family variables. *Behavior Research and Therapy*, 38, 471–478.
- Elder, G. (1998). The life course as developmental theory. *Child Development*, 69, 1–12.

- Eskow, K. G., Pineles, L., & Summers, J. A. (2011). Exploring the effect of autism waiver services on family outcomes. *Journal of Policy and Practice in Intellectual Disabilities*, 8, 28–35.
- Folkman, S., & Lazarus, R. S. (1988). *Manual for the Ways of Coping Questionnaire*. Palo Alto, CA: Consulting Psychologists Press.
- Garmezy, N. (1993). Vulnerability and resilience. In D. C. Funder, R. D. Parke, C. A. Tomlinson-Keasey, & K. Widaman (Eds.), *Studying lives through time: Personality and development* (pp. 377–398). Washington, DC: American Psychological Association.
- Ghimbult, O., & Opre, A. (2013). Assessing resilience using mixed methods: Youth resilience measure. *Procedia: Social and Behavioral Sciences*, 78, 310–314.
- Gillham, J. E., Reivich, K. J., Freres, D. R., Lascher, M., Litzinger, S., Shatté, A., & Seligman, M. E. P. (2006). School-based prevention of depression and anxiety symptoms in early adolescence: A pilot of a parent intervention component. *School Psychology Quarterly*, 21, 323–348.
- Graetz, J. E. (2010). Autism grows up: Opportunities for adults with autism. *Disability and Society*, 25, 33–47.
- Halcón, L. L., Robertson, C. L., & Monsen, K. A. (2010). Evaluating health realization for coping among refugee women. *Journal of Loss and Trauma*, 15, 408–425.
- Hass, M., & Graydon, K. (2009). Sources of resiliency among successful foster youth. *Children and Youth Services Review*, 31, 457–463.
- Hendricks, D., & Wehman, P. (2009). Transition from school to adulthood for youth with autism spectrum disorders: Review and recommendations. *Focus on Autism and Other Developmental Disabilities*, 24(2), 77–88.
- Hennessey, M. L., Roessler, R., Cook, B., Unger, D., & Rumrill, P. (2006). Employment and career development concerns of postsecondary students with disabilities: Service and policy implications. *Journal of Postsecondary Education and Disability*, 19, 39–55.
- Hjemdal, O., Friberg, O., Stiles, T. C., Martinussen, M., & Rosenvinge, J. H. (2006). A new scale for adolescent resilience: Grasping the central protective resources behind healthy development. *Measurement and Evaluation in Counseling and Development*, 39, 84–96.
- Hoffman, L., Marquis, J. G., Poston, D. J., Summers, J. A., & Turnbull, A. (2006). Assessing family outcomes: Psychometric evaluation of the Family Quality of Life Scale. *Journal of Marriage and Family*, 68, 1069–1083.
- Individuals With Disabilities Education Improvement Act of 2004, Pub. L. 108–446, 20 U.S.C. §§ 1400–1482.
- Jackson, L., & Arbesman, M. (2005). *Occupational therapy practice guidelines for children with behavioral and psychosocial needs*. Bethesda, MD: AOTA Press.
- Jerusalem, M., & Schwarzer, R. (1992). Self-efficacy as a resource factor in stress appraisal processes. In R. Schwarzer (Ed.), *Self-efficacy: Thought control of acting* (pp. 195–213). Washington, DC: Hemisphere.
- Kelley, T. M. (2005). Natural resilience and innate mental health. *American Psychologist*, 60, 265.
- Keough, J., Pierce, D., & Thomas, T. (2005). Using ritual to support client change at discharge. *OT Practice*, 10, 17–18.
- Khanlou, N., & Wray, R. (2014). A whole community approach toward child and youth resilience promotion: A review of resilience literature. *International Journal of Mental Health Addiction*, 12, 64–79.
- Kohler, P. (1993). Best practices in transition: Substantiated or implied? *Career Development for Exceptional Individuals*, 16, 107–121.
- Koome, F., Hocking, C., & Sutton, D. (2012). Why routines matter: The nature and meaning of family routines in the context of adolescent mental illness. *Journal of Occupational Science*, 19, 312–315.
- Kramer, J., ten Velden, M., Kafkes, A., Basu, S., Federico, J., & Kielhofner, G. (2014). *Child Occupational Self-Assessment (COSA)*, version 2.2. Available at <http://www.cade.uic.edu/moho/productDetails.aspx?aid=3>
- Landgraf, J. L., Abetz, L., & Ware, J. E. (1996). *The CHQ user's manual*. Boston: New England Medical Center, The Health Institute.
- Leake, D. W. (2012). Self-determination requires social capital, not just skills and knowledge. *Review of Disability Studies: An International Journal*, 8, 34–43.
- Lin, K. K., Sandler, I. N., Ayers, T. S., Wolchik, S. A., & Luellen, L. J. (2004). Resilience in parentally bereaved children and adolescents seeking preventative services. *Journal of Clinical Child and Adolescent Psychology*, 33, 673–683.
- Masten, A. S., Best, K. M., & Garmezy, N. (1990). Resilience and development: Contributions from the study of children who overcome adversity. *Development and Psychopathology*, 2, 425–444.
- Masten, A. S., & Reed, M. G. (2002). Resilience in development. In C. S. Snyder & S. J. Lopez (Eds.), *The handbook of positive psychology* (pp. 74–88). New York: Oxford University Press.
- McDonnell, M. C., & Crudden, A. (2009). Factors affecting the successful employment of transition-age youths with visual impairments. *Journal of Visual Impairment and Blindness*, 103, 329–341.
- McGoldrick, M., Carter, B., & Garcia-Preto, N. (2011). *Individual, family, and social perspectives: The expanded family life cycle* (4th ed.). Upper Saddle River, NJ: Pearson.
- Mehling, M. H., & Tasse, M. J. (2015). Impact of choice on social outcomes on adults with ASD. *Journal of Autism and Developmental Disorders*, 45, 1588–1602.

- Missuna, C., Pollock, N., & Law, M. (2004). *Perceived Efficacy and Goal Setting System (PEGS)*. San Antonio, TX: Psychological Corporation.
- Moos, R. H. (1993a). *Coping Responses Inventory: Adult Form professional manual*. Odessa, FL: PAR.
- Moos, R. H. (1993b). *Coping Responses Inventory—Youth Form: Professional manual*. Odessa, FL: PAR.
- Murphy, R. F. (1987). *The body silent*. New York: Norton.
- Murphy, R. F., Scheer, J., Murphy, Y., & Mack, R. (1988). Physical disability and social liminality: A study in the rituals of adversity. *Social Science and Medicine*, 26, 235–242.
- Murray, C. (2003). Risk factors, protective factors, vulnerability and resilience: A framework for understanding and supporting the adult transitions of youth with high incidence disabilities. *Remedial and Special Education*, 24, 16–26.
- Neugarten, B. L., Havinghurst, R. J., & Tobin, S. S. (1961). The measurement of life satisfaction. *Journal of Gerontology*, 16, 134–143.
- Park, J., Hoffman, L., Marquis, J., Turnbull, A. P., Poston, D., Mannan, H., ... Nelson, L. L. (2003). Toward assessing family outcomes of service delivery: Validation of a family quality of life survey. *Journal of Intellectual Disability Research*, 47, 367–384.
- Patterson, J., & McCubbin, H. I. (1996). Adolescent Coping Orientation for Problem Experiences (A-COPE). In H. I. McCubbin, A. I. Thompson, & M. A. McCubbin (Eds.), *Family assessment: Resiliency, coping, and adaptation: Inventories for research and practice* (pp. 537–583). Madison: University of Wisconsin.
- Pedro-Carroll, J. L. (2001). The promotion and wellness in children and families: Challenges and opportunities. *American Psychologist*, 56, 993–1004.
- Poston, D., Turnbull, A., Park, J., Mannan, H., Marquis, J., & Wang, M. (2003). Family quality of life: A qualitative inquiry. *Mental Retardation*, 41, 313–328.
- Prince-Embury, S. (2006). *Resiliency Scales for Children and Adolescents: A profile of personal strengths*. San Antonio, TX: Harcourt Assessment.
- Ravanera, Z. R., Rajulton, F., & Burch, T. K. (2004). Patterns of age variability in life course transitions. *Canadian Journal of Sociology*, 29, 527–542.
- Reivich, K., & Gillham, J. (2010). Building resilience in youth: The Penn Resiliency Program. *Communiqué*, 38(6), 1–19.
- Renty, J., & Royers, H. (2006). Quality of life in high functioning adults with autism spectrum disorder. *International Journal of Research and Practice*, 10, 511–524.
- Richaud, M. C. (2013). Contributions to the study and promotion of resilience in socially vulnerable children. *American Psychologist*, 68, 751–758.
- Sandler, I. N., Tein, J. Y., & West, S. G. (1994). Coping, stress, and the psychological symptoms of children of divorce: A cross-sectional and longitudinal study. *Child Development*, 65, 1744–1763.
- Schultz-Krohn, W. (2004). The meaning of family routines in a homeless shelter. *American Journal of Occupational Therapy*, 58, 531–542. <http://dx.doi.org/10.5014/ajot.58.5.531>
- Topolski, T. D., Patrick, D. L., Edwards, T. C., Huebner, C. E., Connell, F. A., & Mount, K. K. (2001). Quality of life and health-risk behaviors among adolescents. *Journal of Adolescent Health*, 29, 426–435.
- Turnbull, A., & Turnbull, R. (2000). *Enhancing individual and family quality of life*. Paper presented at the 7th International Conference of the Division on Mental Retardation and Developmental Disabilities, Baltimore.
- Turner, V. (1972). *The ritual process: Structure and anti-structure*. Ithaca, NY: Cornell University Press.
- Wagner, M. (1995). Outcomes for youths with serious emotional disturbance in secondary school and early adulthood. *Future of Children*, 5, 90–112.
- Wagnild, G. M., & Young, H. M. (1993). Development and psychometric evaluation of the Resilience Scale. *Journal of Nursing Measurement*, 1, 165–178.
- Wang, M., Mannan, H., Poston, D., Turnbull, A. P., & Summers, J. A. (2004). Parents' perceptions of advocacy activities and their impact on family quality of life. *Research and Practice for Persons With Severe Disabilities*, 29, 144–155.
- Wehmeyer, M. L., & Abery, B. H. (2013). Self-determination and choice. *Journal of Intellectual and Developmental Disabilities*, 51, 399–411.
- Wehmeyer, M. L., & Schwartz, M. (1997). Self-determination and positive adult outcomes: A follow-up study with youth with mental retardation or learning disabilities. *Exceptional Children*, 63, 245–255.
- Willett, J., & Deegan, M. J. (2001). Liminality and disability: Rites of passage and community in hypermodern society. *Disability Studies Quarterly*, 21, 137–152.
- Woodard, W. (2009). Psychometric properties of the ASPeCT-DD: Measuring positive traits in persons with developmental disabilities. *Journal of Applied Research in Intellectual Disabilities*, 22, 433–444.
- World Health Organization. (2011). *Mental health: A state of well-being*. Retrieved from http://www.who.int/features/factfiles/mental_health/en/index.html
- Zuna, N., Summers, J. A., Turnbull, A. P., Hu, X., & Xu, S. (2011). Theorizing about family quality of life. In R. Kober (Ed.), *Enhancing the quality of life of people with intellectual disability: From theory to practice* (pp. 241–278). Dordrecht, Netherlands: Springer.

CHAPTER 10.

SUPPORTIVE ENVIRONMENTS FOR TRANSITION

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Chapter Objectives

At the completion of this chapter, readers will be able to

- ❖ Describe the distinct role of occupational therapy practitioners in establishing supportive environments for transition;
- ❖ Explain universal design and assistive technology principles, and identify examples in everyday life transitions;
- ❖ Provide strategies for transitioning across physical environments, such as home, community, or day care, specifically for transportation and community mobility;
- ❖ Address the social environment's needs and supports during transition; and
- ❖ Recognize the costs associated with transitions, and identify potential funding sources for services.

Key Terms and Concepts

- | | |
|----------------------------|--|
| ❖ Assistive technology | ❖ Environment |
| ❖ Attachers | ❖ Evaluation |
| ❖ Built environment | ❖ Extenders |
| ❖ Caregivers | ❖ Ground-level play components |
| ❖ Caregiving | ❖ Groups |
| ❖ Community mobility | ❖ Home- and community-based services waiver programs |
| ❖ Confiners | ❖ Human Activity Assistive Technology model |
| ❖ Cultural effectiveness | ❖ Inclusion |
| ❖ Disability | ❖ Individual |
| ❖ Elevated play components | ❖ Intelligent transportation systems |
| ❖ End of life | |

- ❖ Long-term support services
- ❖ Matching Person and Technology model
- ❖ Medicaid service coordinator
- ❖ Occupations
- ❖ Person
- ❖ Person–Environment–Occupation model
- ❖ Person–Environment–Occupation–Performance framework
- ❖ Plan for Achieving Self Support
- ❖ Populations
- ❖ Program of All-Inclusive Care for the Elderly
- ❖ Retrofitting
- ❖ Social model of disability
- ❖ Stabilizers
- ❖ Student Environment Task Tool framework
- ❖ Universal design
- ❖ Universal design for learning
- ❖ Vehicle modifications
- ❖ Vocational rehabilitation
- ❖ Workers' compensation

Everything teaches transition, transference, metamorphosis: therein is human power, in transference, not in creation; and therein is human destiny, not in longevity but in removal. We dive and reappear in new places.
—Ralph Waldo Emerson (1847/1973, p. 76)

This chapter focuses on the distinct role of occupational therapy in analyzing and modifying physical and social environments to promote participation. Occupational therapy's role in considering the environment is critical when preparing for or facing a transition.

This chapter presents legal and theoretical constructs related to establishing accessible environments and creating supportive environments for transition, based on understanding disability as a result of the interaction between the individuals and their various environments.

New Definition of Disability

The National Institute on Disability and Rehabilitation Research (NIDRR; 2008) described a new paradigm of **disability** stating,

Disability is the result of an interaction between characteristics of the individual and those of the natural, built, communications (IT), cultural, and social environments. Personal characteristics, as well as environmental ones, may be either enabling or disabling. The impact of these interactions ebbs

and flows, depending on condition, time, and setting. This view of disability suggests that one of the most effective ways to address particular disabilities may be through the removal of barriers and the provision of accommodation or assistive technology. (par. 13)

NIDRR's view of disability is grounded in the **social model of disability** (Oliver, 1990, 1996), which assumed that people with disabilities have difficulty participating in activities and community settings because of society's failure to provide appropriate accommodations and services.

This paradigm is also built upon the concept of community inclusion. **Inclusion** means that people with disabilities have the right for full and fair access to activities, social roles, and relationships alongside typical community members (Bates & Davis, 2004). Accordingly, occupational therapy practitioners working with individuals during transition should conceptualize new strategies for accommodating individual needs and for promoting people with disabilities' inclusion within their communities regardless of their skill level. Historical background for understanding the new disability paradigm is provided in Exhibit 10.1.

Exhibit 10.1. Ron Mace: A Historical Perspective of Environmental Supports

Ron Mace, an architect and industrial designer, experienced the impact of a change in physical status in the early 1950s. His life story as related by Ostroff, Limont, and Hunter (2002) begins with Mace as a young child building soapbox derby carts with his father and model airplanes with his brother. When he contracted polio at the age of nine years, Mace's parents were advised to institutionalize him. Instead, they circumvented the barriers imposed upon him by building the adaptive equipment he required and carrying him up and downstairs, allowing him to remain active in school and community life despite his mobility limitations.

When he was accepted into the School of Design at North Carolina State University, the dean of the architecture school attempted to discourage Mace from attending the university and predicted he would not succeed. Undeterred, Mace entered the program. Because of inaccessible dormitory accommodations, his mother rented a trailer for him near the school and lived with him. With her support, as well as his own tenacity, Mace graduated and secured employment as an architect. Ironically, he was forced to commute from another city due to lack of accessible housing in the area in which he was employed.

In 1973 Mace was invited to advise a group committed to producing the first building code for accessibility in North Carolina. This code later served as a blueprint for other states. His firsthand experience with architectural barriers, skills as an architect, and ability to speak with authority on the concept of retrofitting existing buildings proved invaluable. Mace began to work with the U.S. Department of Housing and Urban Development (HUD) to retrofit mobile homes. Working with a new federal construction code for mobile homes, Mace designed adaptations to make used mobile homes accessible. Mace's work in accessible design was instrumental in the passage of national legislation prohibiting discrimination against people with disabilities, the Fair Housing Amendments Act of 1988 (Pub. L. 100–430) and the Americans with Disabilities Act of 1990 (Pub. L. 101–336).

Mace is credited with coining the term *universal design (UD)*, referred to in the Tech Act (Improving Access to Assistive Technology for Individuals With Disabilities Act of 2004; Pub. L. 108–364) as

a concept or philosophy for designing and delivering products and services that are usable by people with the widest possible range of functional capabilities, which include products and services that are directly accessible (without requiring assistive technologies) and products and services that are interoperable with assistive technologies. (29 U.S.C. 3002 [19])

UD accommodates a wide range of individual preferences and abilities, as well as the different needs of people of different ages, body sizes, and disabilities (Center for Universal Design, 1997).

Mace established the federally funded Center for Accessible Housing in 1998. Now known as the Center for Universal Design, it serves as a leading national and international resource for research and information on UD in housing, products, and the built environment, at the School of Design at North Carolina State University in Raleigh.

During the same period, the social model of disability was conceptualized (Oliver, 1990). In 1976, the Union of the Physically Impaired Against Segregation and the Disability Alliance, both in the United Kingdom, first made the distinction between impairment and disability. *Impairment* was defined as functional limitations experienced by an individual, while *disability* was defined as "something imposed on top of...impairments, by the way [individuals with impairments] are unnecessarily isolated and excluded from full participation in society" (Shakespeare & Watson, 2002, p. 14). The social model of disability focused on those physical and social barriers that hinder individuals with impairments' access and participation in desired activities. It resulted in anti-discrimination legislation and practices that promote equality and independent living (Shakespeare & Watson, 2002).

Mace's story, along with the social model of disability, emphasize the important role of occupational therapy in providing environmental modifications and adaptations that reduce barriers and enhance individuals' engagement in desired and meaningful occupations. The personal story of Mace also illustrates that the role of the user expert cannot be underestimated, and is aligned with client-centered care.

Legislation

There are several laws to support the transition of individuals with disabilities from school to adult life. They are intended to consider and provide the educational and vocational skills necessary to live, work, and participate in community life. These mandates address planning for life after public school education, vocational training practices, post-secondary education and employment opportunities, accessibility in the workplace, and more.

As policies, laws, and regulations evolve to reflect the current needs of society, occupational therapy practitioners are challenged to stay abreast of emerging issues and how those issues relate to transitions across the lifespan and the environmental supports required to allow individuals full participation. Several pieces of landmark legislation that profoundly affected the rights, dignity, and quality of life of all persons with disabilities, which are relevant for environmental considerations in transition, are described in Exhibit 10.2. These laws emphasize people with disabilities' right to community integration, accessibility, and participation along with mandatory reductions in environmental barriers.

Transition Processes and Challenges

Transition in the Typical Population

One needs only to stroll through the greeting card section of the local drug store to be reminded of the kinds of transitions and challenges experienced in the typical population. There are cards for expectant parents, cards for the birth of a child, birthday cards, graduation cards, and cards offering congratulations on a new job or a promotion.

To adjust to change or thrive in the next setting, certain competencies and supports are required. Competencies associated with successful transitions across the lifespan include maintaining or regaining health; obtaining education; developing skills; securing income; managing finances; establishing social relationships; cultivating hobbies or recreational

pursuits; and accessing support services, housing, and transportation and mobility.

Transition During Illness or Impairment

Transitions may take a different form for those whose lives are affected by an illness or impairment, requiring more or different forms of support, including those offered by occupational therapy, prior to, during, and after the transition. Changes associated with illness can involve accepting limitations, managing schedules impacted by pain, fatigue, or physical disabilities, and adjusting to altered daily roles and routines. Self-identity and confidence may be affected as individuals reflect on the "before and after" aspects of their personal limitations or boundaries. These transitions and examples of considerations for occupational therapy services are illustrated in Table 10.1.

Environment and Occupation

Occupational therapy practitioners recognize that the environment is a powerful component that can enable or challenge occupational performance. Practitioners assess all areas of occupation within the context and setting to promote participation (AOTA, 2015a). In anticipation of a change in status or need, practitioners scan the environment for safety and mobility concerns, while considering the client's overall mental and physical health and well-being. Viewing the environment from the standpoint of how much independence, social contact, or opportunity to engage in meaningful activities is available is part of the process of assessing the impact of the environment. Other considerations include lighting, noise, odors, amount of space and privacy, and how these factors affect mood. Some examples of environmental impacts during transitions are listed in Table 10.2.

Providing environmental supports during transition includes focusing on the changes and adaptations that can be made to environmental elements rather than focusing solely on clients' skills and abilities. Two occupational therapy theories help practitioners in conceptualizing the role of the environment in occupational therapy services: the (1) Person–Environment–Occupation model (PEO; Law et al., 1996) and (2) the Person–Environment–Occupation–Performance framework (PEOP; Baum & Christiansen, 2005).

Exhibit 10.2. Legislation Related to Environmental Considerations in Transition

Individuals with Disabilities Education Improvement Act of 2004 (IDEA; Pub. L. 108–446)

IDEA opens the doors of public schools to all students regardless of disability. School districts are required to provide appropriate assistive technology to students with disabilities when it supports their acquisition of a free appropriate public education. Individualized education programs developed for children identified as needing special education must indicate that AT has been considered to “maximize accessibility for children with disabilities” (20 U.S.C. 1400[c][5][H]) and to support their participation in a regular education curriculum.

Carl D. Perkins Career and Technical Education Improvement Act of 2006 (Perkins IV; Pub. L. 109–270)

Perkins IV supports the development of academic and career and technical skills among secondary and post-secondary education students who enroll in career and technical education (CTE) programs. CTE prepares students for roles outside the paid labor market, and teaches general employment skills and skills required in specific occupations or careers. Institutions that receive Perkins IV funds must ensure access for special populations, including individuals with disabilities, who face difficulty in attaining education and employment.

Rehabilitation Act of 1973 (Pub. L. 93–112)

Amended in 1992 and 1998, this was the first act to address equal access for people with disabilities through the removal of architectural, employment, and transportation barriers. It prohibits discrimination on the basis of disability in programs receiving federal funding.

Section 504 provides opportunities for children and adults with disabilities in education, employment, and various other settings. Requirements common to these regulations include reasonable accommodations for employees with disabilities; program accessibility; effective communication with people who have hearing or vision disabilities; and accessible new construction and alterations.

Later amendments strengthened requirements for access to electronic and information technology in the federal sector (Section 508). With the passage

of the Patient Protection and Affordable Care Act in 2010, a new provision (Section 510) was added to address access to medical diagnostic equipment.

Improving Access to Assistive Technology for Individuals With Disabilities Act of 2004 (Tech Act; Pub. L. 108–364)

First passed in 1988, the Tech Act intends to promote people with disabilities' awareness of and access to AT devices and services so they can more fully participate in education, employment, and daily activities within their communities. It covers people with disabilities of all ages, all disabilities, and all environments (i.e., early intervention, K–12 education, vocational rehabilitation, community living, aging services).

ADA Amendments Act of 2008 (ADAAA; Pub. L. 110–325)

The American with Disabilities Act of 1990 (ADA; Pub. L. 101–336) prohibits discrimination against people with disabilities and provides accessibility, nondiscrimination, and greater access to workplaces, community facilities, and public services, public transportation, and telecommunications. It promotes the employment of individuals with disabilities and protects them by prohibiting discrimination during recruitment, hiring, evaluation, promotion, or any other facet of employment. Employers are further required to provide reasonable accommodations to enable individuals with disabilities to successfully perform their jobs. ADAAA expands the definition of disability and restores the intent and broad protections of the ADA for employees with disabilities.

Person–Environment–Occupation Model

The **PEO model** (Law et al., 1996) is a client-centered approach in which the **person** is recognized as having various roles that change across time and contexts. The **environment** is the cultural, socioeconomic, institutional, physical, and social setting within a household, neighborhood, or community that influences a person's behavior and choice of occupations. **Occupations** are functional tasks comprised of purposeful activities in which a person engages throughout his or her lifespan. During the lifetime of an individual there are different factors and interactions

Table 10.1. Considerations for Occupational Therapy Interventions in Transitions Across the Lifespan

Life Transition	Change in Environment	Considerations for Occupational Therapy Interventions
Birth of a child	Hospital to home	The hospital offers an around-the-clock support system with trained professionals that are not available to follow the infant and his or her parents upon discharge. This transition may be overwhelming to new parents, especially if the infant was born with impairments. Occupational therapy home services are family-centered and holistic.
Begin preschool	Home to school	Services shift from the family to the child as a student; the scope of service narrows to educationally relevant interventions. (See Chapter 3, "Early Childhood Transitions.")
High school completion	School to a variety of adult life environments: work, community, independent living	A student transitioning from school may lose school-provided supports and equipment. (See Chapter 5, "Transition From School to Adult Life.")
Employment	A variety of work environments	The transition to the workforce involves interaction and services from several entities and organizations. It may begin with school-based programs, community rehabilitation providers, or vocational rehabilitation. (See Chapter 6, "Transition and Work.")
Retirement, old age	Age in place (i.e., home), assisted living, or nursing home	Older adults may need to increase their reliance on rehabilitation and other therapeutic services. (See Chapter 7, "Transition and Aging.")
Health transitions throughout life	Home, work, school, community	Health-related changes throughout one's life may affect one's ability to engage in daily occupations and the type of services needed. (See Chapter 8, "Health Care Transition.")

that occur within the three components, and the overlap, or the person's occupational engagement, can differ in size at any one time depending on these factors. Occupational therapy interventions must consider the environment to elicit change.

Person–Environment–Occupation–Performance Framework

The **PEOP framework** (Baum & Christiansen, 2005) focuses on the relationship among the person, the occupation, and the environment. Occupational performance includes personal care, sleep, recreation, and work and is influenced by the person, the distinctive environment in which the person functions, and the actions and tasks that are considered occupational roles. Occupational therapy intervention is viewed as a process of using a broad range of purposeful

client-centered strategies that supports the individual in developing or using resources that enable the successful performance of necessary occupations.

Occupational Therapy's Role in Establishing Supportive Environments

Comprehensive transition services address all areas of occupation, including play or leisure, education, work, independent living, integration into the community, and socialization (AOTA, 2014, 2015b; see Appendix D, "Occupational Therapy's Perspective on the Use of Environments and Contexts to Facilitate Health, Well-Being, and Participation in Occupations"). To establish a supportive environment, it is important to conduct a thorough assessment. Practitioners have the

Table 10.2. Examples of Environmental Impacts During Transition

Environment	Impact
Physical	Wide doorways may be necessary for mobility in wheeled devices.
Cultural	Families may expect that female family members act as primary caregivers.
Social	A teaching assistant should be guided to provide the student with opportunities to interact with his or her peers.
Technical	Computers with proper software or setup can enhance performance.
Political	Changes to laws and funding mechanisms affect benefits and services to people with disabilities during transition.

knowledge and skills necessary to gather and analyze information about the individual—customary environments, client-centered goals, and tasks that the client wants or needs to accomplish—to determine what services are needed to remove barriers to meaningful participation.

Evaluation

Evaluation begins with observation and interview. What is the current level of occupational performance and the intended environment or setting that the client plans to participate in or resume? What are the short- and long-term transition goals that can be established in collaboration with the client and family? Standardized and observational screenings can be used to assess the person's abilities, intrinsic factors, and environmental (i.e., extrinsic) conditions that may affect the desired transitions. Task analysis will help determine the performance demands of desired or anticipated activities that do not match the client's ability at that time. Table 10.3 lists recommended tools that evaluate occupational performance with a focus on the environment.

Table 10.3. Occupational Therapy Assessment Tools That Focus on Environments

Assessment Tool	Purpose
Canadian Occupational Performance Measure (COPM; Law et al., 2005)	COPM is a client-centered, individualized assessment used to detect clients' perceptions of change in their occupational performance in the areas of self-care, productivity, and leisure over time. Via interview, the client is asked to identify which activities are difficult to perform and rate their importance. Based on the resulting performance and satisfaction scores, the client and the therapist plan a course of intervention. The COPM can then be used to determine the change brought about by the intervention.
School Function Assessment (SFA; Coster, Deeney, Haltiwanger, & Haley, 1998)	SFA is a questionnaire that measures the strengths and needs of elementary school students with disabilities in important nonacademic functional tasks. Completed by school personnel who are familiar with the student, it includes 3 scales: (1) participation in school-related activity settings; (2) task supports, including human assistance and environmental modifications; and (3) activity performance in activities such as moving around the classroom and the school, using school materials, interacting with others, following school rules, and communicating needs.
School Assessment of Motor and Process Skills (School AMPS; Fisher, Bryze, Hume, & Griswold, 2012)	School AMPS is used to assess students' performance of school-related tasks in a classroom setting. It measures the student's physical effort, efficiency, safety risks, or need for assistance. It can be used in any classroom environment where there are at least four students and a teacher.

(Continued)

Table 10.3. Occupational Therapy Assessment Tools That Focus on Environments (Cont.)

Assessment Tool	Purpose
Bristol Activities of Daily Living Scale (BADLS; Bucks, Ashworth, Wilcock, & Siegfried, 1996)	BADLS is a 20-item questionnaire designed to measure the ability of persons with dementia to carry out daily activities such as dressing, preparing food, and using transportation.
Assessment of Readiness for Mobility Transition (ARMT; Meuser, Berg-Weger, Chibnall, Harmon, & Stowe, 2013)	ARMT measures emotional and attitudinal readiness associated with the prospect of present or future mobility loss or change in older adults. It serves as a starting point for active discussion and planning for alternative transportation modes.
Kohlman Evaluation of Living Skills (KELS; Kohlman Thomson, 1992)	KELS determines a person's ability to function in 17 basic living skills in 5 areas: (1) self-care, (2) safety and health, (3) money management, (4) transportation and telephone, and (5) work and leisure. It can be used in many settings and with many populations, including with elderly in nursing facilities, inpatient units, and outpatient settings; in acute care units in hospitals; for people with brain injuries; and with adolescents in transition training programs.
Performance Assessment of Self-Help Skills (PASS; Holm & Rogers, 2008)	PASS assesses the person's ability to complete daily living tasks, which may be administered in a clinic or home setting. It includes 26 tasks in ADLs, IADLs, and functional mobility. The dynamic element of the assessment is utilized to determine the amount of assistance the person may require to complete daily living tasks.
Craig Hospital Inventory of Environmental Factors (CHIEF; Craig Hospital Research Department, 2001).	CHIEF and its short form, CHIEF-SF, measure personal and environmental barriers that keep a person from doing what he or she needs to do. It measures factors, including health, weight, education, and motivation, as well as the physical surroundings and accessibility, attitudes and support of others, resources, rules and regulations of organizations, and government policies. Both CHIEF forms track the frequency (how often are they encountered?) and magnitude (how severe are they?) of each potential environmental barrier.
In-Home Occupational Performance Evaluation (I-HOPE; Stark, Somerville, & Morris, 2010)	I-HOPE is a performance based measure that evaluates 44 activities in the home in 4 subscales: (1) activity participation, (2) client's rating of performance, (3) client's satisfaction with performance, and (4) environmental barriers.
Work Environment Impact Scale (WEIS; Moore-Corner, Kielhofner, & Olson, 1998)	WEIS focuses on the fit between a person and his or her work environment. Based on the Model of Human Occupation (MOHO; MOHO Web, 2015), it gathers information on factors in the work environment that support or interfere with the client's work performance, satisfaction, and well-being, as well as opportunities and constraints related to physical spaces, social groups, objects, and tasks.
Community Integration Questionnaire (CIQ; Dijkers, 2000).	CIQ consists of 15 items that measure home integration (H), social integration (S), and productive activities (P). It primarily measures the frequency of performing activities or roles, with secondary measure of whether activities are done jointly with others.
Life Stressors and Social Resources Inventory—Adult and -Youth (LISRES-A & LISRES-Y; Moos, 1994)	LISRES is a structured interview that measures ongoing life stressors and social resources and how life events affect an individual's functioning in major life experiences, including physical health, finances, work, home and neighborhood, friends and social activities, and family.

Interventions

Occupational therapy interventions to provide environmental supports during transitions can enhance participation. Such interventions might include retrofitting, universal design (UD) and universal design for learning (UDL), assistive technology (AT), home modifications, strategies for transportation and community mobility, and adaptations to play.

Retrofitting

Perhaps one of the most common approaches to addressing barriers in the physical environment is changing or retrofitting the existing environment to accommodate for differences in ability caused by various transitions across the lifespan (Figure 10.1). The reality is that the built environment is not always compatible with the physical or sensory needs of individuals who experience a change in health status. Therefore, doorways may need to be widened, ramps built, door handles changed, counters lowered, shower doors removed, or grab bars installed depending on individual need.

Figure 10.1. Retrofitted building with ramped entry.



Source. J. Schoonover. Used with permission.

In the “Prologue,” Cheryl writes movingly about Renzo’s return home from the hospital and describes how friends and neighbors ripped up the carpeting in the living room and exposed the hardwood floors of their century-old home to make it wheelchair accessible.

This process of **retrofitting**, or modifying Cheryl’s home by adding new features that were not available or necessary when the home was built, is a scenario repeated over and over again when a shift happens in an individual’s physical or mental status and modifications are needed to accommodate for the changes. This speaks to the potential of occupational therapy practitioners serving as consultants to the building and construction industry.

Universal design

UD is “the design of products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design” (NIDRR, 2008, para. 16). Because of the incorporation of UD concepts into newly built environments, UD features are now integrated into appliances, devices, environments, processes, and systems such as architecture, vehicles, telecommunications, restrooms, and community and workplace elements. Although no design or product can completely meet the specifications of all users, when all users’ needs are taken into consideration in the initial design process, the result is a design or product that can be used by the broadest spectrum of users.

Specific examples of universally designed features include

- Curb cuts,
- Ramps as alternatives for stairs,
- Levered door handles,
- Software operating systems with options such as speech output instead of visual displays,
- Captioning for television and films as an alternative or adjunct to audio output,
- Ergonomic keyboards,
- Voice-activated telephones, and
- Transportation features (e.g., keyless entry, swivel seats, doors that open automatically).

According to NIDRR (1999), UD principles

can be applied to the built environment, information technology and telecommunications, transportation, and consumer products.

These technological systems are basic to community integration, education, employment, health, and economic development. The application of [UD] principles during the research and development stage would incorporate the widest range of human performance into technological systems. [UD] applications may result in the avoidance of costly retrofitting of systems in use and the possible reduction in the need to develop orphan products. (p. 53)

Occupational therapy practitioners are ideal team members in the UD process because of their expertise in task analysis and environmental adaptation. Their knowledge of human functioning, disability, person–environment, and AT are additional key components (Ringaert, 2003). Practitioners have the opportunity to broaden their practice as consultants to contractors, interior designers, architects, and product design (Christiansen, 1999).

Ringaert (2003) recommends that practitioners interested in working in the UD area should be able to review architectural drawings; have an understanding of environments beyond housing; possess skills to interact with designers, architects, and builders; and be knowledgeable about UD theory as well as building codes, standards, and guidelines. The following questions are aimed at developing an understanding of UD.

Questions

Take a moment to look around your home and consider:

- Are there stairs to the front door? What kind of knob is on the door? How wide is the doorway?

Look at your flooring and room arrangement.

- Would a visitor with a visual impairment or a mobility device be able to navigate your floor plan, use the restroom, or get a drink of water?
- What kind of changes would you need to make to ensure accessibility?

Take a moment to think about questions you might ask to start a conversation about UD with your clients. Some examples are:

- What are your anticipated goals for residency in your home?
- How long do you anticipate living there? Will you age in place?

- If you are a renter, how long do you plan to stay in this home?

Universal design for learning

UD is the foundation for the movement in education known as ***UDL***, which is

a scientifically valid framework for guiding educational practices that (A) provides flexibility in the ways information is presented, in the ways students respond or demonstrate knowledge and skills, and in the ways students are engaged; and (B) reduces barriers in instruction, provide[s] appropriate accommodations, supports, and challenges, and maintains high achievement expectations for all students, including students with disabilities and students who are limited English proficient. (Higher Education Opportunity Act, 2008, 20 U.S.C. 1002 § 103[24])

Rather than focusing solely on learners' capabilities, UDL advocates for examining the environment in which they learn and their interactions with educational goals, materials, methods, and assessments.

Practitioners providing transition services in schools need to be aware of the three pillars of UDL, which are multiple means of (1) engagement, (2) representation, and (3) action and expression (National Center on Universal Design for Learning, 2014). Practitioners also need to understand how they align with occupational therapy practice. For more information on occupational therapy's role in school transitions, see Chapter 4, "Transition Within Schools."

Technology: The game changer

When preparing for transitions, it is important to consider social participation. Technological advancements have expanded the possibilities for social connections. Technology and virtual environments can be used for recreation (e.g., online games), socialization (e.g., social media), information gathering (e.g., search engines), education (e.g., virtual classroom), employment (e.g., telecommuting), wellness (e.g., telehealth), and more. The virtual context offers unique benefits and possibilities to the occupational therapy process and can be considered another tool to use to address obstacles imposed by physical, temporal, and personal barriers (Arce & Smith, 2010).

Assistive technology

AT is any device or equipment needed for the person to be functional in his or her environment. Although called different names, such as *adaptive equipment* or *assistive devices*, AT has been an important tool since the origins of the occupational therapy profession to support meaningful occupational engagement.

Traditionally, tools such as reachers, long-handled shoe horns, button hooks, and pencil grips were employed to circumvent barriers and promote participation in the performance of activities and meaningful occupations throughout one's daily life. The idea of circumventing, as opposed to resolving, a limitation, is a subtle shift from models of practice that emphasize rehabilitation, or "fixing" the person.

Stoller (1998) defined *AT* as

special devices or structural changes that promote a sense of self-competence, the further acquisition of developmental skills into occupational behaviors and/or an improved balance of time spent between the occupational roles in an individual's life as determined by the individual's goals and interests and the external demands of the environment. (p. 6)

Occupational therapy practitioners' training, knowledge, and expertise in understanding clients' occupational needs, abilities, and contexts make them ideal collaborators in the design, development, and clinical application of technological devices that provide clients with access, safety, and efficiency in daily function (AOTA, 2015a).

Evaluating homes, schools, and work spaces and recommending necessary changes to improve accessibility is also considered AT and may include alternative strategies in addition to devices and services. Curb cuts, ramps, and door openers are just a few modifications that may allow persons with physical or sensory impairments to navigate inside and outside of built environments.

Labeling key areas with pictures, text, and Braille, and providing accommodations for persons of varying sizes, or who use wheelchairs to access restrooms, water fountains, playgrounds, or operate elevators, are means of making environments directly accessible, or interoperable with AT.

Choosing the right tool for the job, funding equipment purchases, and receiving appropriate

training in the use of the devices can be daunting. Public policy changes that support the rights of persons with disabilities challenge occupational therapy practitioners to keep abreast of current trends in terms of legislation as well as AT.

Many assessment tools and models for AT assessment and service delivery may provide a guide for considering the need for AT and determining the best tool to meet the personal requirements of the client. Ideally, choosing AT should be a team approach with the client at the center. Evaluating needs, making decisions, and implementing intervention from a variety of perspectives ensure a thoroughness that is not always possible when the evaluation is conducted by one individual. Several assessment tools are described in Table 10.3.

Several models providing frameworks for decision making regarding the selection, implementation, and evaluation of AT.

- The ***Human Activity Assistive Technology model*** (Cook & Polgar, 2008) considers the human (i.e., physical, cognitive, emotional), activity (i.e., self-care, productivity, leisure), and AT (i.e., device, service), within the context of participation, with an emphasis on the context as a determining factor for outcomes.
- The ***Student Environment Task Tool (SETT) framework*** (Zabala, 2005) was developed specifically for school settings and is designed to support decision making through the promotion of collaboration, communication, sharing of knowledge and perspectives, flexibility, and ongoing processes among educational team members. The SETT framework uses a series of questions that are consistent with the type of information the occupational therapy practitioner collects as part of the occupational performance analysis. Developed to guide discussion, evaluation, and intervention, SETT supports a student's participation in curricular and extracurricular activities throughout the school day.
- The ***Matching Person and Technology (MPT) model*** and assessment process (Scherer, 2002) was designed to help individualize the process of matching individuals with the most appropriate AT. It considers three factors: (1) milieu (i.e., characteristics of the environment and psychosocial setting in which the person uses the technology), (2) personality (i.e., personality, temperament, preferences), and (3) technology (i.e., functions, features).

Table 10.4. Outcome Measure Models for Assistive Technology Services

Model	What It Measures
PIADS® (Day & Jutai, 1996)	The PIADS® is a self-assessment questionnaire designed to measure a person's perceptions of how assistive devices affect his or her quality of life. It can be used with persons of all ages and abilities to assess impact of any assistive device, prosthesis, or medical procedure along these dimensions: <ul style="list-style-type: none"> • <i>Competence</i>—feelings of competence and usefulness • <i>Adaptability</i>—willingness to try new things • <i>Self-esteem</i>—feelings of emotional well-being and happiness.
Quality Indicators of Assistive Technology (QIAT; Zabala et al., 2000)	The QIAT includes quality indicators, intent statements, and common errors for 8 interrelated areas (consideration, assessment, AT in the IEP, implementation, evaluation of the effectiveness of AT, AT in transition, administrative support for AT, and AT professional development) important to the development and delivery of AT services in schools. It emphasizes that all AT services developed and delivered by states or districts should align with mandates and expectations of federal and state laws and district policies; AT efforts, at all stages, involve ongoing collaborative work by families and caregivers, school personnel, and other needed individuals and service agencies; and professional team members involved in AT processes bear responsibility for following their own specific professional code of ethics. There is a forum associated with QIAT that provides a supportive environment for those who are involved with AT services housed on the National Assistive Technology Research Institute (NATRI) website: (see http://natri.uky.edu/assoc_projects/qiat/qualityindicators.html). <p>Postings and search of the archives can provide support for service providers in decision making, implementation, and problem solving. NATRI conducts AT research, translates theory and research into AT practice, and provides resources for improving the delivery of AT services.</p>

Note. AT = assistive technology; IEP = individualized education program.

When providing UD strategies and AT to persons during transition, it is important to evaluate whether the strategies enhanced and resulted in a smooth, successful transition. Several methods are available to measure the outcomes of AT services and are listed in Table 10.4.

Home modifications

Persons of all ages can benefit from adaptations to the environment that are intended to increase usage, safety, security, and independence (AOTA, 2005a; Siebert, Smallfield, & Stark, 2014). Occupational therapy practitioners recognize the impact of acute and chronic conditions on performance, and use task analysis and problem solving to determine what aspects of the environment inhibit access and participation. Barrier reduction can ease transitions, especially when a person transitions from a more restrictive environment (e.g., hospital, skilled nursing

facility, mental institution) to environments with fewer supports, such as the home.

Home modifications can take many forms, from dramatically altering the physical structure of the home to subtle changes in lighting and floor covering (Siebert et al., 2014). Table 10.5 describes considerations for home modifications.

Moving across environments: Transportation and community mobility

Although the methods of transportation and the necessary supports may evolve and change throughout the lifespan as individuals transition from one phase to another, participating in necessary or desired occupations creates an ongoing need for going and getting to places (AOTA, 2012).

For example, if a person is transitioning from school to work, and a school bus is no longer available, how

Table 10.5. Considerations in Home Modifications

Home Element	Considerations
Entry and access to the home	<ul style="list-style-type: none"> • Surface leading to the door (e.g., grass, paving stone, cement) • Door (e.g., handle, lock, amount of effort required to open and close) • Flooring (e.g., carpet, throw rugs, hardwood, linoleum) • Ramps to provide increased access to ease entry
Hallways	<ul style="list-style-type: none"> • Wide enough to allow passage and turning space for those using wheeled mobility devices
Bathrooms	<ul style="list-style-type: none"> • Installing railings and grab bars to facilitate independent transfers or support caregivers in the process • Modifying bathroom facilities to include roll-in showers, sink, bathtub, and toilet modifications, water faucet controls, floor urinals, and plumbing • Requiring trapeze and mobility tracks to aid in lifting and transfers
Kitchen and laundry room	<ul style="list-style-type: none"> • Rearranging objects so that needed items are within view and reach
Other equipment	<ul style="list-style-type: none"> • Universal remotes to provide environmental control over temperature, lighting, and appliances, including voice-activated, light-activated, motion-activated, and electronic devices • Cognitive supports such as lists, alarms, and timers • Visual cues such as labels, checklists, and photos • Designing for a logically organized work space with materials needed for an activity grouped and visible • Removing clutter from floors, rooms, and surfaces to reduce distractions, improve safety, and support the development or maintenance of habits to maintain function • Using adaptive equipment and AT to facilitate completion of tasks but not alter the process so significantly that it is not used or causes confusion.

Note. AT = assistive technology.

will he or she get to work? On the basis of their knowledge of the client, occupational therapy practitioners can suggest the attributes required for a vehicle to be accessible with sufficient interior space so that a passenger with a disability can be assisted with transfers into and out of the vehicle, if any additional seating equipment can be accommodated, and if seat belts can be fastened and unfastened with ease (Shaw, Miller Polgar, Vrklijan, & Jacobson, 2010). Other considerations might include additional safety restraints.

Mobility is a significant area of occupation, representing independence and identity. It begins with the car seat required by law to transport a newborn home and continues throughout the lifespan by riding a school bus, using public transportation, or acquiring a driver's license. Connecting and staying connected to the community is an important aspect of quality of life, not only for work and leisure but

also to acquire essentials such as food and clothing. For many people, driving and other forms of transportation are the means to actively engage with the environment outside their homes. For some, mobility may involve dependence on others for transport.

Community mobility. The *Occupational Therapy Practice Framework: Domain and Process* (3rd ed.; AOTA, 2014) describes **community mobility** as, "Planning and moving around in the community and using public or private transportation, such as driving, walking, bicycling, or accessing and riding in buses, taxi cabs, or other transportation systems" (p. S19). Community mobility takes many forms, including walking with or without the use of an ambulation aid, riding wheeled mobility devices (e.g., stroller, bicycle, manual wheelchair) operating powered devices (e.g., motorcycle, power wheelchair, scooter), riding as a

passenger in a motor vehicle, driving in a vehicle with or without modifications, and using public transportation (Zahoransky, 2009).

Occupational therapists addressing community mobility assess clients as well as their communities to determine the client's ability to access transportation alternatives and use available resources and equipment. These interventions include, but are not limited to,

- Passenger safety by helping individuals access and ride safely in vehicles (e.g., designing mechanisms to assist children with disabilities to get on and off the school bus, securing wheelchairs or car seats);
- Community mobility, including walking, biking, and riding as a passenger in a motor vehicle or on mass transit to enhance independence and prevent injury;
- Evaluation, education, and training of persons with learning disabilities, attention disorders, developmental disabilities, and acquired disabilities such as brain injuries and amputations in preparation of acquiring a first driver's license;
- Evaluation and training of experienced drivers who have impairments or age-related changes that interfere with driving and community mobility; and
- Exploration of alternative transportation options with older adults and drivers of other ages who must temporarily abstain or retire from driving.

Ensuring passenger safety. Ensuring passenger safety presents challenges and responsibilities for transportation providers. More intensive needs may require physical handling, behavioral management, child safety seats, restraint systems, safety vests, wheelchairs and occupant securement systems, special equipment management, and more. For example, the design of any vehicle being considered for purchase should support safe transfers for individuals with disabilities (e.g., vehicles with adjustable or hip-level seat heights, easy access for entry and exit). Occupational therapy practitioners can anticipate individual and family needs by conducting a screening and referring to specialized training centers as appropriate.

Driving. Just as acquiring a driver's license is considered a rite of passage, or transition, for a teen, signaling greater independence and choices, losing a license because of age or disability signals a loss of autonomy for others. Driving provides

access to work and play in and beyond the community, allowing those who qualify with the means to maintain an active and meaningful lifestyle for those interests, occupations, and daily activities that require leaving the house. Driving also represents a set of visual, cognitive, and motor skills that can allow access or become a barrier to the independent operation of a motor vehicle (Stav, 2015).

Occupational therapists assessing clients as potential drivers or individuals returning to driving following a transition in health status evaluate vision, cognition, attention and focus, motor performance, reaction time, knowledge of traffic rules, and behind-the-wheel assessment of skills (Classen, Dickerson, & Justiss, 2012).

Vehicle modifications. On the basis of the findings from the evaluation, occupational therapy practitioners make recommendations regarding specific vehicle modifications such as a wide-angle mirror, window tinting, antiglare mirrors, steering wheel spinner knobs, seat cushions, left-foot gas pedal, or hand controls (Figure 10.2).

Figure 10.2. Car with accommodations to transport wheelchair.



Source. J. Schoonover. Used with permission.

Arbesman and Pellerito (2008) described vehicle modifications as falling into three general categories:

1. Adaptive equipment, which includes intelligent transportation systems (ITS) and lower technology adaptive equipment;
2. Modifications to improve visibility during driving; and
3. Changes to the automobile that improve safety in the event of a crash.

ITSs are universally designed technologies developed for the general driving population, which include global positioning systems, route guidance (navigation systems), emergency vehicle location and response, vision enhancement systems, cruise control, lane change aids, parking assistance, telecommunication aids, and collision warning systems (Arbesman & Pellerito, 2008). These vehicular technologies can facilitate the task of driving, yet at the same time, may place greater demands on the driver (Vrkljan & Miller Polgar, 2005). Other considerations include advanced crash protection of newer cars, and the ability to transfer self and other mobility equipment in and out of the vehicle.

Alternatives to driving. The **built environment**, which refers to man-made physical surroundings, including buildings, streets, or parks, affects a person's mobility, access to physical activity, and personal safety while engaging in physical activity. Alternatives to driving might include ambulation or the use of AT (e.g., canes, walkers, wheeled mobility devices).

Walker et al. (2010) argued that community mobility skills training should be specialized for the mobility device used and concluded that while some mobility device skills assessed in clinical environments appear to transfer to community settings, other skills, primarily higher level, are unique to the community setting, with challenging community tasks seeming to differ among device users. Additionally, community services such as specialized transportation systems and grocery delivery can provide alternative access to needed resources.

Adapting play environments

According to AOTA (2008),

Occupational therapy practitioners support, enhance, and defend children's right to play as individuals and as members of their families,

peer groups, and communities by promoting recognition of play's crucial role in children's development, health, and well-being; establishing and restoring children's skills needed to engage in play; adapting play materials, objects, and environments to facilitate optimal play experiences; and advocating for safe, inclusive play environments that are accessible to all. (p. 707)

Adapting play materials, objects, and environments might begin simply with determining through child observation and caregiver interview what opportunities and barriers exist. Making changes in the physical environment as well as training parents, caregivers, and service providers in effective ways to promote play can result in increased participation and satisfaction in the occupation of play (Hamm, 2006).

Toy modifications. Mistrett, Lane, and Goetz (2000) suggested these simple environmental and toy modifications:

- **Attachers** bring items closer to the child to facilitate reaching and grasping, such as hooks and loops made of fabric, curtain rings, or elastic.
- **Extenders** build up certain access features making them easier to grasp and manipulate, such as knobs on puzzle pieces and foam roller "handles."
- **Stabilizers** prevent a toy from moving out of reach or stabilize it for exploration, such as hooks and loops made of fabric, suction cups, and non-skid shelf liners.
- **Confiners** keep toys from moving out of reach, such as box lids and raised edged trays. Confiners can also be used to define play space with items such as hula-hoops and carpet squares.

Accessible playgrounds. Play is a primary childhood occupation that contributes to physical and mental health benefits. For example, research indicates that recess is associated with improved behavior and attention (Jarrett, 2013). Embedded in playground experiences are opportunities to collaborate, socialize, strategize, negotiate, and compromise. Modern playgrounds often include structures that connect many different pieces of equipment, which can be used to create routes to navigate or exercise routines. Often playgrounds offer additional features such as areas for playing other games or sports, such

as basketball and tennis courts, a baseball diamond, horseshoe pits, and so on.

Play is a basic right and rite of childhood that enhances development and brings children of differing perspectives and ability levels together to develop social skills and learn about behavior, communication, acceptance, and friendship. Consistent with the original purpose of ADA, public play areas are now required to apply the ruling to the design, planning, and layout of outdoor play areas in public areas. The Architectural and Transportation Barriers Compliance Board (or, the U.S. Access Board) develops accessibility guidelines for buildings and facilities covered by ADA. The U.S. Access Board's (2007) guide on play areas includes recommendations for

- ***Ground-level play components***, which can be approached and exited at ground level, such as spring rockers, swings, and stand-alone climbers; and
- ***Elevated play components***, which are above or below grade and are part of composite structures that provide a variety of play activities.

For more information, see U.S. Access Board's website on play areas (<http://www.access-board.gov/guidelines-and-standards/recreation-facilities/guides/play-areas>). The guide on play areas provides design criteria for play components that are considered essential for accessibility, including

- Space for wheelchair maneuvering to and from the play component,
- Wheelchair space at the play component,
- Height and clearances of play tables,
- Height of entry points or seats, and
- Provision of transfer supports (e.g., a graspable edge or some other means of support).

Children instinctively seek sensory challenges and experiences they need for their development. Universal playground design should include opportunities for visual, tactile, kinesthetic, and auditory exploration along with the traditionally associated vestibular experiences provided by movement through space.

When considering the total playground layout, diversity in all these areas is important. Children who have limited mobility or use positioning or mobility equipment should be provided with

alternatives when safely possible. An accessible route should lead to the playground and other play activities, and have space for the participants and their caregivers for maneuvering and transfers.

Improving End of Life: The Final Transition

Occupational therapy practitioners' role in *end of life*, including hospice care, is to adapt the environment and activity demands to maintain functional performance, participation, and quality of life while preventing discomfort. Modifying the demands of the activity to fit with the abilities of the client will not prolong life but may allow the client to continue to be engaged in occupational roles. Interventions may occur directly with the client or with the client and the client's caregivers. Occupational therapy can offer the caregivers support and education. Improved quality of life is progress in hospice care (AOTA, 2005b).

Considering Individuals, Groups, and Populations

Acting on behalf of an *individual* may mean visiting a playground with a child or caregiver, and brainstorming how the child can best participate by suggesting strategies and modifications. An example of acting on behalf of *groups* might include advocating for the health and social benefits of recess in schools. Acting on behalf of *populations*, practitioners provide consultation to towns, museums, zoos, and others on using UD principles in designing public parks, gardens, zoos, and museums so they are more accessible to all people.

Social Environment

Many gathering places such as churches, malls, and movie theaters are providing an increasing variety of environmental modifications to allow families to gather and engage in desired and meaningful activities outside of the home, together. Libraries offer print materials in a variety of formats and story times delivered in alternative formats. Movie theaters offer companion seating to allow guests in wheelchairs to sit next to their movie-going companions. Some have descriptive video for guests who are sight impaired. Assisted listening devices for individuals with hearing impairments,

including frequency modulation systems (i.e., transmitter hooked up to the sound system which sends the audio to a receiver), can be found in movie theaters, churches, conference centers, and museums.

Caregiving

Part of the social environment of a person with a disability might include his or her support systems, including caregivers. **Caregivers** provide physical and emotional support to those requiring assistance during times of illness, disability, or emotional distress. They are often family members but additionally could include child care providers, classroom assistants, home health aides, paid companions, and others. **Caregiving** is a shared occupation involving an interaction between the caregiver and the recipient (AOTA, 2014). This shared relationship involves experiences and feelings that can be rewarding or frustrating.

Occupational therapy practitioners should consider these interactions as part of client-centered care. If the caregiver is not able to fulfill his or her role due to poor training, limited understanding of the client's needs, over-protectiveness, or burnout, the client's level of participation is also altered.

Sheehy (2010) equated caregiving with walking a labyrinth. Using that metaphor and making the distinction that a labyrinth has a specific route to the center and back out, Sheehy identified turning points, or transitions, in the journey of caregiving, and described them as nonlinear but universal in taking individuals involved from the role of caregiver to the role of care manager:

- *Shock and mobilization*—when life changes forever
- *The new normal*—when new roles materialize out of necessity
- *Boomerang*—just when new routines and occupations have been established, another crisis hits;
- *Playing God*—when the caregiver feels he or she is the only one who completely understands the situation and is able to meet the client's needs
- *"I can't do this anymore"*—when the caregiver experiences burnout
- *Coming back*—acceptance, letting go of old dreams and roles, and getting on with life
- *The in-between stage*—when nothing really seems to change
- *The long good-bye*—although Sheehy equates this stage to providing care to those who are

chronically or terminally ill, it could also be considered the gradual replacement of pre-disability expectations with new ones, and the less frequent reminders of life "before."

When providing transition services it is important to determine which family members will be supporting the individual during transition or affected by the transition, and what their roles will be. Caregiver support can include guidance and strategies for providing care for the individual, referral to other services and resources, and emotional support. A caregiver may also need assistance in establishing and maintaining his or her occupational profile and engaging in meaningful occupations outside of the caregiving responsibilities.

Interactions in the Social Environment

Communication among stakeholders is an essential part of supporting all life transitions. It is important to develop an environment of mutual respect and acceptance in order to establish and maintain meaningful interactions. It is possible that some interactions may need to take place over distance and time, requiring negotiations about how (e.g., physical, electronically) and when to meet. Maintaining professional courtesy and communicating effectively help create an environment that is conducive to providing necessary and accessible information.

Communication

Collaboration depends on effective communication among all vested parties. Timely, consistent, and constructive communications can be a challenge. Communication occurs on many levels and it is important to understand the communication styles and competencies of all stakeholders. Communicating in understandable terms without medical jargon is only the beginning of effective communication. With the use of technology, including telephones and email, the nuances of gestures and facial expressions as a form of communication are lost. Communicating exclusively through print may affect those with print disabilities or whose primary language is not English. Creating a safe and open environment for communication begins with occupational therapy practitioners.

In her study of the transition experiences from school to adult life of students with disabilities and their families, Orentlicher (2008) found that a major barrier for effective transition was poor communication between families and service providers. Families expressed a desire for better communication, including returning phone calls and emails in a timely manner, inviting family members to meetings in which the student is discussed, reporting on progress on the transition plan, and notifying families of any changes to the plan or other decisions. Both family members and service providers agreed that the responsibility for initiating and maintaining positive communication lies with the service providers.

Cultural effectiveness

Another important aspect of positive interaction in the social environment is the practice of cultural effectiveness. **Cultural effectiveness** is demonstrated by understanding and appreciating differences in health beliefs and behaviors, recognizing and respecting variations that occur within cultural groups, and adjusting practice to provide effective interventions for people from various cultures (AOTA, 2014). For example, being sensitive to the ways different cultures address assertiveness, eye contact, or personal space can help avoid assumptions based on how the client appears to receive and respond to information.

Cultural sensitivity also means developing a non-judgmental approach to accepting people's transition choices. For example, a person might choose to live in a nursing home, even when the practitioner might value, prefer, and recommend living at home.

Developing cultural effectiveness results in the ability to understand, communicate with, and effectively interact with people across cultures and allows occupational therapy practitioners to be objective and accept differences in their clients' values. Creating a nonjudgmental environment enhances the therapeutic relationship between clients and therapists.

Funding for Transition

In nearly all circumstances, transitions cost money. For example, persons experiencing a change in health may require interior and exterior modifications to their homes so they can continue to live independently or receive care in their residence. These

costs can be prohibitive, especially when considering the other expenses associated with a disabling or chronic health condition. It is important for clients, family members, caregivers, health care professionals, educators, rehabilitation specialists, and others to be informed about public and private financing options.

Children and Youth

Transition services for children transitioning from early intervention to preschool and from high school to adult life are mandated by, and therefore funded by IDEA (see Chapter 3, "Early Childhood Transitions," and Chapter 5, "Transition From School to Adult Life," for more information about transition mandates in IDEA). Although transition throughout school is not directly covered (see Chapter 4, "Transition Within School," for more information on supporting students during school transitions), transition-focused goals may be included in a student's individualized education program (IEP). The implementation of an IEP is funded by IDEA.

Specialized equipment that would assist a student during transition, such as an augmentative communication device, may be covered using IDEA funds, Medicaid, private insurance, or through state AT programs.

Adults and Older Adults

Community integration

To help people with disabilities transition into the community and manage their needs, Medicaid programs provide funding for **long-term support services (LTSS)**, which are state-based programs that provide medical and nonmedical services to people with disabilities and include services that aid in the home or institutional setting.

The majority of LTSS funds are distributed through **home- and community-based services (HCBS) waiver programs** (Rizzolo, Friedman, Lulinski-Norris, & Braddock, 2013). The HCBS waiver programs were established to support individuals in their communities while waiving the requirement for institutionalization in long-term care facilities. Funding is now available for a range of home and community services on a long-term basis as alternatives to institutional care. The HCBS waiver

programs vary from state to state; reimbursable services may include behavior management, respite care, habilitation training, employment, and other forms of therapy.

Many states now offer HCBS waiver programs that are self-directed, which allow Medicaid HCBS waiver recipients to manage a monthly or yearly cash allowance that is, in many states, equivalent to the expenditure of a traditional service budget (Crozier, Muechberger, Colley, & Ehrlich, 2014). Instead of receiving state-mandated services, the individual has the freedom to choose and purchase services depending on his or her needs (Orentlicher, 2011). These funding options offer many opportunities for individuals who are transitioning to life in the community and looking to engage in meaningful occupations. Consultation with a **Medicaid service coordinator** can help determine which waiver program is most suitable for the person, and what services will be funded.

A similar Medicaid program that can support the transition of older adults back home after suffering an illness or an injury is the **Program of All-Inclusive Care for the Elderly (PACE)**; National PACE Association, 2002). PACE is based on the principle that it is better for the well-being and quality of life of seniors with chronic care needs and their families to be served in the community whenever possible. The program serves individuals 55 years old or older, who are certified by their state to need nursing home care, able to live safely in the community, and live in a PACE service area (National PACE Association, 2002).

PACE services include

- Adult day care that offers nursing; physical, occupational, and recreational therapies; meals; nutritional counseling; social work and personal care;
- Medical care;
- Home health care and personal care;
- Prescription drugs;
- Social services;
- Medical specialties, such as audiology, dentistry, optometry, podiatry, and speech therapy;
- Respite care; and
- Hospital and nursing home care when necessary.

Employment

State **vocational rehabilitation (VR)** services offer funding for a range of employment and independent

living services that may be required by persons with disabilities throughout the lifespan with a goal of promoting a greater level of independence in work and living environments. Typically, the VR office coordinates transition services for students with disabilities from school to adult services; vocational rehabilitation services for working-age persons with disabilities; independent living services for people with disabilities of all ages; and business services for hiring a qualified diverse workforce.

Plan for Achieving Self Support is an SSI work incentive that allows the use of personal income or assets to reach employment goals. Rather than losing unemployment benefits such as SSI, the person with disabilities can set aside the money for education, specialized training for a job, or to start a business.

Workers' compensation is a state-managed program that provides benefits and care for workers injured on the job. It provides benefits such as recovery of lost wages, medical treatment, and compensation for permanent disability. Many states' workers' compensation programs also provide vocational retraining and return-to-work programs (Nolo, 2014). Some workers are able to return to work with accommodations or modifications to the work environment, schedule, or job requirements.

Home modifications and assistive technology

HUD administers two programs that can help people with disabilities finance home modifications via the Federal Housing Administration. Under the Title I program, approved lenders make loans from their own funds, insured by HUD, to finance property improvements.

For people ages 62 years or older with low income, the Section 504 Rural Housing Grant Program may be used for repairs and improvements that will improve health and safety hazards or to repair or remodel residences to make them more accessible and usable for members of the household with disabilities.

Eligible veterans may receive home loans as well as grants for home improvements needed to provide access to the home. Three different types of grants are available through the U.S. Department

of Veterans Affairs that allow veterans with disabilities to make home accommodations:

1. Special Housing Adaptation program for building, buying, or remodeling a home that is specially adapted to the needs of a veteran whose disability is service related
2. Special Housing Adaptation program home modifications for veterans who have a service-connected loss of the use of both hands or are blind
3. Home Improvement and Structural Alteration program for making home accommodations.

Private insurance or Medicaid may cover some amount of durable medical equipment if prescribed by a physician. Additional funds for specialized equipment for people in need may be obtained from family-based wills and trusts, some banks, trust companies, and savings and loan institutions, special interest groups, church groups, and community service organizations (e.g., Knights of Columbus, Masons, Lions, Kiwanis, Rotary).

Note that equipment and accommodations installed for medical purposes may be tax deductible. Practitioners should encourage clients to review all possible tax implications with their accountant.

Summary

The environment affects a person's health condition and participation in meaningful activities, tasks, and life roles. NIDRR encourages us to think of *participation* in terms of providing environmental modifications, so people with disabilities are better able to transition to and within a variety of environments. Addressing transition may involve environmental modifications to support mental or physical health, daily routines, a job, or relationships with other persons; or may pertain to the infrastructure of a community. Appendix 10.A provides resources for supportive environments for transitions.

Occupational therapy practitioners are specifically trained to recognize the impact of transition on individuals and influence outcomes when barriers are identified. Challenges and opportunities for occupational therapy practitioners include collaborating with clients and consumers, expanding practice scope and settings, collection of data that demonstrates the power of the environment to influence lives, and the provision of environmental intervention training within occupational therapy programs (Letts, Rigby, & Stewart, 2003, p. 294).

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References

- ADA Amendments Act of 2008, Pub. L. 110–325 (S. 3406) 42 USCA § 12101 note.
- American Occupational Therapy Association. (2005a). *Home modifications and occupational therapy*. Retrieved from <http://www.aota.org/-/media/Corporate/Files/AboutOT/Professionals/WhatIsOT/PA/Home-Mod.pdf>
- American Occupational Therapy Association. (2005b). Occupational therapy and hospice. *American Journal of Occupational Therapy*, 59, 671–675. <http://dx.doi.org/10.5014/ajot.59.6.671>
- American Occupational Therapy Association. (2008). AOTA's societal statement on play. *American Journal of Occupational Therapy*, 62, 707–708. <http://dx.doi.org/10.5014/ajot.62.6.707>
- American Occupational Therapy Association. (2012). *Driving and transportation options for older adults*. Retrieved from <http://www.aota.org/-/media/Corporate/Files/AboutOT/Professionals/WhatIsOT/PA/Driving-Aging.pdf>
- American Occupational Therapy Association. (2014). Occupational therapy practice framework: Domain and process (3rd ed.). *American Journal of Occupational Therapy*, 68(Suppl. 1), S1–S48. <http://dx.doi.org/10.5014/ajot.2014.682006>
- American Occupational Therapy Association. (2015a). Complex environmental modifications. *American Journal of Occupational Therapy*, 69(Suppl. 3), 6913410010. <http://dx.doi.org/10.5014/ajot.2015.696S01>
- American Occupational Therapy Association. (2015b). Occupational therapy's perspective on the use of environments and contexts to facilitate health, well-being, and participation in occupations. *American Journal of Occupational Therapy*, 69(Suppl. 3), 6913410050. <http://dx.doi.org/10.5014/ajot.2015.696S05>
- Americans With Disabilities Act of 1990, Pub. L. 101–336, 42 U.S.C. §§ 12101–12213.
- Arbesman, M., & Pellerito, J. M. (2008). Evidence-based perspective on the effect of automobile-related modifications on the driving ability, performance, and safety of older adults. *American Journal of Occupational Therapy*, 62, 173–186. <http://dx.doi.org/10.5014/ajot.62.2.173>
- Arce, J., & Smith, K. B. (2010, March). Using the virtual community: Facilitating role development with an adult

- with developmental disabilities. *Developmental Disabilities Special Interest Section Quarterly*, 33, 1–3.
- Bates, P. E., & Davis, F. A. (2004). Social capital, social inclusion and services for people with learning disabilities. *Disability and Society*, 19(3), 195–207.
- Baum, C. M., & Christiansen, C. H. (2005). Person–Environment–Occupation–Performance: An occupation-based framework for practice. In C. H. Christiansen, C. M. Baum, & J. D. Bass-Haugen (Eds.), *Occupational therapy: Performance, participation, and well-being* (pp. 242–267). Thorofare, NJ: Slack.
- Bucks, R. S., Ashworth, D. L., Wilcock, G. K., & Siegfried, K. (1996). Assessment of activities of daily living in dementia: Development of the Bristol Activities of Daily Living Scale. *Age and Aging*, 25, 113–120. <http://dx.doi.org/10.1093/ageing/25.2.113>
- Carl D. Perkins Career and Technical Education and Improvement Act of 2006, Pub. L. 109–270, 120 Stat. 683.
- Center for Universal Design. (1997). *The principles of universal design*. Retrieved from http://www.ncsu.edu/ncsu/design/cud/about_ud/udprinciplestext.htm
- Christiansen, M. A. (1999). Embracing universal design. *OT Practice*, 4(9), 12.
- Classen, S., Dickerson, A., & Justiss, M. D. (2012). Occupational therapy driving evaluation: Using evidence-based screening and assessment tools. In M. McGuire & E. Schold Davis (Eds.), *Driving and community mobility: Occupational strategies across the lifespan* (pp. 221–278). Bethesda, MD: AOTA Press.
- Cook, A. M., & Polgar, J. M. (2008). *Cook and Hussey's assistive technologies: Principles and practice*. Maryland Heights, MO: Mosby/Elsevier.
- Coster, W., Deeney, T., Haltiwanger, J., & Haley, S. (1998). *School Function Assessment*. San Antonio, TX: Psychological Corp.
- Craig Hospital Research Department. (2001). *Craig Hospital Inventory of Environmental Factors (CHIEF)*. Retrieved from <http://www.craighospital.org/repository/documents/Research%20Instruments/CHIEF%20Manual.pdf>
- Crozier, M., Muechberger, H., Colley, J., & Ehrlich, C. (2014). The disability self-direction movement: Considering the benefits for an Australian response. *Australian Journal of Social Issues*, 48(4), 455–596.
- Day, H., & Jutai, J. (1996). Measuring the psychosocial impact of assistive devices: The PIADS. *Canadian Journal of Rehabilitation*, 9(2), 159–168.
- Dijkers, M. (2000). *The Community Integration Questionnaire (CIQ)*. Retrieved from <http://www.tbims.org/combi/ciq>
- Emerson, R. W. (1847/1973). *The journals and miscellaneous notebooks of Ralph Waldo Emerson: 1847–1848*. Cambridge, MA: Belknap Press.
- Fair Housing Amendments Act of 1988, Pub. L. 100–430, 102 Stat. 1619.
- Fisher, A. G., Bryze, K., Hume, V., & Griswold, L. A. (2012). *School AMPS: School version of the Assessment of Motor and Process Skills manual* (2nd ed.). Fort Collins, CO: Three Star Press.
- Hamm, E. (2006). Playfulness and the environmental support of play in children with and without developmental disabilities. *OTJR: Occupation, Participation, and Health*, 26(3), 88–96.
- Higher Education Opportunity Act, Pub. L. 110–315 20 U.S.C. 1002 § 103 (2008).
- Holm, M. B., & Rogers, J. C. (2008). The Performance Assessment of Self-Help Skills (PASS). In B. J. Hemphill-Pearson (Ed.), *Assessments in occupational therapy mental health: An integrative approach* (2nd ed., pp. 101–112). Thorofare, NJ: Slack.
- Jarrett, O.S., (2013). *A researched-based case for recess*. Retrieved from <http://usplaycoalition.clemson.edu/blogs.php?id=17>
- Kohlman Thomson, L. (1992). *KELS: Kohlman Evaluation of Living Skills* (3rd ed.). Rockville, MD: American Occupational Therapy Association.
- Improving Access to Assistive Technology for Individuals With Disabilities Act of 2004, Pub. L. 108–364, 118 Stat. 1707.
- Individuals With Disabilities Education Improvement Act of 2004, Pub. L. 108–446, 20 U.S.C. §§ 1400–1482.
- Law, M., Baptiste, S., Carswell, A., McColl, M. A., Polatajko, H., & Pollock, N. (2005). *Canadian Occupational Performance Measure* (4th ed.). Toronto, ON: Canadian Association of Occupational Therapists.
- Law, M., Cooper, B., Strong, S., Stewart, D., Rigby, P., & Letts, L. (1996). The Person–Environment–Occupation model: A transactive approach to occupational performance. *Canadian Journal of Occupational Therapy*, 63, 9–23.
- Letts, L., Rigby, P. & Stewart, D. (2003). Using environments in occupational therapy: Challenges and future directions. In L. Letts, P. Rigby, & D. Stewart (Eds.), *Using environments to enable occupational performance* (pp. 287–296). Thorofare NJ: Slack.
- Meuser, T. M., Berg-Weger, M., Chibnall, J. T., Harmon, A. C., & Stowe, J. N. (2013). Assessment of Readiness for Mobility Transition (ARMT): A tool for mobility transition counseling with older adults. *Journal of Applied Gerontology*, 32, 484–507. <http://dx.doi.org/10.1177/0733464811425914>
- Mistrett, S., Lane, S., & Goetz, A. (2000). *A professional guide to assisting families in creating play environments for young children with disabilities*. Retrieved from <http://letsplay.buffalo.edu/products/PlayManual.pdf>
- MOHO Web. (2015). *Model of Human Occupation: Theory and application*. Retrieved from <http://www.cade.uic.edu/moho/resources/about.aspx>
- Moore-Corner, R. A., Kielhofner, G., & Olson, L. (1998). *Work Environment Impact Scale (WEIS)*. Chicago: University of Illinois at Chicago: MOHO Clearinghouse.
- Moos, R. H. (1994). *Life Stressors and Social Resources Inventory—Adult and Youth (LISRES-A and LISRES-Y)*. Lutz, FL: PAR.

- National Center on Universal Design for Learning. (2014). *The three principles of UDL*. Retrieved from <http://www.udlcenter.org/aboutudl/whatisudl/3principles>
- National Institute on Disability and Rehabilitation Research. (1999). *NIDRR's long-range plan for fiscal years 1999–2003*. Washington, DC: U.S. Department of Education.
- National Institute on Disability and Rehabilitation Research. (2008). *Frequently asked questions (FAQs) about NIDRR*. Retrieved from <http://www.ed.gov/about/offices/list/osers/nidrr/faq.html>
- National PACE Association. (2002). *What is PACE?* Retrieved from http://www.npaonline.org/website/article.asp?id=12&title=Who,_What_and_Where_Is_PACE
- Nolo. (2014). *An overview of workers' comp law: When you are covered, what benefits you'll get, and how to file a claim*. Retrieved from <http://www.disabilitysecrets.com/resources/workers-compensation-law.htm>
- Oliver, M. (1990). *The politics of disablement: A sociological approach*. New York: St. Martin's Press.
- Oliver, M. (1996). *Understanding disability: From theory to practice*. New York: St. Martin's Press.
- Orentlicher, M. L. (2008). *Striving for typical: Collective experiences of person-centered planning for young adults with disabilities during transition* (Unpublished dissertation), New York University
- Orentlicher, M. L. (2011, January 24). Person-centered planning: An innovative approach for transition planning. *OT Practice*, 16, CE1–CE8.
- Ostroff, E., Limont, M., & Hunter, D.G. (2002). Building a world fit for people: Designers with disabilities at work. *PN: Paraplegia News*, 56(10), 76.
- Patient Protection and Affordable Care Act, Pub. L. 111–148, 42 U.S.C. §§ 18001–18121 (2010).
- Rehabilitation Act of 1973, 29 U.S.C. § 701, Pub. L. 93–112.
- Ringaert, L. (2003). Universal design of the built environment to enable occupational therapy performance. In L. Letts, P. Rigby, & D. Stewart (Eds.), *Using environments to enable occupational performance* (pp. 97–115). Thorofare, NJ: Slack.
- Rizzolo, M., Friedman, C., Lulinski-Norris, A., & Braddock, D. (2013). Home- and community-based service waivers: A nationwide study of the states. *Intellectual and Developmental Disabilities*, 51(1), 1–21.
- Scherer, M. J. (Ed.). (2002). *Assistive technology: Matching device and consumer for successful rehabilitation*. Washington, DC: American Psychological Association.
- Shakespeare, T., & Watson, N. (2002). The social model of disability: An outdated ideology? *Research in Social Science and Disability*, 2, 9–28.
- Shaw, L., Miller Polgar, J., Vrkljan, B., & Jacobson, J. (2010). Seniors' perceptions of vehicle safety risks and needs. *American Journal of Occupational Therapy*, 64, 215–224. <http://dx.doi.org/10.5014/ajot.64.2.215>
- Sheehy, G. (2010). *Passages in caregiving: Turning chaos into confidence*. New York: HarperCollins.
- Siebert, C., Smallfield, S., & Stark, S. (2014). *Occupational therapy practice guidelines for home modifications*. Bethesda, MD: AOTA Press.
- Stark, S. L., Somerville, E. K., & Morris, J. C. (2010). In-Home Occupational Performance Evaluation (I-HOPE). *American Journal of Occupational Therapy*, 64, 580–589. <http://dx.doi.org/10.5014/ajot.2010.08065>
- Stav, W. (2015). *Occupational therapy practice guidelines for driving and community mobility for older adults*. Bethesda, MD: AOTA Press.
- Stoller, L. C. (1998). *Low-tech assistive devices: A handbook for the school setting*. Framingham, MA: Therapro.
- U.S. Access Board. (2007). *Accessible play areas: A summary of accessibility guidelines for play areas*. Retrieved from <http://www.access-board.gov/guidelines-and-standards/recreation-facilities/guides/play-areas>
- Vrkljan, B. H., & Miller Polgar, J. (2005). Advancements in vehicular technology: Potential implications for the older driver. *International Journal of Vehicle Information and Communication Systems*, 1, 88–105.
- Walker, K. A., Morgan, K. A., Morris, C. L., DeGroot, K. K., Hollingsworth, H. H., & Gray, D. B. (2010). Development of a community mobility skills course for people who use mobility devices. *American Journal of Occupational Therapy*, 64, 547–554. <http://dx.doi.org/10.5014/ajot.2010.08117>
- Zabala, J. (2005). *Using the SETT Framework to level the learning field for students with disabilities*. Retrieved from http://www.joyzabala.com/uploads/Zabala_SETT_Leveling_the_Learning_Field.pdf
- Zabala, J., Bowser, G., Blunt, M., Hartsell, K., Carl, D., Korsten, J., ... Reed, P. (2000). Quality indicators for assistive technology services in school settings. *Journal of Special Education Technology*, 15(4), 25–36.
- Zahoransky, M. (2009, December). Community mobility: It's not just driving anymore. *Home and Community Health Special Interest Section Quarterly*, 16, 1–3.

Appendix 10.A. Resources for Supportive Environments for Transition

General Resources

- **Center for Universal Design at North Carolina State University:** http://www.ncsu.edu/www/ncsu/design/sod5/cud/pubs_p/pudpcountdown.htm
Includes many free resources for those interested in UD. One of these resources is a checklist to help individuals think about their own needs and those of potential users when selecting products.
- **Practical Guide to Universal Home Design:** <http://n.b5z.net/i/u/10125099/f/Practical-GuideUniversalHome2011.pdf>
A free publication with practical guidelines for home design.
- **Rehabilitation Engineering Research Center on Wheelchair Transportation Safety at the University of Michigan:** <http://www.travelsafer.org>
A resource for information regarding safe travel in motor vehicles for persons seated in mobility equipment such as wheelchairs.
- **National Center for the Safe Transportation of Children With Special Healthcare Needs:** <http://www.preventinjury.org>
A resource for families, health care professionals, transportation providers, and child passenger safety advocates. An occupational therapist trained to identify the appropriate child safety restraint required for a broad range of health conditions is available for consultation.
- **National Association of State Directors of Pupil Transportation Services:** <http://nasdpts.org/index.html>
A collection of information pertaining to safe transportation of young children with disabilities can also be found on this website.
- **Safe Routes to School National Partnership:** <http://www.saferoutespartnership.org/home>
A fast-growing network of hundreds of organizations, government agencies, and professional groups working to set goals, share best practices, leverage infrastructure and program funding, and advance policy change to help agencies that implement

Safe Routes to School programs. The National Center for Safe Routes to School established a National Review Group comprised of more than 30 transportation, education, health, and advocacy leaders to provide advice and feedback on the goals and objectives of the National Center, including Sandra Schefkind from AOTA. This provides another example of serving the client as a “population.”

- **CarFit:** <http://www.car-fit.org/>

A free, community-based program for adults 65 years or older, was created by the American Society on Aging and developed in collaboration with AOTA, AAA, and AARP. The program, which is designed to be offered locally by trained individuals, teaches older drivers about how aging affects the way they fit in their vehicle, how their driving can be affected, and how to adjust and “fit” themselves in their cars to improve their safety and community mobility. For more information on CarFit See Chapter 7, “Transition and Aging.”

- A group of occupational therapy students created a **video to promote the importance of play**, the need for accessible playgrounds, and occupational therapy’s role in designing and advocating for accessible playgrounds: <http://www.youtube.com/watch?v=oqavAgSbQ8U>
- **State assistive technology programs:** <http://resnaprojects.org/allcontacts/statewidecontacts.html>
- **Information about PASS:** <http://www.ssa.gov/disabilityresearch/wi/pass.htm> or <http://www.ilr.cornell.edu/edi/pass/>

AOTA Resources

- **AOTA resources on environmental interventions:** <http://www.aota.org/Practice/Work-Industry/Emerging-Niche/New-Technology-at-Work.aspx>
- **Fact sheet on universal design for learning:** <http://www.aota.org/-/media/Corporate/Files/AboutOT/Professionals/WhatIsOT/CY/Fact-Sheets/UDL%20fact%20sheet.pdf>
- **FAQ on youth transportation:** <http://www.aota.org/-/media/corporate/files/secure/practice/children/faq-safe-youth-transportation-july-2014.pdf>

- **AOTA position paper:** Occupational Therapy's Perspective on the Use of Environments and Contexts to Support Health and Participation in Occupations (see Appendix D), *American Journal of Occupational Therapy*, 2010, Vol. 64(Suppl.), pp. S57–S69. <http://dx.doi.org/10.5014/ajot.2010.64S57>
- **AOTA official document:** Specialized Knowledge and Skills in Technology and Environmental Interventions for Occupational Therapy Practice, *American Journal of Occupational Therapy*, 2010, Vol. 64(Suppl.), pp. S44–S56. <http://dx.doi.org/10.5014/ajot.2010.64S44>

CHAPTER 11.

TRANSITION IN PREVENTION AND WELLNESS

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Chapter Objectives

After reading this chapter, readers will be able to

- ❖ Describe the connections among role attainment, transitions, and health and wellness;
- ❖ Identify the nature and impact of stress in role transitions through the lifespan; and
- ❖ Explain the distinct role of occupational therapy in facilitating healthy transitions and promoting and maintaining health and wellness in occupational performance.

Key Terms and Concepts

- ❖ Adaptation
- ❖ Adrenal gland
- ❖ Beliefs
- ❖ Biopsychological dysregulation
- ❖ Caregiving
- ❖ Care recipient
- ❖ Chronic stress response
- ❖ Coaching
- ❖ Companionship
- ❖ Consultation
- ❖ Coping frame of reference
- ❖ Cortisol
- ❖ Ecology of family situations
- ❖ Gerotranscendence
- ❖ Healthy habits and routines
- ❖ Healthy lifestyle
- ❖ Hypothalamic–pituitary–adrenocortical system
- ❖ Hypothalamus
- ❖ Learned helplessness
- ❖ Leisure
- ❖ Life balance
- ❖ Life Balance Model
- ❖ Life transitions
- ❖ Mindfulness
- ❖ Occupational deprivation
- ❖ Optimism
- ❖ Possible selves
- ❖ Psychoeducational groups
- ❖ Restorative sleep
- ❖ Role demands
- ❖ Roles
- ❖ Role strain
- ❖ Social support
- ❖ Spirituality
- ❖ Stress
- ❖ Values

People confront numerous transitions across their lifespan. Some are universal transitions that all people experience, and others are specific to a particular stage of life as a result of life circumstance or health condition. Successfully negotiating the personal, social, environmental, occupational, and activity demands and adaptively reorganizing one's life in response to shifts in roles require a capacity to weather the stress associated with change.

When stress is not managed, physical, cognitive, and psychosocial adaptations are threatened. To manage stress and promote well-being, people need to establish and maintain healthy roles and routines during times of predictable or typical change and unpredictable or atypical change. During these times of increased stress, adaptations must occur. Occupational therapy has a role in prevention and promotion of healthy routines and in preparation for these times of transition.

This chapter explores the connections among role attainment, transition, and health and wellness; role development, components of role strain, and the nature and impact of stress in role transitions through the lifespan; and occupational therapy's role in facilitating healthy transitions and promoting and maintaining clients' health and wellness in occupational performance. The chapter refers to Renzo's story ("Prologue"), the early childhood transitions of Mikala (Chapter 3, "Early Childhood Transitions"), James's transitions in schools (Chapter 4, "Transition Within School"), and Emma's transitions in aging (Chapter 7, "Transition and Aging").

Understanding Role Development and Role Strain

Roles are "sets of behaviors expected by society and shaped by culture and context" (American Occupational Therapy Association [AOTA], 2014b, p. S27). Roles define who we are; provide purpose and structure to our daily lives; and shift in response to our physical, social, and mental development. They also shift in response to needs or demands presented by a person's social systems, including family, work, and community. For example, a single mother who works outside of the home may work more hours and shifts to support her family compared with a married stay-at-home parent who may devote more hours caring for his or her spouse's daily needs.

How successfully a person can transition depends, in part, on how actively he or she is engaged in current roles, how deeply he or she identifies with these roles, and how well prepared he or she is for the change. In times of transition, people may need to reconfigure how they carry out current roles to accommodate new ones. For example, a new parent must adjust his or her work and recreation time to allow for child care responsibilities.

Role strain is the stress people experience when the expectations or responsibilities of a role or competing roles exceed their capacities for meeting **role demands** (i.e., the expected behaviors and competencies needed to be perceived as effective in a role). Role strain is common during transitions and occurs when a person is stressed from struggling to meet the expectation of a new identity, such as entering school and becoming a student or becoming a parent. People in transition may find it difficult to adequately fulfill current obligations while simultaneously fulfilling personal and skill demands associated with newly emerging roles.

Experience of role strain is affected by the number of current roles a person has and whether the transition to a new role results in a loss of or change in relationship patterns.

Number of Current Roles

The number of current roles that shape a person's identity and occupy his or her time influences the intensity of the impact of changing roles in transition. When considering role strain, it is important to remember that engaging in too few roles may be more disabling to a person's sense of well-being than experiencing too many role demands (Kielhofner, 2008). Having multiple roles allows people to explore and express different sides of themselves and to have different opportunities to develop interpersonal relationships for companionship and support. It provides a cushion when a person's capacity to participate in any particular role is thwarted.

Loss of or Change in Relationship Patterns

A second component in role strain is the loss of or change in the patterns of interpersonal relationships and interactions (Jetten, Haslam, Iyer, & Haslam, 2010). Routine relationships typically provide a sense

of stability, security, and social support. In periods of transition, such as when a person moves to a new environment or takes on new roles, lack of frequent contact may weaken these relationships. As the person grieves the loss of familiar relationships and a comfortable pattern of interaction, new relationships and new patterns of interactions have not yet developed, thereby reducing support for taking on new roles. For example, a person transitioning into retirement may lose supportive relationships he or she developed with coworkers.

Gutman's (2000) study of young men who experienced a traumatic brain injury exemplified the effect of role strain on relationships. After their injuries, the young men had substantial losses in life roles such as worker and in role-related relationships such as coworker or friend. Through the losses, the young men's identities deteriorated and they became marginalized. They experienced limited role participation and few interpersonal relationships beyond their paid caregivers. Through occupational therapy assessment and intervention, Gutman guided the men in identifying the multiple roles that each wanted to rebuild and exploring the specific key activities that they would need to participate in for successful role enactment.

Lifespan Examination of Role Strain

Role strain is experienced by people of all ages and life circumstances. The following sections discuss role strain across the lifespan—in children, young adults, adults, and older adults.

Role Strain in Children and Young Adults

Children and young adults can face role strain in their student role, family and social roles, and other roles. Typically developing young adults can experience role strain when transitioning to new roles such as college student, spouse, or worker. Hettich (2010) studied young adults transitioning from the role of full-time college student to the role of full-time worker and advocated for workplace supports in the form of mentorship and education to facilitate successful and healthy transitions of young adults into the workforce. The study highlighted several losses these young

adults experienced, including relinquishing some control over their daily schedules, having less leisure time, and having less opportunity to demonstrate independent thinking in the workplace. In the process of adjusting to their new full adult status, participants struggled with making adjustments to the habits and routines of their former roles as college students and experienced role strain.

Role Strain in Adulthood and Older Adulthood

Role strain may be experienced in adulthood as a result of juggling many roles such as work, homemaking, family and spouse, social and community, and caregiver roles. Role strain is common in the transition to parenthood. New parents may have underestimated the amount of time required to care for an infant and struggle to meet the needs of their newborns while also fulfilling demands of other roles such as full-time worker or spouse (Newman, 2000). They may experience additional stress as a result of disagreements with their partners about how to carry out parenting roles or may receive competing advice or criticism from others in their social network.

In reporting on a study of young low-income working mothers, Morris and Coley (2004) concluded that although these mothers may experience additional social support and increased self-esteem if they work outside the home, it is important to consider the role strain of fulfilling the demands of motherhood and paid employment. They advocated for more study and adjustment of work ecologies so that resources are directed to support working mothers in balancing their roles and the demands of each role. When mothers have difficulty meeting worker role demands and balancing them with the role of mother, they are less likely to demonstrate optimal parenting practices, more likely to have diminished satisfaction with parenting, and more likely to have children who exhibit behavior problems (Morris & Coley, 2004).

Older adults are vulnerable to role strain during transitions such as to parent of adult children, to grandparent, and to caregiver. Changes in the spousal role, such as losing one's spouse or becoming a caregiver, can cause role strain. Successful role transitions in these types of situations require the ability to allow relationships to evolve.

The degree of preparedness for a transition may greatly affect health and well-being, such as for the

transition to retirement. As described in Chapter 7, “Transition and Aging,” Mae did not have the opportunity to prepare for the changes in her relationships; for her role as care recipient; or for retirement, which was forced on her with the onset of disability. She experienced a difficult transition into her new roles.

Role Strain and Caregiving

Caregiving is tending to the needs of another. The transition to the role of caregiver for a family member with a disability can be a source of role strain. Caregiving for a child, spouse, parent, or other can be a service of love, yet, it can deplete the emotional, physical, and financial resources of the caregiver.

In Renzo’s story (“Prologue”), Cheryl described her transition to caregiver of Renzo after his brain injury. She described the struggle of overcoming exhaustion while managing her son’s daily care and the process to feel competent in caregiving. The transition of James’s parents (Chapter 4, “Transition Within School”) and Emma’s daughter (Chapter 7, “Transition and Aging”) to the role of caregiver necessitated their involvement in the care recipients’ roles, routines, habits, and rituals. James’s parents were intimately involved in his role as student, his health care routines, and his homework habits. Emma’s daughter adjusted her routine to meet Emma’s needs and routine and tended to her health and daily habits.

The transition to **care recipient** can also be a source of role strain. Becoming a recipient of care from a spouse, family, home health aide, or an other individual often requires the ability to alter perceptions of one’s self-image and still maintain a sense of self-worth. **Learned helplessness** is unwittingly created when caregivers and health professionals assist persons with disabilities by doing tasks for them instead of teaching strategies for independence and supporting their functional abilities (Colangelo & Olson, 2013). In this case, people with disabilities stop trying to do tasks and come to believe that they need others to do the tasks for them. Optimism about their own capacities for creating positive change in their own lives is diminished, and passivity and dependence on others is promoted. Development of executive function and self-regulatory capacities is also inhibited, which further lessens their potential for effectively coping with challenges (Colangelo & Olson, 2013).

Questions

- Consider points in your life when you may have experienced role strain. What were the causes? What assisted with the resolution?
- Identify potential sources of role strain for Cheryl and for Renzo.
- Identify the impact of role strain on James as he transitioned in his role as student.
- Identify potential points in Emma’s life when she may have experienced role strain.

Role Strain for People With Disabilities

People with disabilities are more vulnerable to role strain; therefore, role strain is an important consideration in transitions for people with disabilities at any age. Kielhofner (2008) identified how the expenditure of time and physical energy for self-care and home maintenance can deplete the personal resources of people with disabilities for occupying or developing other roles. In addition to possibly having fewer roles, people with disabilities are more at risk for chronic stress because they may already have more life demands, fewer choices in the role transition process, and fewer personal and external resources to support successful coping than typical people.

One example of role strain for people with disabilities is the story of 5-year-old Malika, who had a diagnosis of cerebral palsy (CP; Chapter 3, “Early Childhood Transitions”), which describes the role strain on Malika and her family in the transition from a specialized program to a district elementary school. Another is James’s story (Chapter 4, “Transition Within School”), which describes his role strain and change in affect and behavior as he transitioned from his role in grade school to a new middle school and then high school.

In a qualitative study, adolescents with CP reported that they successfully coped with disability-related challenges by thinking through how important and meaningful activities within their life roles are to them in light of the potential barriers that they expect to confront in the activities (Stewart et al., 2012). A study of parents with children with a chronic illness found that these parents had higher levels of stress compared with parents raising healthy children (Quittner et al., 1998). They reported higher levels

of conflict over child rearing, larger numbers of daily child care tasks, greater frustration with current role division, and lower levels of positive interactions with marital partners. The impact of role strain on families is discussed later in this chapter.

Stress During Transitions

Stress is inherent in the process of change and role transition. **Stress** is tension that a person experiences physically, emotionally, or cognitively when demands are beyond perceived abilities. In moderate amounts for short periods of time, stress is a part of learning and mobilizes people to action. Conversely, sustained stress adversely affects health.

Cortisol

To understand health and wellness in transitions, practitioners must understand the physiological nature of stress on the body. In response to stressors, the **hypothalamic–pituitary–adrenocortical (HPA) system** functions in an adaptive process that mobilizes one's physical and cognitive resources through signaling the regulation of cortisol, a stress hormone.

As long as a person has the resources to meet life challenges, the short-term moderate increases in cortisol levels support learning and the ability to meet new life demands (Blair, Granger, & Razza, 2005). To meet challenges, the **hypothalamus**, through nervous and hormonal signals, prompts the cortex of the **adrenal gland** to release several hormones, including cortisol. **Cortisol** stimulates the release of insulin and other hormones that affect blood glucose levels, glucose use, heart rate, and blood pressure. Simultaneously, cortisol curbs functions that would be nonessential or detrimental while facing a challenge, including the digestive system, the reproductive system, and the growth processes. Cortisol also affects mood, motivation, and fear. Once a challenge is met, the HPA system stimulates a negative feedback loop to reduce cortisol levels, which allows physiological systems to resume their regular activity (Cicchetti, 2013; Randall, 2010).

Chronic Stress Response

When a person does not have a sense of self-efficacy or the resources to manage stressors and demands, the

HPA axis is chronically activated, resulting in chronic stress response and biopsychological dysregulation.

Chronic stress response occurs when, in response to trauma or chronic stress, one's system becomes hyperactive and produces larger amounts of cortisol than needed under situations of everyday stress (D'Andrea, Sharma, Zelechoski, & Spinazzola, 2011; Hanson & Chen, 2010).

Biopsychological dysregulation, the impairment of physiological, cognitive, and emotional regulatory mechanisms, can occur if there is long-term activation of the stress response. Biopsychological dysregulation becomes detrimental to physical, cognitive, and psychosocial health.

Chronically high levels of cortisol adversely affect brain development and neural systems needed for regulation (D'Andrea et al., 2011; Hanson & Chen, 2010; Kay, 2010; McEwen, 2005). Elevated cortisol levels have a negative impact on the efficiency of executive function in general and on a person's mood and emotional regulation (Kay, 2010). The hippocampus, a crucial part of the brain for memory, is particularly sensitive to cortisol, and high levels interfere with memory (D'Andrea et al., 2011). Chronic stress can also provoke development and exacerbation of health conditions such as cardiovascular disease, stroke, arthritis, depression, and anxiety disorders (Kay, 2010; McEwen, 2005).

Chronic Stress

During certain stages of life, chronic stress with concurrent high levels of cortisol can have more severe negative physiological effects than at other points. Felitti et al. (1998) identified that adverse childhood experiences such as abuse and household dysfunction are major risk factors for some of the leading causes of illness, death, and poor quality of life, such as alcoholism, drug abuse, depression, suicide attempt, smoking, sexual promiscuity, and severe obesity. They found a relationship between adverse childhood experiences and adult diseases, including heart disease, cancer, lung disease, fractures, and liver disease.

Essex, Klein, Cho, and Kalin (2002) found that young children whose mothers had high stress levels were more likely to have higher cortisol levels and to exhibit weaker executive function skills than other children. High levels of stress in childhood environments have been found to affect children's current functioning and function in adulthood (Hanson & Chen, 2010). Chronic stress

in the transition to motherhood affects the mother's health and has also been linked to low birthweight in infants and higher levels of cortisol in offspring throughout childhood (Hanson & Chen, 2010).

In adolescence and young adulthood, high levels of cortisol with chronic stress can have deleterious effects on executive function because this is the stage of life when frontal lobes are still developing (Lupien, McEwen, Gunnar, & Heim, 2009).

In a randomized trial, Mohr et al. (2012) demonstrated that adults with multiple sclerosis who participated in individual stress management therapy developed fewer lesions or remained free of new lesions compared with study participants who did not participate in the stress management program. During older adulthood, stressful transitions are common, and older adults are more sensitive to the effects of cortisol as their system processing capacities slow down (Kay, 2010).

Health and Wellness Through Occupational Participation

Occupational participation is a key contributor to health and wellness (AOTA, 2013b). Occupational therapy empowers clients in vulnerable times of transition to have greater control over their life and can facilitate the successful management of occupational role transitions and adaptation. **Adaptation** occurs when the desire to participate in occupation and the desire for mastery result in a response to occupational challenges.

Occupational therapy practitioners can support the health and wellness of clients experiencing their own or their loved ones' life transitions by working collaboratively with the client, family members, and supports in the community. They can play an important role in building community partnerships, specifically when working in education, health, and rehabilitation systems.

Across the lifespan, people need to be able to engage in occupations and use time in a purposeful way (Wilcock, 1993; Yerxa et al., 1989). Through occupations, people learn to adapt to changing needs and conditions. **Occupational deprivation**, the denial of opportunities or resources necessary for occupational participation, can be detrimental to health and well-being (Whiteford, Townsend, & Hocking 2000). Conversely, engagement in meaningful and

purposeful occupations can positively influence physical, mental, spiritual, and social health and well-being. Therefore, promoting occupations, including leisure and play, work, social participation, education, rest and sleep, activities of daily living, and instrumental activities of daily living (IADLs), reduces stress levels and restores physical, psychological, and emotional well-being, demonstrating the therapeutic value of activity. Participating in these activities promotes healthy functioning at any time of life but is especially important during transitions, when it can reduce the degree of stress experienced (Middleton et al., 2011; Morris & Coley, 2004; Salmon, 2001).

Areas of Occupation Affecting Healthy Transitions

Participation in meaningful activities affects and is affected during transitions. This section discusses transitions in these areas of occupation: work, the IADL of caregiving, leisure, exercise, social participation, and rest and sleep. For a discussion about transition in education, see Chapter 4, "Transition Within School."

Work

In supporting young adults in their transition to work, Hettich (2010) recommended that organizations monitor new workers' challenges to reduce the level of stressors encountered and offer education on stress management. Hettich also identified the importance of helping young adults develop relationships with supervisors and coworkers to facilitate their successful socialization at work and support their future career development.

Supervisors and coworkers can support the development of a mentoring infrastructure so that young adults learn not only the key tasks of their jobs and how to manage multiple tasks and roles but also develop an understanding of the organizational structure and informal practices of their work. Healthy work transitions are further discussed in Chapter 6, "Transition and Work."

Caregiving

Caregiving is an important IADL, but it can deplete resources and contribute to role strain and stress in people transitioning to a caregiver role (e.g., caregiving for a family member with dementia,

parenting, caregiving for children with disabilities). Therefore, caregivers may need to be educated about the importance of including restorative occupations in their lives.

Caregiving and dementia

In addition to health care professionals addressing the needs of care recipients with dementia, interdisciplinary interventions tailored to caregivers' many faceted needs can be beneficial. Effective intervention methods address caregiver burden, depression, well-being, knowledge, respite, problem-solving skills, stress, relaxation skills, coping ability, and management of self-care and problem behaviors. As part of an interdisciplinary care team, occupational therapy practitioners provide intervention and education to address identified needs in occupational performance of both care recipients and their caregivers (Dooley & Hinojosa, 2004; Gitlin & Corcoran, 2005; Graff et al., 2008; Gitlin et al., 2003; Samia, Hepburn, & Nichols, 2012; Schulz et al., 2003; Sörensen, Pinquart, & Duberstein, 2002).

Parenting

Increasing caregivers' sense of personal control has been commonly used to decrease stress. For example, Levy-Shiff, Dimitrovsky, Shulman, and Dov (1998) found that in new parents, a sense of control enhanced feelings of mastery, which seemed to foster more responsive caregiving. They also found that mothers who viewed parenting as a controllable challenge adjusted better to parenting. Aligned with research on chronic and acute forms of stress surrounding parenthood, maladjustment to parenting occurred when parenting was viewed as a stressful situation.

Newman (2000) identified the importance of new parents being helped to identify their range of expectations and the nature of competing expectations for their new role and being provided guidance in exploring the possibilities for meeting their new role expectations. Newman also emphasized the importance of helping new parents articulate their key values and beliefs so that they could develop parenting goals and expectations that align with what they believe is central to their success in the parental role.

Caregiving and children with disabilities

Williamson and Szczepanski (1999) created the *coping frame of reference* to support occupational therapy

practitioners in promoting congruence between the coping resources and environmental demands and expectations of children with disabilities. The authors outlined an intervention process whereby practitioners consult with caregivers to modify demands so that they are consistent with the children's capacities. In addition, practitioners work to enhance children's personal coping resources, including developing positive beliefs about their own capacities and an effective coping style for managing challenges. Improving children's ability to succeed in occupations and better manage challenges should alleviate some of the caretakers' stress and role strain.

Research suggests that high levels of parental stress, especially during early childhood transitions, negatively affects the health and well-being of both parents and children (Bella, Garcia, & Spadari-Bratfisch, 2011; Shonkoff, 2011). In response, Shonkoff (2011) calls for a shift from focusing solely on enriching children's learning environments to considering ways of protecting adult caregivers' health through stress reduction. Bella et al. (2011) advocated for family-centered health care service models instead of child-centered models.

Leisure

Although participation in leisure activities may be sacrificed when people are immersed in managing the stress of transitions, leisure is a powerful buffer for coping with stress (Olson, 2014). **Leisure** is what people do when they are not engaged in activities related to self- or family management, work, or education. People are free to participate in activities of their choice, and the goals and direction of leisure activity are personal.

Successful participation in leisure is personal enjoyment of the activity. Personally meaningful leisure activities can provide a safe haven where people can immerse themselves in identity-affirming activities. Leisure also provides opportunities for social participation. Sharing leisure activities with family and friends maintains and strengthens a person's support system and provides a sense of belonging and well-being (Olson, 2014).

Leisure activities

Kleiber, Larson, and Csikszentmihalyi (1986) identified different ways that leisure can support youth in their transitions toward adulthood. Relaxed leisure activities, which place minimal demands on skills

(e.g., watching television, listening to music), provide escape from the pressures of everyday life and can rejuvenate the body and mind.

Leisure activities that challenge current skills and require attention and expenditure of energy and effort (e.g., playing sports, participating in a band, exploring art or dance activities) promote physical, social, and cognitive skill development. These well-organized youth activities also facilitate the development of important executive function capacities crucial for supporting the ability to meet transitional challenges and maintaining healthy relationships with others, including initiative, teamwork, and self-regulatory skills (Larson, 2007; Larson, Hansen, & Monetta, 2006; Larson, Hansen, & Walker, 2005; Wood, Larson, & Brown, 2009). Children who participate in sports and hobbies are more likely to transition to well-adjusted adolescents than those who do not (McHale, Crouter, & Tucker, 2001).

Family leisure

Family leisure activities can promote an overall sense of well-being in all family members and maintain or strengthen the support that family members can offer one another (Olson, 2014). Although leisure activities experienced as a family are important for many people at any age, they may be especially important for youth with developmental disabilities because these youth typically depend on the support and companionship of their parents and siblings throughout their lives (Orentlicher & Olson, 2010).

Occupational therapy practitioners can educate families on the positive benefits of shared leisure activities. However, in the “Prologue,” Cheryl described how she and her husband sought balance in their roles as parents to Renzo and spouses to one another and in personal roles and interests. They eventually recognized that taking care of themselves improved the quality of life for all of them. Their engagement in occupations as a couple and as individuals also allowed Renzo the opportunity to enjoy an independent life and participate in activities typical of his peers. Time for recreation may ameliorate role strain for couples raising young children, particularly children with disabilities.

Meaningful leisure activities are essential for health and well-being at all ages. Leisure activities that require the use and development of cognitive, physical, and social skills are especially supportive for successful aging because they encourage personal growth, self-efficacy,

and positive identities of older adults (Brown, McGuire, & Voelkl, 2008). As described in Chapter 7, “Transition and Aging,” Emma’s successful aging is, in part, attributed to her involvement in favored pastimes, including playing cards and games and sewing. She honored her limitations but engaged in physical and mental activities to the extent she was able.

Exercise

Exercise can decrease the stress related to difficult transitions. For example, growing evidence supports incorporation of routine exercise in reducing cortisol and the psychophysiological responses to stress (Chow, Dorcas, & Siu, 2012; Hillier, Murphy, & Ferrara, 2011; Kelly & Loy, 2008). Exercise also produces physiological adaptations, including reduced sympathetic activity, which counters the increases that occur in response to stress, and improved vagal tone (Salmon, 2001).

People who exercise on a daily basis may have some protection from the physical effects of stress through a decrease in stress reactivity (Salmon, 2001). Aerobic fitness also positively affected executive function of preadolescents (Hillman, Buck, Themanson, Pontifex, & Castelli, 2009). Older adults who were active in a range of activities had a lower incidence of cognitive impairment (Middleton et al., 2011). This study suggested that even low-intensity physical activities embedded across an older adult’s daily life may be protective of cognitive function. Regular physical activity, including walking, was correlated with preservation of cognitive function in women with cardiovascular disease (Vercambre, Grodstein, Manson, Stampfer, & Kang, 2011).

Social Participation

Social participation with family, peers, and the community promotes health during transition. Social networks increase well-being and facilitate management of stress through companionship and social support. Maintaining and expanding supportive relationships also provide a sense of well-being and stress reduction during transitions. No matter how well new parents concretely prepare to welcome new children into their lives, they need support from others currently in their social network as well as new friends who may provide comfort and guidance by sharing their own parenthood experiences.

Healthy families sustain themselves throughout the transitions of their families as a unit and can also support the transitions of individual members through family activities that keep them positively connected to each other and others in their communities.

Social networks

Social networks support health and wellness in two ways: (1) companionship and (2) social support. **Companionship**, which is fellowship with others that provides a sense of intimacy and camaraderie, influences health and wellness. Most people look forward to time spent with a friend during a school or work break or to a family meal or activity after a day of school or work. Olson (2014) described shared leisure activities that support a person's sense of well-being and regulate mood states. Companionship also boosts emotional well-being and helps reduce health-compromising behaviors because others can monitor and regulate risky behaviors. In addition, companionship facilitates protective health effects and contributes to resilience and optimism (Rook, August, & Sorkin, 2011).

Rook et al. (2011) reviewed evidence that suggests that **social support**, the emotional or instrumental assistance that people receive from others, is a key buffer in facilitating people's capacities to manage the adverse effects of life stress. Social support helps people restore their equilibrium when confronted with life stressors and encourages the planning of effective actions for transitions. Lazarus and Folkman's (1984) transtheoretical model of stress and coping suggests that the effect that a stressor has on a person is largely determined by the person's social support. People's social identity is tied to the groups to which they belong, and these groups offer social support and an appraisal of stressors.

Maintaining and expanding relationships

Maintaining relationships within their current social milieu while working to establish themselves in new roles or environments during transition supports people's well-being and stress management. The broader the network of social relationships that people have, the more likely they will gain support during transitions and positively

experience role transitions (Jetten et al., 2010). A large network increases the possibility that some of these sources of support will be maintained across a transition and that some relationships will remain compatible with the new identity that a person may take on after a transition. When a current social network provides a sense of belonging to the person with a new identity, stress resulting from identity loss in a transition can be ameliorated (Jetten et al., 2010). It also provides a sense of continuity and coherence across a transition and a lifespan.

In one study, people who belonged to more social groups before experiencing a stroke and were able to maintain membership in many of those groups after the stroke reported greater life satisfaction and sense of well-being than people who had a stroke who did not (Jetten et al., 2010). Haslam, O'Brien, Jetten, Vormedal, and Penna (2005) similarly reported that patients recovering from heart surgery who had belonged to multiple groups that offered them support experienced lower levels of stress than patients who did not.

Fung and Siu (2010) highlighted differences in needs for social participation relative to people's view of the expanse of time before them. The young tend to attach more importance to expanding the social sphere because unfamiliarity increases their opportunities for learning and new experiences. When people age, are faced by a shorter life expectancy as a result of terminal illness, or are exposed to the deaths of others, they reprioritize their goals and tend to focus on fewer social partners who are more emotionally meaningful to them and deepen those ties.

Fung and Siu (2010) also questioned common social services practices that assume that all people benefit from increased social contacts and increased learning opportunities. For example, encouraging older adults to expand social networks in the same way as young adults and encouraging people who are terminally ill to transition back to their previous work and school environments in the same way as people expected to return to full health fail to recognize that people with a limited time perspective may have different social participation needs. Therefore, Fung and Siu recommended that interventions meant to increase health and wellness in people with a limited time perspective should begin with an analysis of the kind of relationships these people already have and value and explore ways of strengthening these relationships.

Relationships for new parents

New parents may need guidance in examining which parts of their present social network may be helpful to them in defining and establishing their new role as parents. Quittner et al. (1998) highlighted the importance of analyzing the *ecology of family situations*, the different relationships within a family that affect how new parents function and with whom they share parenting responsibilities (e.g., grandparents, other extended family members, nannies and babysitters). Some new parents lack a social network, which may increase stress.

When practitioners examine the ecology of a family situation, they should also consider how the physical environment affects family relationships. Some new parents share living space with extended family members or live in physical environments that have limited resources for engaging parents and infants with each other within community settings. According to Quittner et al. (1998), occupational therapy assessments must measure the daily sources of parental role strain instead of focusing on uncovering psychopathology in parents.

Relationships for healthy families

Positive caregiving facilitates healthy family environments, which affect social participation during transitions. Conversely, social participation can improve family relationships during transition. It has long been recognized that the presence and support of primary caregivers serve as the key resource that increases children's capacities for self-regulation and ability to cope with challenges (Coleman, 2003; Lewis, Feirig, & Rosenthal, 2000; Murphy & Moriarty, 1976).

Ahnert, Gunnar, Lamb, and Barthl (2004) demonstrated in young children a correlation between secure attachment to their mothers and the ability to modulate cortisol secretion when transitioning to child care out of the home. Hanson and Chen (2010) found that compared with healthy adults, adults who grew up in difficult family environments were more likely to have increased levels of cortisol and sleep less in response to stress.

Steiner, Bigatti, Hernandez, Lydon-Lam, and Johnston (2010) researched role strain in the spouses of chronically ill women and factors that alleviated it. They found that social support was critical for reducing role strain and increasing marital satisfaction.

Animals

In addition to human social participation, Adams (2010) described the role of animals in supporting people in stressful life transitions. He reported that in some studies, animal-assisted therapy increased physical well-being and decreased stress. Findings included subjective measures indicating decreased stress and physical measures such as reduced blood pressure and heart rate.

Although pets' ability to offer social support sometimes goes unrecognized, they offer unconditional positive regard that sustains and supports many people through life transitions.

Rest and Sleep

Poor sleep quality and patterns can be an outcome of stress and persistent high levels of cortisol. Unless the effect of stress on sleep is managed, it can lead to a cascade of other functional deficits.

In studies of adults, even partial sleep deprivation impaired executive functions, whereas sleeping after learning seems to increase memory capacity (Buckhalt, 2011). Studies of children have found that poor sleep quality and quantity and inconsistent sleep routines are associated with negative academic outcomes and behavioral issues (Buckhalt, 2011). Buckhalt advocated for parent education about the importance of a consistent sleep routine and ways to facilitate quality sleep for children.

Restorative sleep has been identified as a critical resource for reducing stress and pain in people with fibromyalgia and rheumatoid arthritis (Hamilton, Catley, & Karlson, 2007). *Restorative sleep* occurs when people wake up in the morning feeling rested and alert. Stress and high levels of cortisol may interrupt sleep, and inadequate sleep may exacerbate and prolong the impact of stress and cortisol. Therefore, adequate sleep is essential for the restoration of equilibrium necessary to cope with stressful transitions.

Questions

- What are some examples of how occupational participation promoted health and wellness through the stress of transitions for James (Chapter 4, "Transition Within School")?
- What are some examples of how occupational participation promoted health and wellness through the stress of transitions for Emma (Chapter 7, "Transition and Aging")?

Health and Wellness Through Context and Environment

Occupational contexts and the environment can enhance a person's health and wellness, specifically during transitions. The context and environment should fit the needs of the person to support occupational performance and ease the stress of transitions. An intimate relationship and interplay exists between the person and his or her health, environment, and occupations; the better the fit, the better the performance (Christiansen & Baum, 2005; Law et al., 1996). Practitioners must be in tune with the transactions between the person and his or her context to promote health and wellness through times of transition.

The physical environment can be a facilitation or barrier to health and wellness during transitional periods. Altering the physical environment, such as at school, work, and home, at any age, to accommodate needs may be accomplished through universal design, hazard reduction, environmental modifications, and equipment.

School Environments

An example of modifications of the school environment to enhance a person's well-being during transition is given in Mikala's story (Chapter 3, "Early Childhood Transitions"). Mikala's therapists provided information to the elementary school team members to help them begin addressing Mikala's needs in the new school environment. For instance, she needed adapted seating and equipment to assist with writing, feeding, and eating. The therapists educated the staff at her new school about these physical modifications and equipment, which assisted with her transition to the school.

Work Environments

In a qualitative research study on the perceptions and experiences of people with back injuries transitioning back to work after rehabilitation, barriers to health maintenance were found (Soeker, Wegner, & Pretorius, 2008). Participants reported that their needs for physical adaptations were not communicated to employers; employers were not educated about disability management; and, for some, employers and employees did not have positive relationships. When work environments are not positive and supportive, work productivity frequently decreases (Soeker et al., 2008). Soeker et al.

(2008) stressed the importance of health professionals taking a holistic approach in supporting clients' transition back to work by collaborating with all stakeholders, including employers and coworkers, so that the physical environments are effectively adapted.

Shaw and Lindsay (2008) advocated for health professionals to establish strong partnerships with each other, clients, and employers in spite of the challenges of high workloads, limited time, and resources. They emphasized that these partnerships are essential for creating processes that facilitate clients' return to work after rehabilitation and for developing and maintaining healthy workplaces that allow all workers to safely engage in their work occupations.

Home Environments

Physical environmental modifications that Emma (Chapter 7, "Transition and Aging"), an older adult, made to her home as she aged facilitated wellness by allowing her access to the community and to social participation with her family and friends. Simple environmental modifications enabled performance. Conversely, Mae's (Chapter 7, "Transition and Aging") physical environment at home was not a good fit and deprived her of occupational participation in her environment. Thus, her health and occupations were not maintained and eventually declined.

Questions

- How did the environment or context affect health and wellness through the stress of transitions for Mikala (Chapter 3, "Early Childhood Transitions")?
- What impact did the environment or context have on health and wellness through the stress of transitions for Emma (Chapter 7, "Transition and Aging")?

Health and Personal Well-Being

Health and well-being interrelate and are affected by transitions. This section discusses the importance of engagement in balanced occupations to enhance the relationship between healthy body functions and personal well-being, especially during transitions.

Occupational Balance

Matuska, Bass, and Schmitt (2013) described the importance of life balance for well-being. *Life balance* is “a satisfying pattern of daily activity that is healthful, meaningful, and sustainable to an individual within the context of his or her current life circumstances” (Matuska & Christiansen, 2008, p. 11). Matuska et al. (2013) asserted that individual differences exist in perceptions of what constitutes life balance because of individual perceptions of what is considered stressful.

In the *Life Balance Model* (Matuska et al., 2013), the configuration of everyday activities in a balanced life meets a person’s needs for physiological health, satisfactory relationships, positive identity, and challenge. Desired activity configuration requires time management and goal setting, and activities are influenced by environmental factors. Balanced activity configuration is associated with positive health and well-being outcomes such as reduced perceived stress.

Healthy Habits and Routines

Healthy habits and routines are an essential element to personal well-being, physiological well-being of body functions, and, therefore, stress management. Fiese, Winter, and Botti (2011) reported that family routines tend to cluster together and that if a family under stress has a breakdown in one routine, disruptions in other routines may follow.

Healthy lifestyle incorporates regularity of healthy habits and routines such as leisure activity, socialization, sleep, exercise, mealtime practices, and a healthy diet. To support people who are managing the stress of transitions, occupational therapy intervention plans should address the development of healthy habits, routines, roles, and rituals. In this way, occupational therapy promotes healthy lifestyles and a state of well-being in physiological functions of the body, enabling readiness for and recovery from the stress of transitions (AOTA, 2013b; see Appendix E, *Occupational Therapy in the Promotion of Health and Well-Being*).

Transitions challenge people to examine their routines and activities and the purpose and meaning attributed to them (Schlossberg, Waters, & Goodman, 1981). Blair (2000) described *life transitions* as periods of disequilibrium, and asserted the centrality of occupation to well-being. Addressing interests and values, habits, roles, routines, and capacity to improve skills for performance

and participation in purposeful and meaningful occupations is empowering (Kielhofner, 2008).

For example, healthy family routines, including mealtime, can promote wellness in family members and provide stability and support during transitions. Fiese et al. (2011) reported on the important relationship between family time spent together in mealtime interaction and children’s health. Regular family mealtimes were associated with healthy child development, whereas infrequent family mealtimes were more likely to indicate poorer health outcomes for children.

Neumark-Sztainer (2008) summarized the findings of Project EAT (Eating Among Teens): Adolescents who ate more frequently with their families exhibited healthier diets and were less likely to use unhealthy weight control methods such as diet pills and laxatives. These findings emphasize the importance of social interactions within families and suggest that families in chronically stressed environments or challenged by transitional events may benefit from education about the importance of family mealtimes and support in developing healthy mealtime routines.

When considering interventions for family mealtime to support families in managing stress, it is critical to help families develop healthy routines and communication strategies around mealtimes (Fiese et al., 2011). It is also important to help families understand how children’s age and development affect their participation and behavior at mealtimes and help parents develop appropriate expectations.

It is not enough to eat together if conversation is negative or avoided. Larson’s (2011) research echoed this point: It is not just the occurrence of family meals that is important, it is critical that what happens at the meal be positive. Practitioners can educate families on the positive benefits of healthy family meal routines. (For more information, refer to AOTA’s [2014a] *Establishing Mealtime Routines for Children Tip Sheet*.)

When supporting families in developing healthy routines, occupational therapy practitioners must use a culturally sensitive approach to avoid increasing stress on families already under stress (Fiese et al., 2011). (For useful information on cultural sensitivity, see *How Can Occupational Therapy Strive Toward Culturally Sensitive Practices?* [AOTA, 2013a].)

Questions

- What are examples of how Emma’s daughter (Chapter 7, “Transition and Aging”) created life

- balance through the configuration of activities in her role as caregiver?
- What are examples of healthy routines and habits that assisted in reducing the stress of transitions for Cheryl (“Prologue”), James (Chapter 4, “Transition Within School”), and Emma (Chapter 7, “Transition and Aging”)?

Wellness Through Spirituality, Values, and Beliefs

Exploring people’s spiritual views, values, and beliefs can be a method for occupational therapy practitioners to fully address the needs of clients, caregivers, or significant others managing stressful transitions. How people understand the world and make sense of suffering and stress is shaped by their spirituality, values, and beliefs. **Spirituality** refers to a person’s understanding of and expression of what is sacred (AOTA, 2014b). **Values** refers to the principles, qualities, and standards that a person considers to be important (AOTA, 2014b). **Beliefs** indicate what a person considers to be truth (AOTA, 2014b). This section discusses wellness through spiritual or religious affiliation, mindfulness, gerotranscendence, and optimism.

Spiritual or Religious Affiliation

Spiritual or religious affiliation is one predictor of a self-reported sense of well-being, health, and family life satisfaction (Wheeler, 2010). Wheeler (2010) highlighted the importance of religious community organizations for support. Although most of these organizations can be an important source of support in times of transitions, she used the example of African-American churches being a key social support for African-Americans throughout their lives. Studies also suggest that, in college students, a relationship exists between spirituality and coping mechanisms for stress (Bowen-Reid & Smalls, 2004; Ma, Gonzalez, Wang, & Shea 2013; Papazisis, Nicolaou, Tsiga, Christoforou, & Sapountzi-Krepia, 2014; Samuel & Kannappan, 2011).

Stolley, Buckwalter, and Koenig (1999) reported that caregivers in their study used prayer, trust in God, and participation in religious activities to assist them in coping with the stress of caregiving. When people apply coping strategies that are consistent with their religious beliefs and practices, they are likely to positively manage stress (Park, Edmondson,

& Mills, 2010). Therefore, in supporting people affiliated with a religious group who are experiencing stress in life transitions, community religious organizations should be considered key partners in intervention. Incorporating habits, routines, and rituals that emphasize spiritual expression and uphold values and beliefs may contribute to a religious person’s health and well-being.

Mindfulness

Mindfulness can be a healthy habit that promotes personal wellness and keeps focus on a person’s values in times of stressful transitions. **Mindfulness** is a form of meditation practice that develops a person’s capacity for remaining in the present moment and supports disengagement from constant thinking and worrying about concerns and emotional states. It includes practices of controlled breathing and progressive muscle relaxation. Occupational therapy practitioners can incorporate practices that promote mindfulness as part of the intervention process.

Mindfulness can shift a person’s perception of his or her emotions so that emotions are viewed as a fleeting phenomenon, not fundamental part of the self, thus supporting emotional regulation (Davidson, 2010). Studies have demonstrated that regular mindfulness practice can have positive psychological, social, and physiological effects, including increasing motivation, capacities for social connectedness, and readiness to reflect on choices for action and positively altering the underlying physiology of the autonomic nervous system, neuroendocrine function, and immune system (Koole, Van Dillen, & Sheppes, 2010; Ludwig & Kabat-Zinn, 2008).

Koole et al. (2010) reported that mindfulness training reduced the symptoms of stress, depression, and anxiety in study participants. Lutz et al. (2009) found that after 3 months of intensive training in meditation, study participants demonstrated improved attention and needed to apply less effort for regulating focused attention. Jha, Stanley, Kiyonaga, Wong, and Gelfand (2010) found that regularly practiced mindfulness protected and supported the working memory capacity of military personnel in stressful situations.

Mindfulness has been incorporated into frameworks for supporting positive parenting and promoting secure attachment relationships (Duncan, Coatsworth, & Greenberg, 2009). Through mindful awareness, parents are guided to stop and shift their

awareness to the moment so they are more likely to attend and actively listen to their children without judging their children or themselves. Mindful practices may also serve as a coping resource for managing stresses within the lives of parents, children, and families. Duncan et al. (2009) reported the results of three studies that suggest that mindful parenting interventions may increase parent satisfaction and family functioning.

Duncan et al. (2009) developed a protocol for teaching parents mindfulness that can be incorporated into occupational therapy practice. They first taught parents how to sit quietly and focus on their present breathing or thoughts and then focused their sessions on guiding parents in reflecting on their parenting goals. They coached parents in developing a child-centered, open, nonjudgmental, accepting stance through mindful practices. Parents were then taught how to recognize and label their moment-to-moment comfortable and uncomfortable emotions in parenting as an initial step toward reducing negative cycles of parent-child interaction. This parent training was focused on using mindfulness practices to shift escalating emotions and physiological stress reactions.

People of all ages who regularly use mindfulness in daily life are less likely to interpret behavior as hostile, report lower levels of anger, and are less likely to report a desire to retaliate (Heppner et al., 2008).

Gerotranscendence

Tornstam's (2011) theory of **gerotranscendence** could be considered a form of or result of mindfulness in older adulthood. In attaining gerotranscendence, a person has a deepened affinity with the past; appreciation for the commonplace; and communion with the universe, time, life, and death. Gerotranscendence emphasizes change and development of self and may include a greater need for solitude, more selective social ties, and emancipation from social convention.

Optimism

Optimism, the tendency to expect positive outcomes, may contribute to physical and psychological health and superior adjustment to stressful life transitions (Brissette, Scheier, & Carver, 2002; Jobin & Wrosch, 2014; Rasmussen, Scheier, & Greenhouse, 2009). Optimists also exhibit more effective coping strategies and tend to generate more social support compared

with non-optimists. Tirella, Tickle-Degnen, Miller, and Bedell's (2012) study of adoptive parents learning to meet the needs of their newly adopted child from another country found that parents' success in supporting their children's transition and their own well-being seemed linked to a positive outlook, marital strength, extended family availability, and community support.

Occupational therapy considers optimism a strength to be protected; therefore, interventions that might lessen this protective factor should be modulated. Emphasis on habits, routines, and rituals that promote optimism may contribute to health, stress reduction, and ease of transitions.

Occupational Therapy Assessment of Health and Wellness in Transitions

Several occupation-based assessments are helpful for identifying people's health and wellness needs during transitional periods.

Occupational Performance History Interview

The Occupational Performance History Interview-II (Kielhofner et al., 2004) provides a structure for the therapist to collect information about a client's past and present occupational adaptation. It explores the client's occupational identity and sense of competence and the impact of settings on occupational functioning.

Person-Environment Fit

A tool for assessing the fit between the environment and the person is available from the Center for the Model of Human Occupation. When the therapist is concerned about the child or adolescent's healthy transition within a school setting, the School Setting Interview (Hemmingsson, Egilson, Hoffman, & Kielhofner, 2005), a semistructured interview tool, guides the therapist in assessing the fit between the student and the school environment. It is also useful for facilitating discussions with students about ways to successfully manage stressors in the school environment. This assessment does not identify client factors; its goal is to explore how a school environment meets the needs of an individual student.

Coping Frame of Reference

Williamson and Szczepanski's (1999) Coping Frame of Reference can be used to conceptualize occupational therapy assessment and intervention relative to helping children with disabilities adaptively manage developmental stress. It includes strategies for assessing how children confront external demands and expectations and methods for assessing children's internal and external coping resources.

Early Coping Inventory and Coping Inventory are tools that measure critical internal coping resources within a child's coping style. The Early Coping Inventory (Zeitlin, Williamson, & Szczepanski, 1988) and the Coping Inventory (Zeitlin, 1985) help therapists reflect on their observations of how the children and adolescents with whom they work approach developmental challenges and demands. Youth's adaptive coping strategies and their least adaptive coping strategies can be pinpointed so that interventions can be focused on increasing the number and use of adaptive coping strategies to support reduction of stress and children's success.

SF-36

The SF-36 (Ware, Kosinski, & Dewey, 2000) is a health survey that yields a profile of functional health and well-being scores and physical and mental health measures. It is a generic measure that is applicable to people with various states of health through the lifespan.

Work Environment Impact Scale

The Work Environment Impact Scale (Moore-Corner, Kielhofner, & Olson, 1998), a semistructured interview and rating scale, assesses adult clients' experiences in the work environment.

Occupational Therapy Health and Wellness Service Delivery Models

Occupational therapy services can be provided to people or groups, in person, or virtually, such as through telehealth. Potential service models include education, consultation, and coaching, and possible selves intervention. The choice of service delivery model

depends on the particular needs and preferences of the institutions or communities offering services and of the people and caregivers seeking services.

Practitioners should give particular attention to approaches that support clients gaining new health-related knowledge, applying it in ways that are particular to their temperament and lifestyles, and taking ownership of the health promotion strategies that they choose. Collaboration between occupational therapy practitioners and clients to establish goals and outcomes is an essential part of all occupational therapy service delivery models. Clear, behavioral objectives guide practitioners and clients in identifying goals, potential for progress, strategies and methods for attaining the goal, and measuring progress.

Education

Psychoeducational groups are widely used by health and educational professionals to share new information and provide clients with the opportunity to reflect on the content introduced and begin to apply or practice some of the information learned to their activities (Brown, 2008; DeLucia-Waak, 2006). Well-developed psychoeducational groups have been shown to be an effective way to build client skills.

Consultation

Consultation service delivery models use interventions that emphasize collaboration among the occupational therapy practitioners, the client, and other stakeholders to design successful strategies for clients within their occupational environments. These models promote clients taking responsibility for their own healthy development and can be used in both individual and group intervention.

When practitioners use a **consultation** model, they support clients' performance by working with others who directly support the client, including parents, teachers, aides, or community members. They assess the needs of the client's support system through dialogue with caregivers and through observation of client participation with caregivers. Practitioners then share their observations and suggest possible strategies for improving the clients' function. They also help caregivers develop strategies that fit with their styles and client needs. Practitioners then design learning materials to support education about and

implementation of the chosen strategies. They may also monitor the effectiveness of strategy use and help caregivers modify plans as needed.

Coaching

Coaching as a model for assessment and intervention in rehabilitation, education, and early intervention is a growing trend (Dawson & Guare, 2012; Rush & Shelden, 2011). **Coaching** is a strategy for building capacity in clients by helping them identify their strengths and abilities to achieve self-identified goals, recognize and use current and new skills for achieving their preferred outcomes, and facilitating clients finding opportunities and taking responsibility for working toward their goals. It is an excellent model for transition intervention because it focuses on helping clients identify, obtain, and mobilize the knowledge and skills necessary to achieve an intended outcome.

A key difference between coaching and consultation is that the occupational therapy coaches use questioning to elicit goals, plans, and strategies from clients as opposed to introducing them to clients. Rather than sharing their own ideas after observing clients' performances, coaches have clients reflect on their performance before offering feedback. Coaches promote clients' ongoing self-assessment to enhance performance by teaching clients to ask self-reflective questions. In this way, clients become aware of their own behavior and then are guided by their coaches to examine and refine their behavior to achieve their preferred outcomes.

Increasing evidence in multiple fields has indicated that coaching is an effective approach in helping clients transfer new knowledge and skills to their everyday life. Ylvisaker and Feeney (2002) created a model for rehabilitation professionals, educators, and parents to coach and guide children and youth with disabilities in carrying out new executive function routines in their everyday activities so that they build optimism in their abilities to set goals, make plans, and solve problems.

Dawson and Guare (2012) provided education professionals with a coaching manual for promoting executive function development in youth. They identified the central goal of coaching youth in schools as enhancing their self-regulatory capacities related to affect, attention, and behavior so that they are no longer or less reliant on adult caregivers. They emphasized the importance of students setting their

own academic goals for improving motivation and performance. They also described how coaching develops executive functions, including goal-directed persistence, planning, time management, organization, flexibility, task initiation, sustained attention, and response inhibition.

Hutchinson, Versnel, Chin, and Munby (2008) addressed the importance of professionals coaching young adults with developmental disabilities to learn skills to negotiate their own social supports and physical accommodations in the workplace rather than relying on professionals to negotiate accommodations. They reported on applying a framework for career development that also supported these young adults in learning to set goals, act on their goals, and develop self-efficacy.

In a study mentioned previously, adolescents with CP reported managing role strain by determining what activities they wanted to do and the potential barriers that they expected to confront in each activity (Stewart et al., 2012). This study highlights the importance of occupational therapy practitioners coaching youth with disabilities to articulate what activities are most important and meaningful to them, the barriers that they will likely encounter in attempting to participate in them, and the strategies or tradeoffs they may be willing to make for successful participation in those activities. In this way, they will more likely be prepared to advocate for needed supports and learn the skills and strategies that will support their participation in the future.

Graham, Rodger, and Ziviani (2009) developed an occupational therapy-specific coaching approach for collaborating with parents so that they learn to recognize and make environmental and social adaptations to support their young children's participation in everyday activities. Parents identify goals about their own performance as parents or about their children's occupational performance. Practitioners observe and analyze parents' or children's performance, but it is a collaborative performance analysis done with the parent. Through questioning and reflection, practitioners guide parents in analyzing the performance and in discovering problems in performance and solutions to problems that work for them and their children. Rush and Shelden (2011) provided guidance for rehabilitation professionals to develop skills for coaching parents of young children with disabilities.

Coaching can be an effective method for facilitating transitions in adulthood, including the transition to parenthood, into the workplace, into retirement,

or to caregiving. For example, practitioners can address the occupational engagement and environmental barriers of the care recipient and the personal well-being of the caregiver.

Possible-Selves Intervention

Possible-selves intervention is one way to assist people to set goals and promote healthy transitions to new roles and identities. This intervention focuses on guiding people in identifying their future positive possible selves and the selves they want to avoid.

This approach promotes self-direction in planning transitions over a person's lifespan. It facilitates insight into the process of change and supports people in recognizing their continuity as they transition to another phase of life. As people focus on working toward ideal possible selves and avoiding feared possible selves, occupational therapy practitioners can assist them in identifying and using self-regulatory coping strategies to support health and wellness (Frazier & Hooker, 2006).

Oyserman and Fryberg (2006) found that adolescents who identified possible selves that they felt were attainable were more likely to have higher self-esteem than those who did not. They also identified the importance of adolescents having a balance of positive and feared possible selves. In their studies, youth who lacked this balance were more likely to act without considering potential negative consequences of their behavior as they work toward their ideal future self.

Having a vision of oneself in the future supports healthy behavior in the present. People are more likely to expend effort to reach their goals and avoid the possible selves that they fear. For example, students who examine their possible selves exhibit greater self-efficacy relative to school and life in general (Hock, Deschler, & Shumaker, 2006). Murru and Martin Ginis (2010) found that using possible selves interventions increased people's exercise behavior. Frazier and Hooker (2006) found that older adults who identified how they wished to age and what they feared most in their future demonstrated positive health beliefs and behaviors such as monitoring cholesterol, eating well, or exercising compared with older adults who did not. In addition, Hock et al. (2006) reported that people who experience acute injury or illness and who have hopes for their future recover faster and perform at higher physical and cognitive levels than those with similar injuries who do not have hopes for their future.

Question

- What are examples of how and why education, consultation, coaching, or possible-selves intervention could have been appropriate service delivery models to promote wellness through transitions for Cheryl ("Prologue"), James (Chapter 4, "Transition Within School"), and Emma (Chapter 7, "Transition and Aging")?

Summary

Maintaining health and reducing stress are critical during transitions and should be a part of occupational therapy assessment and intervention. Current evidence suggests that a person's functional capacity and adaptation increase when health is maintained.

When stress is not managed and becomes a persistent physiological state, a person may face dire implications for physical, cognitive, and psychosocial functioning. This chapter explored the negative and pervasive effect of chronic stress on physical, cognitive, and psychosocial health and how healthy habits and routines positively affect function during transitions.

It is critical that all health professionals address stress reduction and health-promoting habits and routines. The range and depth of need in this area are beyond the resources of any single professional or group of professionals. To successfully promote health and wellness, the health professional needs to collaborate with other professionals; other stakeholders; and the communities in which clients work, go to school, or live. Service delivery models should support clients' ownership of their own health and wellness.

References

- Adams, J. M. M. (2010). The role of animals and animal-assisted therapy in stressful life transitions. In T.W. Miller (Ed.), *Handbook of stressful transitions across the lifespan* (pp. 643–651). New York: Springer.
- Ahnert, L., Gunnar, M. R., Lamb, M. E., & Barthl, M. (2004). Transition to childcare: Association with infant–mother attachment, infant negative emotion, and cortisol elevation. *Child Development*, 75, 639–650.
- American Occupational Therapy Association. (2013a). *How can occupational therapy strive toward culturally sensitive practices?* Retrieved from <http://www.aota.org/-/media/corporate/files/secure/practice/multicultural/faqculturalsensitivity.pdf>

- American Occupational Therapy Association. (2013b). Occupational therapy in the promotion of health and well-being. *American Journal of Occupational Therapy*, 67, S47–S59. <http://dx.doi.org/10.5014/ajot.2013.67S47>
- American Occupational Therapy Association. (2014a). *Establishing mealtime routines for children*. Retrieved from <http://www.aota.org/-/media/Corporate/Files/AboutOT/consumers>Youth/Establishing-Mealtime-Routines-for-Children-Tip-Sheet.pdf>
- American Occupational Therapy Association. (2014b). Occupational therapy practice framework: Domain and process (3rd ed.). *American Journal of Occupational Therapy*, 68(Suppl. 1), S1–S48. <http://dx.doi.org/10.5014/ajot.2014.682006>
- Bella, G. P., Garcia, M. C., & Spadari-Bratfisch, R. C. (2011). Salivary cortisol, stress, and health in primary caregivers (mothers) of children with cerebral palsy. *Psychoneuroendocrinology*, 36, 834–842.
- Blair, C., Granger D., & Razza, R. P. (2005). Cortisol reactivity is positively related to executive function in preschool children attending Head Start. *Child Development*, 76, 554–567.
- Blair, S. (2000). The centrality of occupation during life transitions. *British Journal of Occupational Therapy*, 63, 231–237.
- Bowen-Reid, T. L., & Smalls, C. (2004). Stress, spirituality, and health promoting behaviors among African American college students. *Western Journal of Black Studies*, 28(1), 283–291.
- Brissette, I., Scheier, M. F., & Carver, C. S. (2002). The role of optimism in social network development, coping, and psychological adjustment during a life transition. *Journal of Personality and Social Psychology*, 82, 102–111.
- Brown, C. A., McGuire, F. A., & Voelkl, J. (2008). The link between successful aging and serious leisure. *International Journal of Aging and Human Development*, 66, 73–95.
- Brown, N. (2008). *Psychoeducational groups: Process and practice* (3rd ed.). New York: Routledge.
- Buckhalt, J. A. (2011). Insufficient sleep and the socioeconomic status achievement gap. *Child Development Perspectives*, 5, 59–65.
- Christiansen, C., & Baum, C. (Eds.). (2005). *Occupational therapy: Performance, participation, and well-being* (3rd ed.). Thorofare, NJ: Slack.
- Chow, Y. W. Y., Dorcas, A., & Siu, A. M. H. (2012). The effects of gigong on reducing stress and anxiety and enhancing body-mind well-being. *Mindfulness*, 3, 51–59.
- Cicchetti, D. (2013). Stress physiology and developmental psychopathology: Past, present, and future. *Development and Psychopathology*, 25, 1359.
- Colangelo, C., & Olson, L. (2013). Best practices in supporting children with physical disabilities. In G. Florek Clark & B. Chandler (Eds.), *Best practices in school occupational therapy* (pp. 341–354). Bethesda, MD: AOTA Press.
- Coleman, P. K. (2003). Perceptions of parent-child attachment, social self-efficacy, and peer relationships in middle childhood. *Infant and Child Development*, 12, 351–368.
- D'Andrea, W., Sharma, R., Zelechoski, A. D., & Spinazzola, J. (2011). Physical health problems after single trauma exposure: When stress takes root in the body. *Journal of the American Psychiatric Nurses Association*, 17, 378–392.
- Davidson, R. J. (2010). Empirical explorations of mindfulness: Conceptual and methodological conundrums. *Emotion*, 10, 8–11.
- Dawson, P., & Guare, R. (2012). *Coaching students with executive skills deficits*. New York: Guilford.
- De Lucia-Waak, J. L. (2006). *Leading psychoeducational groups for children and adolescents*. Thousand Oaks, CA: Sage.
- Dooley, N., & Hinojosa, J. (2004). Improving quality of life for persons with Alzheimer's disease and their family caregivers: Brief occupational therapy intervention. *American Journal of Occupational Therapy*, 58, 561–569. <http://dx.doi.org/10.5014/ajot.58.5.561>
- Duncan, L. G., Coatsworth, J. D., & Greenberg, M. T. (2009). A model of mindful parenting: Implications for parent-child relationships and prevention research. *Clinical Child and Family Psychology Review*, 12, 255–270.
- Essex, M. J., Klein, M. H., Cho, E., & Kalin, N. H. (2002). Maternal stress beginning in infancy may sensitize children to later stress exposure: Effects on cortisol and behavior. *Behavioral Psychiatry*, 52, 776–784.
- Felitti, V., Anda, R., Nordenberg, D., Williamson, D., Spitz, A., Edwards, V.,...Marks, J. (1998). Relationship of childhood abuse and household dysfunction to many of the leading causes of death in adults. *American Journal of Preventive Medicine*, 14, 245–258. [http://dx.doi.org/10.1016/S0749-3797\(98\)00017-8](http://dx.doi.org/10.1016/S0749-3797(98)00017-8)
- Fiese, B. H., Winter, M. A., & Botti, J. C. (2011). The ABCs of family mealtimes: Observational lessons for promoting healthy outcomes for children with persistent asthma. *Child Development*, 82, 133–145.
- Frazier, L. D., & Hooker, K. (2006). Possible selves in adult development: Linking theory and research. In C. Dunkel & J. Kerpelman (Eds.), *Possible selves: Theory, research and application* (pp. 41–59). Hauppauge, NY: Nova Science.
- Fung, H. H., & Siu, T. M. Y. (2010). Time, culture, and life-cycle changes of social goals. In T. W. Miller (Ed.), *Handbook of stressful transitions across the lifespan* (pp. 441–464). New York: Springer.
- Gitlin, L. N., & Corcoran, M. (2005). *Occupational therapy and dementia care: The Home Environment Skill-Building Program for individuals and families*. Bethesda, MD: AOTA Press.
- Gitlin, L., Winter, L., Corcoran, M., Dennis, M., Schinfeld, S., & Hauck, W. (2003). Effects of the Home Environmental Skill-Building Program on the caregiver-care recipient dyad: 6-month outcomes from the Philadelphia REACH initiative. *The Gerontologist*, 43, 532–546.

- Graff, M. J. L., Adang, E. M. M., Vernooij-Dassen, M. J. M., Dekker, J., Jönsson, L., Thijssen, M.,... Rikkert, M. G. M. O. (2008). Community occupational therapy for older patients with dementia and their caregivers: Cost effectiveness study. *British Medical Journal*, 336(7636), 134–138. <http://dx.doi.org/10.1136/bmj.39408.481898.BE>
- Graham, F., Rodger, S., & Ziviani, J. (2009). Coaching parents to enable children's participation: An approach for working with parents and their children. *Australian Occupational Therapy Journal*, 56, 16–23.
- Gutman, S. A. (2000). *Brain injury and gender role strain: Rebuilding adult lifestyles after injury*. Binghamton, NY: Haworth Press.
- Hamilton, N. A., Catley, D., & Karlson, C. (2007). Sleep and the affective response to stress and pain. *Health Psychology*, 26, 288–295.
- Hanson, M. D., & Chen, E. (2010). Daily stress, cortisol, and sleep: The moderating role of childhood psychosocial environments. *Health Psychology*, 29, 394–402.
- Haslam, S. A., O'Brien, A., Jetten, J., Vormedal, K., & Penna, S. (2005). Taking the strain: Social identity, social support, and the experience of stress. *British Journal of Social Psychology*, 44, 355–370.
- Hemmingsson, H., Egilson, S., Hoffman, O., & Kielhofner, G. (2005). *School Setting Interview (SSI; Version, 3.0)*. Nacka: Swedish Association of Occupational Therapists.
- Heppner, W. L., Kernis, M. H., Lakey, C. E., Campbell, W. K., Goldman, B. M., Davis, P. J., & Cascio, E. V. (2008). Mindfulness as a means of reducing aggressive behavior: Dispositional and situational evidence. *Aggressive Behavior*, 34, 486–496.
- Hettich, P. I. (2010). College-to-workplace transitions: Becoming a freshman again. In T. W. Miller (Ed.), *Handbook of stressful transitions across the lifespan* (pp. 87–109). New York: Springer.
- Hillier, A., Murphy, D., & Ferrara, C. (2011). A pilot study: Short-term reduction in salivary cortisol following low-level physical exercise and relaxation among adolescents and young adults on the autism spectrum. *Stress and Health*, 27, 395–402.
- Hillman, C. H., Buck, S. M., Themanson, J. R., Pontifex, M. B., & Castelli, D. M. (2009). Aerobic fitness and cognitive development: Event-related brain potential and task performance indices of executive control in preadolescent children. *Developmental Psychology*, 45, 114–129.
- Hock, M. F., Deshler, D. D., & Shumaker, J. B. (2006). Enhancing student motivation through the pursuit of possible selves. In C. Dunkel & J. Kerpelman (Eds.), *Possible selves: Theory, research, and application* (pp. 205–221). New York: Nova Sciences.
- Hutchinson, N. L., Versnel, J., Chin, P. I., & Munby, H. (2008). Negotiating accommodations so that work-based education facilitates career development for youth with disabilities. *Work*, 30, 123–136.
- Jetten, J., Haslam, S. A., Iyer, A., & Haslam, C. (2010). Turning to others in times of change: Social identity and coping with stress. In S. Sturmer & M. Snyder (Eds.), *The psychology of prosocial behavior* (pp. 139–156). Somerset, NJ: Wiley-Blackwell.
- Jha, A. P., Stanley, E. A., Kiyonaga, A., Wong, L., & Gelfand, L. (2010). Examining the protective effects of mindfulness training on working memory capacity and affective experience. *Emotion*, 10(1), 54–64.
- Jobin, J., & Wrosch, C. (2014). Associations between dispositional optimism and diurnal cortisol in a community sample: When stress is perceived as higher than normal. *Health Psychology*, 33, 382–391.
- Kay, J. (2010). The neurobiology of stress throughout the life cycle. In T. W. Miller (Ed.), *Handbook of stressful transitions across the lifespan* (pp. 35–57). New York: Springer.
- Kelly, C., & Loy, D. P. (2008). Comparing the effects of aquatic and land-based exercise on the physiological stress response of women with fibromyalgia. *Therapeutic Recreation Journal*, 42, 103–118.
- Kielhofner, G. (2008). *Model of Human Occupation: Theory and application* (4th ed.). Baltimore: Lippincott Williams & Wilkins.
- Kielhofner, G., Mallinson, T., Crawford, C., Nowak, M., Rigby, M., Henry, A., & Walens, D. (2004). *Occupational Performance History Interview-II (OPHI-II; Version 2.1)*. Chicago: Model of Human Occupation Clearinghouse, University of Illinois at Chicago.
- Kleiber, D. A., Larson, R., & Csikszentmihalyi, M. (1986). The experience of leisure in adolescence. *Journal of Leisure Research*, 18, 169–176.
- Koole, S. L., Van Dellen, L. F., & Sheppes, G. (2010). The self-regulation of emotion. In K. D. Vohs & R. F. Baumeister (Eds.), *Handbook of self-regulation: Research, theory, and applications* (2nd ed., pp. 22–40). New York: Guilford.
- Larson, R. W. (2007). From "I" to "we": Development of the capacity of teamwork in youth programs. In R. K. Silbereisen & R. M. Lerner (Eds.), *Approaches to positive youth development* (pp. 277–292). Los Angeles: Sage.
- Larson, R. W. (2011). Positive development in a disorderly world. *Journal of Research in Adolescence*, 21(2), 317–334.
- Larson, R. W., Hansen, D., & Monetta, G. (2006). Differing profiles of developmental experiences across types of organized youth activities. *Developmental Psychology*, 42, 849–863.
- Larson, R. W., Hansen, D., & Walker, K. (2005). Everybody's gotta give: Development of initiative and teamwork within a youth program. In J. L. Mahoney, R. W. Larson, & J. S. Eccles (Eds.),

- Organized activities as contexts of development: Extracurricular activities, after-school and community programs* (pp. 159–183). Mahwah, NJ: Lawrence Erlbaum.
- Law, M., Cooper, B., Strong, S., Stewart, D., Rigby, P., & Letts, L. (1996). The Person–Environment–Occupation model: A transactive approach to occupational performance. *Canadian Journal of Occupational Therapy*, 63, 9–23.
- Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. New York: Springer.
- Levy-Shiff, R., Dimitrovsky, L., Shulman, S., & Dov, H.-E. (1998). Cognitive appraisal, coping strategies, and support resources as correlates of parenting and infant development. *Developmental Psychology*, 34, 1417–1427.
- Lewis, M., Feirig, C., & Rosenthal, S. (2000). Attachment over time. *Child Development*, 71, 707–720.
- Ludwig, D. S., & Kabat-Zinn, J. (2008). Mindfulness in medicine. *JAMA*, 300, 1350–1352.
- Lupien, S. J., McEwen, B. S., Gunnar, M. R., & Heim, C. (2009). Effects of stress throughout the lifespan on the brain, behavior, and cognition. *Nature Reviews Neuroscience*, 10, 434–445.
- Lutz, A., Slagter, H. A., Rawlings, N. B., Francis, A. D., Greischar, L. L., & Davidson, R. J. (2009). Mental training enhances attentional stability: Neural and behavioral evidence. *Journal of Neuroscience*, 29, 13418–13427.
- Ma, P., Gonzalez, R., Wang, S., & Shea, M. (2013). *College stress and spirituality as correlates of psychological adjustment among college students*. Poster session presented at the American Psychological Association 121st Annual Convention, Honolulu.
- Matuska, K., Bass, J., & Schmitt, J. (2013, August). Life balance and perceived stress: Predictors and demographic profile. *Occupational Therapy Journal of Research*, 33, 146–158.
- Matuska, K., & Christiansen, C. (2008). A proposed model of lifestyle balance. *Journal of Occupational Science*, 15, 1, 9–19.
- McEwen, B. S. (2005). Stressed or stressed out: What is the difference? *Journal of Psychiatry and Neuroscience*, 30, 315–318.
- McHale, S. M., Crouter, A. C., & Tucker, C. J. (2001). Free-time activities in middle childhood: Links with adjustment in early adolescence. *Child Development*, 72, 1764–1778.
- Middleton, L. E., Manini, T. M., Simonsick, E. M., Harris, T. B., Barnes, D. E., Tylavsky, F.,... Yaffe, K. (2011). Activity energy expenditure and incident of cognitive impairment in older adults. *Archives of Internal Medicine*, 171, 1251–1257.
- Mohr, D. C., Lovera, J., Brown, T., Cohen, B., Neylan, T., Henry, R.,... Pelletier, D. (2012). A randomized trial of stress management for the prevention of new brain lesions in MS. *Neurology*, 79, 412–419.
- Moore-Corner, R., Kielhofner, G., & Olson, L. (1998). *Work Environment Impact Scale (WEIS; Version 2.0)*. Chicago: Model of Human Occupation Clearinghouse, University of Illinois at Chicago.
- Morris, J. E., & Coley, R. L. (2004). Maternal, family, and work correlates of role strain in low-income mothers. *Journal of Family Psychology*, 18, 424–434.
- Murphy, L. B., & Moriarty, A. E. (1976). *Vulnerability, coping, and growth*. New Haven, CT: Yale University Press.
- Murru, E. C., & Martin Ginis, K. A. (2010). Imagining the possibilities: The effects of a possible selves intervention on self-regulatory efficacy and exercise behavior. *Journal of Sport and Exercise Psychology*, 32, 537–554.
- Neumark-Sztainer, D. (2008). Family meals in adolescents: Findings from Project EAT. *Social Policy Report*, 22(4), 11.
- Newman, B. M. (2000). The challenges of parenting infants and young children. In P. C. McKenry & S. J. Price (Eds.), *Family and change* (2nd ed., pp. 45–70). Thousand Oaks, CA: Sage.
- Olson, L. (2014). Leisure occupations. In J. Hinojosa & M. L. Blount (Eds.), *The texture of life: Occupations and related activities* (4th ed., pp. 285–316). Bethesda, MD: AOTA Press.
- Orentlicher, M. L., & Olson, L. J. (2010). Transition from school to adult life for students with an autism spectrum disorder. In H. Miller-Kuhaneck & R. Watling (Eds.), *Autism: A comprehensive occupational therapy approach* (3rd ed., pp. 665–700). Bethesda, MD: AOTA Press.
- Oyserman, D., & Fryberg, S. (2006). Possible selves of diverse adolescents: Content and function across gender, race, and national origin. In C. Dunkel & J. Kerpelman (Eds.), *Possible selves: Theory, research, and applications* (pp. 17–39). Hauppauge, NY: Nova Science.
- Papazisis, G., Nicolaou, P., Tsiga, E., Christoforou, T., & Sapountzi-Krepia, D. (2014). Religious and spiritual beliefs, self-esteem, anxiety, and depression among nursing students. *Nursing and Health Sciences*, 16, 232–238.
- Park, C. L., Edmondson, D., & Mills, M. A. (2010). Religious worldviews and stressful encounters: Reciprocal influence from a meaning-making perspective. In T. W. Miller (Ed.), *Handbook of stressful transitions across the lifespan* (pp. 485–501). New York: Springer.
- Quittner, A. L., Espelage, D. L., Opipari, L. C., Carter, B., Eid, N., & Eigen, H. (1998). Role strain in couples with and without a child with chronic illness: Associations with marital satisfaction, intimacy, and daily mood. *Health Psychology*, 17, 112–124.
- Randall, M. (2010, Fall). The physiology of stress: Cortisol and the hypothalamic–pituitary–adrenal axis. *Dartmouth Undergraduate Journal of Science*. Retrieved from <http://dujs.dartmouth.edu/fall-2010/the-physiology-of-stress-cortisol-and-the-hypothalamic-pituitary-adrenal-axis#.VeYKmk2FN6o>

- Ragmussen, H., Scheier, M., & Greenhouse, J. (2009). Optimism and physical health: A meta-analytic review. *Annals of Behavioral Medicine, 37*, 239–256.
- Rook, K. S., August, K. J., & Sorkin, D. H. (2011). Social network functions and health. In R. J. Contrada & A. Baum (Eds.), *The handbook of stress science: Biology, psychology, and health* (pp. 123–135). New York: Springer.
- Rush, D. D., & Shelden, M. L. (2011). *The early childhood coaching handbook*. Baltimore: Paul H. Brookes.
- Salmon, P. (2001). Effects of physical exercise on anxiety, depression, and sensitivity to stress: A unifying theory. *Clinical Psychology Review, 21*, 33–61.
- Samia, L., Hepburn, K., & Nichols, L. (2012). Flying by the seat of our pants: What dementia family caregivers want in an advanced caregiver training program. *Research in Nursing and Health, 35*, 598–609.
- Samuel, A., & Kannappan, R. (2011). Spirituality and coping strategies of physiotherapy students. *Journal of Psychosocial Research, 6*, 241–249.
- Schlossberg, N. K., Waters, E. B., & Goodman, J. (1981). *Counseling adults in transitions: Linking practice to theory* (2nd ed.). New York: Springer.
- Schulz, R., Burgio, L., Burns, R., Eisdorfer, C., Gallagher-Thompson, D., Gitlin, L., & Mahoney, D. (2003). Resources for enhancing Alzheimer's caregiver health (REACH): Overview, site-specific outcomes, and future directions. *The Gerontologist, 43*, 514–531.
- Shaw, L., & Lindsay, R. (2008). Renewing focus and building capacity for enacting authentic collaboration in work rehabilitation. *Work, 30*, 215–218.
- Shonkoff, J. P. (2011). Protecting brains, not simply stimulating minds. *Science, 333*, 982–983.
- Soeker, M. S., Wegner, L., & Pretorius, B. (2008). I'm going back to work: Back injured clients' perceptions and experiences of their worker roles. *Work, 20*, 161–170.
- Sørensen, S., Pinquart, M., & Duberstein, P. (2002). How effective are interventions with caregivers? An updated meta-analysis. *The Gerontologist, 42*(3), 356–372.
- Steiner, J. L., Bigatti, S. M., Hernandez, A. M., Lydon-Lam, J. R., & Johnston, E. L. (2010). Social support mediates the relations between role strains and marital satisfaction in husbands of patients with fibromyalgia syndrome. *Family Systems and Health, 28*, 209–223.
- Stewart, D. A., Lawless, J. J., Shimmell, L. J., Palisano, R. J., Freeman, M., Rosenbaum, P. L., & Russell, D. J. (2012). Social participation of adolescents with cerebral palsy: Trade-offs and choices. *Physical and Occupational Therapy in Pediatrics, 32*, 167–179.
- Stolley, J., Buckwalter, K., & Koenig, G. (1999). Prayer and religious coping for caregivers of persons with Alzheimer's disease and related disorders. *American Journal of Alzheimer's Disease, 14*, 181–191.
- Tirella, L. G., Tickle-Degnen, L., Miller, L. C., & Bedell, G. (2012). Parent strategies for addressing the needs of their newly adopted child. *Physical and Occupational Therapy in Pediatrics, 32*, 97–110.
- Tornstam, L. (2011). Maturing into gerotranscendence. *Journal of Transpersonal Psychology, 43*(2), 166–180.
- Vercambre, M. N., Grodstein, F., Manson, J. E., Stampfer, M. J., & Kang, J. H. (2011). Physical activity and cognition in women with vascular conditions. *Archives of Internal Medicine, 171*, 1244–1250.
- Ware, J. E., Kosinski M., & Dewey J. E. (2000). *How to score version two of the SF-36 Health Survey*. Lincoln, RI: QualityMetric.
- Wheeler, E. A. (2010). Life stress buffer: The salubrious role of African-centered spirituality. In T. W. Miller (Ed.), *Handbook of stressful transitions across the lifespan* (pp. 503–662). New York: Springer.
- Whiteford, G., Townsend, E. A., & Hocking, C. (2000). Reflections on a renaissance of occupation. *Canadian Journal of Occupational Therapy, 67*(1), 61–69. <http://dx.doi.org/10.1177/000841740006700109>
- Wilcock, A. A. (1993). A theory of the human need for occupation. *Journal of Occupational Science, 1*, 17–24.
- Williamson, G. G., & Szczepanski, M. (1999). Coping Frame of Reference. In P. Kramer & J. Hinojosa (Eds.), *Frames of reference for pediatric occupational therapy* (2nd ed., pp. 431–468). Baltimore: Lippincott Williams & Wilkins.
- Wood, D., Larson, R. W., & Brown, J. R. (2009). How adolescents come to see themselves as more responsible through participation in youth programs. *Child Development, 80*, 295–309.
- Yerxa, E. J., Clark, F., Frank, G., Jackson, J., Parham, D., Pierce, D.,... Zemke, R. (1989). An introduction to occupational science: A foundation for occupational therapy in the 21st century. *Occupational Therapy in Health Care, 6*(4), 1–17.
- Ylvisaker, M., & Feeney, T. (2002). Executive functions, self-regulation, and learned optimism in pediatric rehabilitation: A review and implications for intervention. *Pediatric Rehabilitation, 5*, 51–70.
- Zeitlin, S. (1985). *Coping Inventory*. Bensenville, IL: Scholastic Testing Service.
- Zeitlin, S., Williamson, G. G., & Szczepanski, M. (1988). *Early Coping Inventory*. Bensenville, IL: Scholastic Testing Service.

APPENDIX A.

Specialized Knowledge and Skills for Occupational Therapy Practice in the Neonatal Intensive Care Unit

Purpose

The purpose of this paper is to provide a reference for occupational therapists on the advanced knowledge and skills necessary to practice in a neonatal intensive care unit (NICU). Occupational therapy practice with infants in the NICU and their families is high risk and specialized, only appropriate for occupational therapists with advanced knowledge and skills in neonatal care.

Introduction

Occupational therapy philosophy and education provide the foundation for this profession to make a valuable contribution to neonatal practice (American Occupational Therapy Association [AOTA], 2004b). Specialized knowledge of neonatal medical conditions and developmental variability and abnormality in infants cared for in the NICU is essential to safe, effective practice. The therapist must recognize the complex medical needs and vulnerabilities of acutely ill or premature infants. These infants frequently are physiologically fragile and easily compromised by environmental conditions. Interactions and therapeutic interventions that may appear innocuous can trigger physiologic instability in an infant and can be life threatening. In fact, protecting the fragile neonate from excessive or inappropriate sensory aspects of the environment is often a more urgent priority than direct interventions or interactions with the infant. Occupational therapy approaches, such as sensory integration and neurodevelopmental intervention, are applicable within the NICU setting. However, these approaches may need to be modified according to the infant's medical status, physiological homeostasis, and developmental and family needs.

The special needs of families whose infants are in the NICU also must be recognized. The infant's medical status and uncertain outcome, the highly technical environment of the NICU, separation from parents, and potential maternal complications after labor and delivery may contribute to family stress or crisis. These situations often alter the parent-infant attachment process, which is essential to optimal infant developmental outcomes. Families are best served by an occupational therapist who is not only knowledgeable about infant needs, but also sensitive to family circumstances, priorities, concerns, and cultural beliefs. The occupational therapist must seek ways to establish supportive, collaborative, and therapeutic relationships with family members in order to foster the infant's optimal development.

The social and physical aspects of the environment can be stressful to both the infant and the family. All persons who interact with the infant constitute the social environment. The physical environment is composed of inanimate elements and properties (e.g., lighting, sound, bedding, equipment). The occupational therapist must understand the interplay of the social and physical features of the NICU and the way in which this interplay influences the infant, family, and staff members. This knowledge is used as a basis for the occupational therapy evaluation and contributes to effective intervention strategies.

Working within the social and physical bounds of the NICU environment, an important role of the occupational therapist is to assist each family to foster optimal infant development, including the encouragement of developmentally appropriate occupations, sensorimotor processes, and neurobehavioral organization. This must occur while considering the often fragile medical and physiological status of the

infant. Through direct observation, intervention, consultation, education, and research, the occupational therapist collaborates with others to provide the infant with the most effective and appropriate social and physical environment.

The occupational therapist working in the NICU must have a basic knowledge of occupational therapy, pediatric experience, and specialized knowledge and skills related to the complex needs of high-risk infants, their families, and the NICU environment. Basic occupational therapy education includes knowledge of biological sciences, disease processes, mental health, and typical and atypical child and adult family development. Occupational therapy's domain of concern, encompassing the interaction among the biological, developmental, and social-emotional aspects of human function as expressed in daily activities and occupations, makes it particularly suited to address the needs of the developing infant and family (AOTA, 2002). The occupational therapy method of activity analysis and adaptation to achieve a functional outcome is valuable in promoting "goodness of fit" (i.e., the match between the infant's capabilities and the physical and social environment), as there is often a mismatch between the NICU environment, parental expectations, and the infant's capabilities.

Experience in pediatric occupational therapy is essential for practice in the NICU. This experience provides a perspective on the continuum of typical and atypical child development and on the significance of the family in the child's life. Experience in pediatric occupational therapy affords the practitioner opportunities for development of the critical thinking skills necessary for evaluation and intervention to promote competent occupational performance and emotional well-being of children and their families. Therefore, the therapist interested in practicing in the NICU should have experience in the following areas: pediatric occupational therapy with infants and young children, longitudinal follow-up of infants treated in the NICU, and collaboration with families.

In addition to basic occupational therapy education and pediatric experience, the occupational therapist working in the NICU requires advanced knowledge and skills to provide complex interventions to critically ill neonates and their families. These interventions require continuous evaluation and a dynamic approach to intervention planning. They also require knowledge of grief reactions, social structures, attachment, medical procedures, and other issues relating to the health and well-being of the family unit. Intervention in the NICU context is not a recommended area of practice for occupational therapy assistants because such knowledge and skills are beyond the scope of their practice. Since practice in the NICU requires advanced-level expertise and clinical reasoning, this area of practice also is not recommended for entry-level occupational therapists or occupational therapists who do not have the pediatric experience described above. Extensive continuing education; mentoring by an occupational therapist experienced in neonatal care; and graded, closely supervised, mentored practice are recommended for any occupational therapist entering neonatal practice. Supervision often is required until the therapist demonstrates competency in working with infants and their families in the NICU environment (AOTA, 2004a).

The specialized knowledge required for practice in the NICU includes familiarity with relevant medical conditions, procedures, and equipment; an understanding of the individualized developmental abilities and vulnerabilities of infants; an understanding of theories of neonatal neurobehavioral organization; working knowledge of family systems, early social-emotional development, infant mental health, and NICU ecology; and an understanding of multidisciplinary team collaboration. Most importantly, the NICU therapist must have a clear understanding of the manner in which these factors interact to influence behavior. The occupational therapist develops the necessary skills through continuing education and supervised mentored clinical experience in evaluation and intervention specific to the NICU. Neonatal practice requires advanced clinical reasoning skills. These skills include the flexibility to recognize and respond to unfamiliar situations and nuances of behavior, the ability to anticipate future directions of intervention, and the ability to perceive the clinical condition as a whole. The occupational therapist in the NICU applies these competencies with regard to the infant; the infant's family and caregivers; and the NICU

environment, including staff. Specifically, the occupational therapist in the NICU designs an individualized intervention plan in collaboration with the family and others that incorporates the family's priorities and NICU contexts along with the individualized needs of the infant. This requires understanding the occupations and activities valued by families and the NICU culture; defining what factors limit each infant's participation or engagement in those occupations and activities; identifying factors that would constitute readiness for engagement in occupations and activities; and finally, delineating what physical and/or social environmental supports will maximize participation for both the infant and the family in the short term and in the long term.

Maintenance of clinical competency and an evidence-based approach to practice are both vitally important in the rapidly changing field of neonatology. Clinical competence can be sustained through regular supervision or a mentoring relationship, participation in peer study groups, reflective process, and formal and informal continuing education. An evidence-based approach to practice necessitates ongoing critical review of the relevant research, literature, and clinical tools available in this rapidly changing field of practice. An occupational therapy practitioner is knowledgeable about evidence-based research and applies it ethically and appropriately to the occupational therapy process (AOTA, 2005b).

Knowledge and Skills: The Infant, Family, and NICU Environment

The following information identifies the knowledge and skills needed to function as an occupational therapist in the NICU. This information is organized under the three main areas of occupational therapy concern described previously: the infant, the family, and the NICU environment.

The Infant

To be competent, the occupational therapist has to have an in-depth understanding of approaches to evaluation and intervention, including use of a developmentally supportive consultative model of service delivery. These approaches are presented in the literature specific to occupational therapy, neonatology, psychology, and infant and family studies. In addition, the therapist has to have a thorough understanding of medical factors and the potential risks they pose to normal fetal and infant growth and development. The therapist must understand and critically analyze this information within the context of occupational therapy practice and the specific philosophy of the NICU in which the occupational therapist works. The therapist develops an evaluation plan that includes use of appropriate standardized tools, parent or caregiver interviews, and observations of infant adaptation to the social and physical environments. The occupational therapist, in conjunction with the family and medical caregivers, then develops appropriate intervention strategies, individually suited to each infant and family.

For clarity in this paper, infant behavior is discussed separately from family and environmental concerns. However, in program implementation, the infant is assessed and treated within the context of the family and the NICU environment.

The following is a comprehensive outline of the essential knowledge base that an occupational therapist must possess for working with NICU infants.

I. Medical knowledge base as the foundation for understanding infant behavior

A. General information

1. Medical terminology and abbreviations used in the NICU
2. Basic principles, uses, and potential complications of the medical equipment and procedures, including precautions and implications for the therapist and infant
3. Medical complications frequently encountered, including pathophysiology, risks, precautions, and prognoses associated with specific conditions.

- B. Specific knowledge
 - 1. NICU equipment
 - 2. Diagnostic procedures
 - 3. Medical procedures
 - 4. Nursing procedures and routines
 - 5. Respiratory support
 - 6. Thermoregulatory support
 - 7. Nutritional support
 - 8. Medication effects
 - 9. Infection control
 - 10. Institution-specific policies and procedures.

II. Factors that may influence infant and child development

- A. Prenatal
 - 1. Maternal and fetal complications during pregnancy
 - 2. Genetic disorders, congenital anomalies, syndromes, isolated defects
 - 3. Teratogens (e.g., licit and illicit drug exposure, radiation, environmental contaminants)
 - 4. Infectious diseases (e.g., rubella, cytomegalovirus, herpes, toxoplasmosis, HIV)
 - 5. Social risk factors (e.g., poverty, inadequate support, stress, environmental toxins).
- B. Perinatal
 - 1. Maternal complications during delivery
 - 2. Neonatal complications during delivery
 - 3. Gestational age and birth weight.
- C. Postnatal conditions and complications
 - 1. Respiratory
 - 2. Cardiovascular
 - 3. Neurologic
 - 4. Sensory
 - 5. Orthopedic
 - 6. Gastrointestinal
 - 7. Metabolic
 - 8. Hemolytic
 - 9. Dermatologic
 - 10. Infectious disease
 - 11. Iatrogenic complications.

III. Knowledge of the developmental course, abilities, and vulnerabilities of infants in the NICU

- A. Differences in body structure and body functions, developmental progression, variations, deviations, and abnormalities in infants in relation to preterm, term, or postterm birth and/or prenatal, perinatal, or postnatal factors
1. Infant neurobehavioral organization
 - a. Physiologic (e.g., cardiorespiratory)
 - b. States of arousal
 - c. Regulatory abilities
 - Sleep and waking states
 - Circadian rhythms
 - Typical and atypical patterns
 - Self-regulation
 - External regulation
 - Medication effects/side effects
 - d. Neurosocial (e.g., attention, interaction).
 2. Sensory development and processing of sensory information
 - a. Sequential developmental progression in utero and adaptations to the extra-uterine environment
 - b. Thresholds for stimulation within the sensory systems: tactile, vestibular, proprioceptive, visual, auditory, olfactory, gustatory
 - c. Responses: arousal, attention, modulation, transition, range, decompensation
 - d. Sensory acuity.
 3. Motor function
 - a. Neuromotor development, including, but not limited to, muscle tone, posture, quality of movement, reflexes and reactions, and motor control
 - b. Biomechanical factors, including, but not limited to, active and passive range of motion, strength, and orthopedic status.
 4. Social-emotional development
 - a. Early communicative cues
 - b. Self-regulation of interaction
 - c. Initial formation of attachment relationships
 - d. Temperament.

B. Emerging competencies in infant occupation

1. General factors that influence participation in daily life activities
 - a. Postconceptional age and weight
 - b. Physical and developmental maturation
 - c. Physiological status and medical conditions
 - d. Neurobehavioral organization

- e. Sensory processing
 - f. Biomechanical and neuromotor function
 - g. Social interaction
 - h. Physical environment
 - i. Social environment.
2. Specific activities
 - a. Ability to cope with and participate in caregiving
 - (1) Feeding process
 - (a) Modes (e.g., breast, bottle, tube)
 - (b) Function (e.g., ability to meet nutritional needs, physiologic cost, endurance)
 - (c) Oral-motor mechanism (e.g., structure, function, quality)
 - (d) Maturation of mechanical and neural control of sucking, swallowing, and breathing
 - (e) Relationship among nutritive and non-nutritive sucking, respiration, and oxygenation
 - (f) Positioning and handling
 - (g) Feeding readiness cues
 - (h) Physiologic issues, such as metabolic and neurologic
 - (i) Competency of the infant as a partner
 - (j) Relationship with primary caregivers
 - (k) Tolerance of oral-facial and intraoral sensations.
 - (2) Bathing
 - (3) Dressing and diapering
 - (4) Medical routines and procedures.
 - b. Engaging in nurturing interactions
 - (1) Skin-to-skin holding (kangaroo care)
 - (2) Physical and social dialogue
 - (3) Feeding.
 - c. Interrelationship between medical and developmental domains
 - (1) Present conditions
 - (2) Future implications.

IV. Knowledge of evolving developmental approaches in the NICU

- A. Historical and current perspectives
 1. Supplemental stimulation
 2. Reduced stimulation
 3. Environmental neonatology

4. Individualized developmental care
 5. Family-centered care
 6. Relationship-based approach.
- B. Modification and integration of current pediatric occupational therapy frames of reference (e.g., sensory integration, neurodevelopmental therapy, coping, dynamic systems).
- V. Specific skills related to occupational therapy with infants in the NICU, including the ability to
- A. Instruct, consult, and communicate with caregivers
 - B. Use NICU equipment appropriately and safely, including understanding of the purpose, basic operation, settings, and precautions of all relevant equipment
 - C. Conduct appropriate assessments
 1. Determine appropriate timing of infant assessments on the basis of the infant's medical and physiological status, postconceptional age, and NICU and family routines
 2. Select and administer formal and informal assessment procedures that are appropriate for postconceptional age and medical condition and that identify developmental abilities, vulnerabilities, and limitations in daily life activities and occupations as they are influenced by medical status and
 - a. Neurobehavioral organization
 - b. Sensory development and processing
 - c. Motor function
 - d. Pain
 - e. Daily activity (e.g., feeding)
 - f. Social-emotional development.
 3. Assess the effects of physical environment, caregiving practices, positioning, and nurturance on the infant's neurobehavioral organization, sensory, motor, and medical status.
 - D. Formulate an individualized therapeutic intervention plan that supports the infant's current level of function and facilitates optimal social-emotional, physical, cognitive, and sensory development of the infant within the context of the family and the NICU
 1. Determine appropriate timing of infant interventions on the basis of the infant's medical and physiological status, postconceptional age, and NICU and family bedside routines
 2. Modify sensory aspects of physical environment according to infant sensory threshold
 3. Participate with the infant and caregivers in occupational therapy interventions that reinforce the role of the family as the constant in the life of the infant and support the individual infant's medical and physiological status in order to
 - a. Enhance infant neurobehavioral organization
 - b. Facilitate social participation
 - c. Promote optimal infant neuromotor functioning and engagement in daily life activities
 - d. Promote developmentally appropriate motor function and engagement in daily life activities through the use of biomechanical techniques, when appropriate
 - e. Facilitate well-organized infant behavior through adaptation of infant daily life activities.

- E. Continuously observe and critically analyze subtle infant responses to the intervention program and modify as needed
- F. Collaborate with family, NICU staff, and other persons who potentially may have an impact on infant well-being to
 - 1. Create and maintain individualized developmental care plans
 - 2. Incorporate the occupational therapy program into NICU routines
 - 3. Modify intervention and discharge plans considering anticipated infant outcome.
- G. Provide documentation that is objective, interpretive, thorough, and concise
- H. Formulate discharge and follow-up plans in coordination with the interdisciplinary team and community resources to meet the developmental needs of the infant and family.

The Family

Parents and other family members are acknowledged to be the most important and consistent influence in the infant's life. Their occupational roles as primary caregivers and nurturers constantly need to be recognized and reaffirmed. Typically, parents are mediators of the infant's affective, sensory, and motor experiences. When an infant is hospitalized in the NICU immediately after birth, parents are not always able to play this mediation role. The bi-directional attachment process, which begins at delivery and in which both infant and parent play a part, can be disrupted. Since attachment provides a foundation for the infant's future development and independent function, its promotion is an important consideration for the occupational therapist. Therefore, the occupational therapist collaborates with family members, on-site and off-site, to facilitate the infant's optimal development, promote the parents' occupational roles, support parent-infant attachment, and ensure a successful transition from hospital to home and community.

The following outline summarizes the knowledge base that would enable an occupational therapist to provide services in the NICU from a family-centered perspective.

- I. Knowledge of the family as a basis for collaboration
 - A. Family systems
 - 1. Family structure, occupational roles, cultural identification, beliefs, values, and practices
 - 2. Family resources: Sources and allocation (e.g., time, money, energy, social-emotional support)
 - 3. Family adaptation: Adjustment to adding a new family member, adjustment to stressful situations
 - 4. Needs, culture, and roles of family members, including siblings.
 - B. Adult learning styles
 - 1. Individual differences in learning
 - 2. Relationship between emotional state and learning capacities
 - 3. Changes in parental focus during NICU course.
 - C. Parent-infant interactions: progression and individual differences
 - 1. Parents' role in the infant's early social-emotional development
 - 2. Attachment as an ongoing two-way process between parents and infant, including the importance of attachment to later developmental function and the influence of hospitalization on parents and infants on the attachment process

3. Development of synchronous interactions
 4. Importance of parents' learning to accurately observe, interpret, and respond to their infant's unique cues.
- D. The transition of the infant from hospital to home and community
1. Possible stresses and difficulties inherent in the transition process for the infant and each family member
 2. Knowledge of community resources and local, state, and federal guidelines and services.
- II. Specific skills related to occupational therapy with families of infants in the NICU. The occupational therapist
- A. Identifies family hopes, dreams, expectations, attitudes, knowledge, strengths, priorities, preferred communication styles, and skills regarding daily care, play, and other interactions with the infant
 - B. Identifies family members' learning styles
 - C. Assists parents in feeling comfortable with their infant and as parents to a new family member
 - D. Guides family members in observing and interpreting their infant's behavior and in adapting their own behaviors in response to the infant's cues to elicit appropriate sensory, motor, and social responses
 1. During daily life activities
 2. During interactions involving exploration, attention, and orientation
 3. While engaged in nurturing interactions.
 - E. Recognizes and acknowledges the infant's contribution and strengths in others' lives
 - F. Fosters successful parent–infant interactions via mutual problem solving, anticipatory guidance, modeling of behaviors, didactic and experiential education, and modification of the infant's environment
 - G. Integrates family observations and priorities in formulating occupational therapy intervention recommendations
 - H. Interprets and discusses occupational therapy evaluation findings in collaboration with the family
 - I. Adapts intervention approaches according to family culture, changing emotions, needs, and resources that may be influenced by the infant's changing medical status or other circumstances
 - J. Formulates and implements a discharge and follow-up plan with the family and other team members to ensure a smooth transition to the community, integrating occupational therapy goals into the overall goals and priorities of the family.

The NICU Environment

The neonate who is born prematurely or acutely ill is not well-adapted to the stressful and technologically complex environment of the NICU. This mismatch between the infant and the environment may have a deleterious effect on the infant's medical and developmental outcomes. Therefore, a primary intervention goal in the NICU is to provide the best match or fit between the infant and the NICU environment. Adapting or structuring the environment to enhance function is a well-accepted occupational therapy approach. However, this first requires knowledge of the various components of the environment as well as their interplay. The occupational therapist assesses the environment and collaborates with others to shape the infant's physical and social environment to provide a milieu of developmentally supportive care. The following competencies are essential:

- I. Knowledge of the unique sensory properties of the NICU and their relationship to each infant's neurobehavioral organization
 - A. *Tactile*: Timing, intensity, texture, handling for medical and nursing procedures, parent interaction
 - B. *Proprioceptive–vestibular*: Timing, intensity, handling for medical and nursing procedures, parent interaction
 - C. *Olfactory and gustatory experiences specific to the NICU* (timing, quality, intensity)
 - D. *Auditory*: Intensity, duration, timing, animate versus inanimate
 - E. *Visual*: Timing, ambient and focal light intensity, contents of visual field.
- II. Knowledge of the social environment and its relationship to each infant's neurobehavioral organization, including interactions and relationships among
 - A. Parents and infant
 - B. Extended family members and infant
 - C. Staff members and infant
 - D. Parents and staff members
 - E. Occupational therapist, parents, staff, and infant.
- III. Knowledge of the physical environment and its relationship to each infant's maturation and behavioral organization
 - A. Medical equipment and procedures as described under the medical knowledge base section
 - B. Frequency, timing, duration, quality, and intensity of sensory input from medical equipment and procedures
 - C. Sensory input from equipment, procedures, and staff activities that is disruptive to the infant's neurobehavioral organization.
- IV. Knowledge of the NICU culture
 - A. The NICU's specific philosophy of care, including its particular orientation toward acute and chronic care of infants
 - B. The team members' roles, functions, attitudes, and positions in the organizational structure of the individual NICU
 - C. The influence of NICU stressors (e.g., census changes and subsequent staffing patterns)
 - D. Communication patterns and structure, both formal and informal, among staff members and between family and staff members
 - E. Spoken and unspoken rules of behavior
 - F. The effect of the physical and social environments on staff performance and morale
 - G. Hospital administrative policies (e.g., confidentiality).
- V. Specific skills related to occupational therapy in assessing and adapting the environment. The occupational therapist
 - A. Assesses the sensory aspects of the NICU physical and social environments and its effect on infant well-being

- B. Develops intervention strategies in collaboration with the family, NICU staff, and other team members to adapt the environment in order to foster optimal infant development and family interactions
 - 1. Communicates with all levels of staff to establish rapport and develop team commitment to developmental and family goals
 - 2. Integrates occupational therapy goals into the infant's medical priorities and the NICU setting.
- C. Develops and implements strategies to influence philosophy and practice of developmental and family-centered care within the NICU
- D. Assesses the effect of intervention strategies and revises the plan accordingly.

VI. Knowledge of structures that support occupational therapy practice in the NICU

The occupational therapist position exists within the NICU structure. The following knowledge and skills are needed to ensure integration of occupational therapy services into the NICU setting for optimal infant-family outcomes:

- A. Ability to articulate the role and function of occupational therapists in the NICU to demonstrate their value and effectiveness
- B. Ability to use relevant research literature to support occupational therapy practice in the NICU
- C. Knowledge of the hospital's structure, mission, strategic plan, and fiscal priorities as they relate to both NICU and occupational therapy programs
- D. Ability to identify and access sources of administrative and fiscal support to maintain occupational therapy services in the NICU
- E. Knowledge of the larger local, state, and national health and social service systems as they influence policy and fiscal support for occupational therapy services in the NICU and early intervention services
- F. Ability to identify sources of administrative and fiscal support for the practice of occupational therapy within the NICU from the community and the health care system at large
- G. Knowledge of confidentiality guidelines (e.g., HIPAA).

Professional and Personal Characteristics Necessary for Occupational Therapists Practicing in the NICU

The NICU, as a critical care area, necessitates certain professional and personal characteristics. These characteristics include the following:

- 1. Ability to synthesize information from multiple sources, including research findings, and judiciously apply it to the NICU
- 2. Ability to observe the infant and environment for prolonged periods, without intervening, and to identify and understand subtle nuances of behavior and physiology
- 3. Interest in and ability to bring about changes in the infant's social and physical environments through direct intervention with the infant and family, consultation and collaboration with other team members, and implementation of policies and procedures at the organizational level
- 4. Understanding of one's interpersonal communication skills and style and the ability to modify them in response to family and staff behavior, learning styles, and needs
- 5. Commitment to seek ongoing knowledge, education, and peer consultation in this field

6. Ability to provide formal and informal educational programs for the hospital and the community
7. Insight into one's professional knowledge and skills
8. Ability to value, communicate, and collaborate with other NICU team members, community-based early intervention programs, and other resources
9. Understanding of and ability to articulate one's values and attitudes about
 - a. The rights and responsibilities of families
 - b. Relationships between cultural or religious beliefs and medical management decisions
 - c. Working with infants who ultimately may not survive
 - d. Working with infants who may have severe and permanent disabilities
 - e. Working with families whose values, attitudes, behaviors, and life circumstances differ from one's own
 - f. Allocating limited fiscal, personnel, and technological resources to sustain life.
10. Understanding of the *AOTA Code of Ethics* (2005a) as it applies to the NICU.

Definitions

Activity

"[T]he performance of a task or action by an individual" (World Health Organization [WHO], 2001, p. 10).

Activity Limitations

"[D]ifficulties an individual may have in executing activities" (WHO, 2001, p. 10).

Attachment

"A bond between an infant and a caregiver, usually its mother. Attachment is generally formed within the context of a family, providing the child with the necessary feelings of safety and nurturing at a time when the infant is growing and developing. This relationship between the infant and his caregiver serves as a model for all future relationships" (Gale, 2005).

Body Functions

"[T]he physiological or psychological functions of body systems" (including psychological functions; WHO, 2001, p. 10).

Body Structures

"[A]natomical parts of the body, such as organs, limbs, and their components" (WHO, 2001, p. 10).

Bonding

See *Attachment*.

Clinical Reasoning Skills in Occupational Therapy

The process by which occupational therapists individualize and modify treatment. It includes not only the application of theory to practice, but also the treatment of the meaning of illness as experienced by the individual and family (Mattingly, 1991).

Environmental Factors

"[T]he physical, social, and attitudinal environment in which people live and conduct their lives" (WHO, 2001, p. 10).

Environmental Neonatology

The study of environment of newborn special care facilities and its impact on the medical and developmental status of at-risk infants (Gottfried & Gaiter, 1985).

Family

A unit composed of individuals who are linked by shared kinship, function, and/or responsibilities and who identify themselves in a common relationship (Crockenberg, Lyons-Ruth, & Dickson, 1993).

Family-Centered Care

A constellation of philosophies, attitudes, and approaches to the care of children with special health and developmental needs that recognizes that the family is the constant in the child's life and that parent-professional partnerships are essential to effective and high-quality service delivery (Dunst, Trivette, & Deal, 1988; Institute for Family-Centered Care, 1990).

Goodness-of-Fit

"When the properties of the environment and its expectations and demands are in accord with the organism's own capacities, characteristics, and style of behaving" (Chess & Thomas, 1999, p. 3).

Impairments

"[P]roblems in body function or structure such as a significant deviation or loss" (WHO, 2001, p. 10).

Infant Mental Health

"Infant" refers to children under 3 years of age. "Mental" includes social-emotional and cognitive domains. "Health" refers to the well-being of young children and families (Fraiberg, 1980). A multidisciplinary intervention approach for the "early identification of risk and treatment to reduce the likelihood of serious developmental failure and relationship disturbance" (Weatherston, 2002, p. 1).

Medical Caregivers

House staff involved in the care of infants in the NICU. Although personnel may vary between institutions, medical caregivers typically include nurses, physicians (e.g., neonatologists, attending physicians, residents, interns), therapists, pharmacists, nutritionists, and other personnel (adapted from U.S. National Library of Medicine, 2005).

Neurobehavioral Organization

An interrelationship among infant central nervous system integrity and maturation, behaviors, and the caregiving environment. The interrelationship is expressed in terms of self-regulation and mutual regulation of autonomic, motoric, state, and interactional functions (Als, 1982).

Neurosocial

The ability to interact as the nervous system matures in preterm infants. There are three developmental stages of neurosocial development: turning in, coming out, and reciprocity (Gorski, Davidson, & Brazelton, 1979).

NICU

Neonatal intensive care unit. Newborn Nurseries are designated as Basic (Level I), Specialty (Level II), or Subspecialty (Level III) on the basis of their responsibilities and the availability of special service. Basic Neonatal Care Nurseries (*Level I*) provide postnatal care to healthy newborn infants and are equipped to provide resuscitation and to stabilize ill newborn infants until they can be transferred to a neonatal intensive care facility. Specialty Care Nurseries (*Level II*) "provide care to infants who are moderately ill with problems that are expected to resolve rapidly or who are recovering from serious illness" after receiving subspecialty care. Subspecialty Nurseries (*Level III*) provide care to infants who are extremely premature, are critically ill, or require surgical management (American Academy of Pediatrics & American College of Obstetricians and Gynecologists, 2004, p. 134).

Participation

"[I]nvolvement in a life situation" (WHO, 2001, p. 10).

Participation Restrictions

"[P]roblems an individual may experience in involvement in life situations" (WHO, 2001, p. 10).

Physiologic Instability

Refers to a lack of balance or equilibrium within the autonomic nervous system. Signs of physiologic instability may include changes in cardiorespiratory status (heart rate, respiratory rate, decreased oxygen saturation), color changes (pale, dusky, mottled, flushed), or visceral cues (yawning, sneezing, gagging, spitting up, hiccupping, having bowel movement). Conversely, an infant with physiologic stability will be calm with stable color and vital signs (Als, 1986).

Regulatory Abilities

The infant's capacity to modulate or modify his or her own state of arousal and neurobehavioral organization (Als, 1982).

Relationship-Based Approach

An approach that is "guided by a neurodevelopmental framework for understanding preterm infants and depends on the capacities of professionals to collaborate with one another and with families in support of the infants medical, developmental, and emotional well being" (Als & Gilkerson, 1997, p. 178).

References

- Als, H. (1982). Toward a synactive theory of development: Promise for the assessment of infant individuality. *Infant Mental Health Journal*, 3, 229–243.
- Als, H. (1986). A synactive model of neonatal behavioral organization: Framework for the assessment of neurobehavioral development in the premature infant and for the support of infants and parents in the neonatal intensive care environment. *Physical and Occupational Therapy in Pediatrics*, 6(3/4), 3–53.
- Als, H., & Gilkerson, L. (1997). The role of relationship-based developmentally supportive newborn intensive care in strengthening outcome of preterm infants. *Seminars in Perinatology*, 21, 178–189.
- American Academy of Pediatrics, & American College of Obstetricians and Gynecologists. (2004). *Guidelines for perinatal care* (5th ed.). Elk Grove Village, IL: Author
- American Occupational Therapy Association. (2002). Occupational therapy practice framework: Domain and process. *American Journal of Occupational Therapy*, 56, 609–639.
- American Occupational Therapy Association. (2004a). Guidelines for supervision, roles, and responsibilities during the delivery of occupational therapy services. *American Journal of Occupational Therapy*, 58, 663–677.
- American Occupational Therapy Association. (2004b). Scope of practice. *American Journal of Occupational Therapy*, 58, 673–677.
- American Occupational Therapy Association. (2005a). Occupational therapy code of ethics (2005). *American Journal of Occupational Therapy*, 59, 639–642.
- American Occupational Therapy Association. (2005b). Standards of practice for occupational therapy. *American Journal of Occupational Therapy*, 59, 663–665.
- Chess, F., & Thomas, A. (1999). *Goodness of fit: Clinical applications from infancy through adult life*. Philadelphia: Brunner/Mazel.

- Crockenberg, S., Lyons-Ruth, K., & Dickson, S. (1993). The family context of infant mental health: II. Infant development in multiple family relationships. In C. H. Zeanah (Ed.), *Handbook of infant mental health* (pp. 38–55). New York: Guilford.
- Dunst, C. J., Trivette, C. M., & Deal, A. G. (1988). *Enabling and empowering families: Principles and guidelines for practice*. Cambridge, MA: Brookline Books.
- Fraiberg, S. (1980). *Clinical studies in infant mental health*. New York: Basic Books.
- Gale, T. (2005). *The Gale encyclopedia of children's health: Infancy through adolescence*. Farmington Hills, MI: Thomson Gale.
- Gorski, P., Davidson, M. E., & Brazelton, T. B. (1979). Stages of behavioral organization in the high-risk neonate: Theoretical-clinical considerations. *Seminars in Perinatology*, 3, 61–73.
- Gottfried, A. W., & Gaiter, J. L. (1985). *Infant stress under intensive care*. Baltimore: University Park Press.
- Institute for Family-Centered Care. (1990). *Association for the care of children's health*. Washington, DC: Author.
- Mattingly, C. (1991). What is clinical reasoning? *American Journal of Occupational Therapy*, 45, 979–996.
- U.S. National Library of Medicine. (2005, December 13). *MedlinePlus medical encyclopedia*. Retrieved January 11, 2006, from <http://www.nlm.nih.gov/medlineplus/ency/article/007241.htm>
- Weatherston, D. J. (2002). Introduction to the infant mental health program. In J. J. Shirilla & D. J. Weatherston (Eds.), *Case studies in infant mental health: Risk, resiliency, and relationships* (pp. 1–13). Washington, DC: ZERO to THREE.
- World Health Organization. (2001). *International classification of functioning, disability, and health (ICF)*. Geneva, Switzerland: Author.

Related Readings

- Als, H., Duffy, F. H., McAnulty, G. B., Rivkin, M. J., Vajapeyam, S., Mulkern, R. V., et al. (2004). Early experience alters brain function and structure. *Pediatrics*, 113, 846–857.
- Als, H., Gilkerson, L., Duffy, F. H., McAnulty, G. B., Buehler, D. M., VanderBerg, K., et al. (2003). A three-center randomized controlled trial of individualized developmental care for very low birth weight infants: Medical, neurodevelopmental, parenting, and caregiving effects. *Journal of Developmental and Behavioral Pediatrics*, 24, 399–408.
- Anzalone, M. E. (1994). Occupational therapy in neonatology: What is our ethical responsibility? *American Journal of Occupational Therapy*, 48, 563–566.
- Browne, J. V. (2003). New perspectives on premature infants and their parents. *ZERO to THREE*, 24(2), 4–12.
- Buehler, D., Als, H., Duffy, F., McAnulty, G., & Liederman, J. (1995). Effectiveness of individualized developmental care for low-risk preterm infants: Behavioral and electrophysiologic evidence. *Pediatrics*, 96, 923–932.
- Carter, B. S. (2003). Collaborative decision making in the NICU: When life is uncertain, satisfice. *ZERO to THREE*, 24(2), 21–25.
- Holloway, E. (1998). Relationship-based occupational therapy in the neonatal intensive care unit. In J. Case-Smith (Ed.), *Pediatric occupational therapy and intervention* (pp. 111–126). Boston: Butterworth-Heinemann.
- Holloway, E. (in press). Fostering early parent–infant playfulness in the neonatal intensive care unit. In L. D. Parham & L. S. Fazio (Eds.), *Play in occupational therapy for children* (2nd ed.). St. Louis, MO: Mosby.

- Hunter, J. G. (2005). Neonatal intensive care unit. In J. Case-Smith, (Ed.), *Occupational therapy with children* (5th ed., pp. 688–770). St. Louis, MO: Elsevier/Mosby.
- Johnson, B. H., Abraham, M. R., & Parrish, R. N. (2004). Designing the neonatal intensive care unit for optimal family involvement. *Clinics in Perinatology*, 31, 353–383.
- McGrath, J. M., & Conliffe-Torres, S. (1996). Integrating family-centered developmental assessment and intervention into routine care in the neonatal intensive care unit. *Nursing Clinics of North America*, 31, 367–368.
- Meyer, E. C., Lester, B. M., Boukydis, C. F. Z., & Bigsby, R. (1998). Family-based intervention with high-risk infants and their families. *Journal of Clinical Psychology in Medical Settings*, 5, 49–69.
- Talmy, A., & Harmon, R. J. (2003). Relationships between preterm infants and their parents: Disruption and development. *ZERO to THREE*, 24(2), 13–20.
- Vergara, E., & Bigsby, R. (2004). *Developmental and therapeutic interventions in the NICU*. Baltimore: Paul H. Brookes.

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APPENDIX B.

Occupational Therapy Services in Early Childhood and School-Based Settings

The primary purpose of this document is to describe how occupational therapy supports children's and youth's learning and development in early childhood and school-based settings. This document is intended for occupational therapists and occupational therapy assistants in practice, academia, research, advocacy, and administrative positions. Other audiences for this statement include regulatory and policymaking bodies, provider groups, accreditation agencies, other professionals, and the general public who may be seeking clarification about occupational therapy's scope of practice and domain of concern related to this topic. The American Occupational Therapy Association (AOTA) provides information and resources to support occupational therapists and occupational therapy assistants in the delivery of effective services for children and youth in a variety of settings, including school-based and early intervention programs, child care, Head Start and Early Head Start, preschool and pre-kindergarten programs, and at home.

Occupational therapists and occupational therapy assistants¹ work with children and youth, parents, caregivers, educators, and other team members to facilitate children's and youth's ability to participate in everyday activities, or *occupations*. Occupations are "activities...of everyday life, named, organized, and given value and meaning by individuals and a culture" (Law, Polatajko, Baptiste, & Townsend, 1997, p. 34). Occupations are meaningful for the child and are based on social or cultural expectations or peer performance. In early childhood (birth–8 years of age) and school-based settings, occupational therapy practitioners² use their unique expertise to help children and youth with and without challenges prepare for and perform important learning and developmental activities within their natural environment. Occupational therapy services support a child's participation in activities of daily living (ADLs), instrumental activities of daily living (IADLs), education, work, play, leisure, rest and sleep, and social participation.

Occupational therapists have knowledge and skills in the biological, physical, social, and behavioral sciences to evaluate and intervene with individuals across the life course. Occupational therapy practitioners apply evidence-based research ethically and appropriately to the evaluation and intervention process following professional *Standards of Practice* (AOTA, 2010b) and the *Occupational Therapy Code of Ethics and Ethics Standards* (AOTA, 2010a).

Legislative Influences on Service Delivery

Occupational therapy practice in schools and early childhood settings is affected by many federal and state laws and regulations, as well as local policies and procedures. Table 1 summarizes some of the policies that directly affect the provision of occupational therapy for children and youth. Additional

¹Occupational therapists are responsible for all aspects of occupational therapy service delivery and are accountable for the safety and effectiveness of the occupational therapy service delivery process. Occupational therapy assistants deliver occupational therapy services under the supervision of and in partnership with an occupational therapist (AOTA, 2009).

²When the term *occupational therapy practitioner* is used in this document, it refers to both occupational therapists and occupational therapy assistants (AOTA, 2006).

Table 1. Federal Laws and Their Influence on Occupational Therapy Services

Law	Influence on Occupational Therapy Services
Individuals with Disabilities Education Improvement Act (IDEA), P.L. 108-446	Federal legislation that specifically includes occupational therapy as a related service for eligible students with disabilities, ages 3–21 years, to benefit from special education (Part B) or as a primary service for infants and toddlers who are experiencing developmental delays (Part C).
IDEA may be reauthorized and amended in 2011.	
Elementary and Secondary Education Act (ESEA) Amendments, No Child Left Behind Act (NCLB), P.L. 107-110	Federal legislation that requires public schools to raise the educational achievement of all students, particularly those from disadvantaged backgrounds, students with disabilities, and those with limited English proficiency, and that states establish high standards for teaching and student learning. While not specifically mentioned in the statute, occupational therapy is generally considered to be a pupil service under ESEA.
ESEA may be reauthorized and amended in 2011.	
Section 504 of the Rehabilitation Act of 1973, as amended, 29 U.S.C. 794; Americans with Disabilities Act (ADA, as amended); Americans with Disabilities Act Amendments Act of 2008 (ADAAA), P.L. 110-325	Civil rights statutes that prohibit discrimination on the basis of disability by programs receiving federal funds (Section 504) and by services and activities of state and local government (ADA and ADAAA). Disability here is defined more broadly than in IDEA. Children and youth who are not eligible for IDEA may be eligible for services under Section 504 or the ADA, such as for environmental adaptations and other reasonable accommodations, to help them access and succeed in the learning environment. Each state or local education agency determines eligibility procedures for children and youth served under Section 504 or the ADA.
Title XIX of the Social Security Act of 1965, as amended; Medicaid, P.L. 89-97	Federal-state match program that provides medical and health services for low-income children and adults. Occupational therapy is an optional service under the state plan but mandatory for children and youth under the Early Periodic Screening, Diagnosis and Treatment (EPSDT) services mandate.
Occupational therapy services provided in early intervention programs are frequently covered by Medicaid. School-based services also may be covered by Medicaid but also must meet applicable medical necessary requirements as well as be educationally relevant.	
Improving Head Start for School Readiness Act of 2007, P.L. 110-134	Federal program that provides comprehensive child development services to economically disadvantaged children (ages birth–5 years) and their families, including children with disabilities. Early Head Start serves children up to 3 years of age. Occupational therapy may be provided in these settings under the Head Start requirements or under IDEA.
Federal program that promotes access to assistive technology for persons with disabilities so that they can more fully participate in education, employment, and daily activities.	
Assistive Technology Act of 2004, P.L. 108-364, as amended	National School Breakfast and Lunch Programs are required to provide food substitutions and modifications of school meals for students whose disabilities restrict their diets, as determined by a doctor.
U.S. Department of Agriculture Food and Nutrition Service (USDA, 2001)	

information about these laws is provided in *Occupational Therapy Services for Children and Youth Under IDEA* (Jackson, 2007).

AOTA believes that occupational therapy practitioners working in early childhood and school settings should have working knowledge of the federal and state requirements to ensure that their program policies are in compliance. Occupational therapy practitioners also should be familiar with their state's occupational therapy practice act and related rules and regulations to ensure that occupational therapy services are provided accordingly.

Occupational Therapy Domain and Process

Occupational therapy supports client health and participation in life through engagement in occupations (AOTA, 2008). Occupational therapy focuses on the following occupations: ADLs, IADLs, education, leisure, play, social participation, work, and rest and sleep.

Occupational therapy practitioners provide services that enable children and youth to organize, manage, and perform their daily life occupations and activities. For example, a middle-school-age child with physical limitations may have difficulty completing written work. The occupational therapy practitioner collaborates with the student, parents, and educators to identify the skills of the student, the demands of the environment, and appropriate solutions for interventions. Another example is the family of a newborn baby with poor feeding skills. The occupational therapist may provide training and support for the family to enhance the baby's ability to drink from a bottle.

In early childhood and school-based practice, occupational therapy clients include individuals (e.g., child, family, caregivers, teachers), organizations (e.g., school districts, community preschools, Head Start), and populations within a community (e.g., homeless children, children at risk for social-emotional difficulties). Occupational therapy services are directed toward facilitating the client's participation in meaningful occupations that are desired and important in the school, family, and community contexts.

Occupational therapy services include evaluation, intervention, and documenting outcomes. During the evaluation, the occupational therapist gains an understanding of the client's priorities and his or her problems when engaging in occupations and activities. Evaluation and intervention address factors that influence occupational performance, including

- Performance skills (e.g., motor and praxis skills, sensory–perceptual skills, emotional regulation skills, cognitive skills, communication and social skills);
- Performance patterns (e.g., as habits, routines, rituals, roles);
- Contexts and environments (e.g., physical, social, cultural, virtual, personal, temporal);
- Activity demands (e.g., required actions, body functions); and
- Client factors (e.g., values and beliefs; mental, neuromuscular, sensory, visual, perceptual, digestive, cardiovascular, and integumentary functions and structures).

Desired outcomes are identified to guide future actions with the client. They also are a means for evaluating the effectiveness of occupational therapy services.

Occupational Therapy Service Provision

Occupational therapy practitioners provide early childhood services in children's homes, child care centers, preschools, Early and Head Start programs, early intervention programs, and clinical settings. Occupational therapy practitioners provide school-based services in both public and private facilities. Funding sources for occupational therapy services vary and may include federal and state funding (e.g., funding through state agencies, Medicaid), insurance, and self-pay.

Children and adolescents may be served under the Individuals with Disabilities Education Act (IDEA) Part C, if they are ages 3 years or younger, or Part B, if they are between the ages of 3 and 21 years. Some states are extending their Part C program to include preschool-age children.

Early Intervention (IDEA Part C; Birth Through Age 2 Years)

Early intervention occupational therapy services are provided to infants and toddlers with developmental delays, with diagnosed physical or mental conditions, or who are at risk for having a developmental delay in order to enhance the family's ability to care for their child with a disability. To be eligible for early intervention services under Part C, a child must have a delay in one or more of five developmental areas: (1) physical (including vision and hearing), (2) cognitive, (3) communication, (4) social–emotional, and (5) adaptive. When evaluating infants or toddlers, the occupational therapist considers aspects of the child's performance that are strengths or barriers to participation within the natural environment and

daily routines. The occupational therapist's knowledge of brain development, assessment, and intervention across developmental domains, early literacy, and feeding/eating skills enables them to work with children with disabilities and their families. Infants and toddlers with significant medical or developmental concerns (e.g., feeding, neurological) should receive services from trained professionals, as they are vulnerable and require ongoing evaluation.

IDEA requires that child and family outcomes and services be developed in collaboration with the child's caregivers, other members of the team, and community agencies. These services become part of the individualized family service plan (IFSP). Some examples of occupational therapy services for the five developmental domains are listed in Table 2.

In Part C programs, occupational therapy is a primary service. The occupational therapist may be the sole service provider but most often is part of a collaborative team that works to enhance the family's capacity to care for the child's health and development within daily routines and natural environments. An occupational therapist may serve as the service coordinator to monitor the implementation of the IFSP and coordinate services with other team members and agencies. When the child is turning 3 years of age, the occupational therapist works collaboratively with the IFSP team to transition children to appropriate community-based programs or to preschool special education services, as applicable.

School Age (IDEA Part B; Ages 3–21 Years)

The local school district is responsible for determining whether school-age children and youth with disabilities, including preschool children from ages 3 to 5 years, qualify for special education and related services under IDEA Part B (§602(3)(A)(ii)). A full and individual evaluation is conducted, and an individualized education program (IEP) is developed if the student is eligible for services. Students with disabilities may be eligible for IDEA if they meet one or more of 10 disability categories:

1. Mental retardation;
2. Hearing impairments, including deafness;
3. Speech or language impairments;
4. Visual impairments, including blindness;
5. Serious emotional disturbance;
6. Orthopedic impairment;
7. Autism;
8. Traumatic brain injury;
9. Other health impairment; or
10. Specific learning disabilities (see §602(3)(A)).

Occupational therapy is one of the related services that may be provided to IDEA-eligible students who are receiving special education in schools; homes; hospitals; and other settings, including juvenile justice and alternative education settings. Related services are "transportation, and such developmental, corrective, and other supportive services (including...occupational therapy)...as may be required to assist a child with a disability to benefit from special education, and includes early identification and assessment of disabling conditions in children" (see §602(26)(A)). As such, occupational therapy is a support service for students and teachers.

When an occupational therapy evaluation is required, data collection is focused on identifying the academic, developmental, and functional needs of the student (see §614(d)(3)(A)(iv)). Information is sought regarding the student's strengths and factors that may be interfering with his or her learning and participation in the context of the educational activities, routines, and environments. Observations are made

Table 2. Occupational Therapy's Role in Early Intervention Developmental Areas

Developmental Area	Occupational Therapy's Role
Adaptive	Promote independence in self-care, such as eating and drinking, dressing, and grooming; collaborate with parents about safe positioning and modification of food textures to enhance eating
Cognitive	Promote ability to notice and attend to objects and people in the environment; promote ability to sort and classify objects and to generalize learning to new daily living tasks; promote ability to sequence steps to complete daily living occupations
Communication	Facilitate language development through social interactions, assistive communication devices, switches, toys
Physical	Promote movement for exploration of the environment, facilitate use of arms and hands to handle and manipulate objects, educate caregivers in handling and positioning techniques
Social-emotional	Foster self-regulation, social participation, and play through interactions with peers and adults

where and when difficulties occur at school (i.e., at the times and in the location in which the student normally engages in the activities and is demonstrating behaviors that are of concern). These locations include the classroom, hallways, cafeteria, restrooms, gym, and playground. The student's work, participation, and behaviors are compared with other students in the same environments and situations. Curricular demands and existing task and environmental modifications are reviewed.

Interviews with instructional personnel, the student, and family members are conducted to gather information about the student's participation and performance. Cultural differences that may exist between home and school are explored. Existing special education supports and services, including strategies utilized to improve performance, are reviewed. Practices consistent with universal design for learning (UDL) guidelines (CAST, 2008) and the availability of assistive technologies to support school performance are assessed. Standardized testing may be conducted when needed to gather additional data.

Occupational therapy evaluation results then are shared with the parents and the multidisciplinary IEP team. According to Nolet and McLaughlin (2005), decisions about an IEP are individualized but "start from the expectation that the student is to learn the general education curriculum, and special education's role is to help the student learn and progress in that curriculum" (p. 14). Annual goals for special education instruction are determined by the IEP team, as well as the accommodations and services and supports required to help the student access and progress in the general curriculum. Occupational therapy practitioners collaborate with the IEP team regarding the educational need for occupational therapy services.

On the basis of current occupational therapy evaluation data; the occupational therapist's professional judgment; and other available information about the student's skills, abilities, goals, and objectives to be achieved, the IEP team decides whether occupational therapy services are needed. The development of the IEP is a collaborative process with participation from all team members. The team determines when the student goals need the expertise of an occupational therapy practitioner, as well as the amount of time, frequency, duration, and location of those services. The team meets regularly (at least annually) to assess whether the student is making progress toward achieving his or her goals and whether special education and/or related services (including occupational therapy) need to be continued, modified, or discontinued.

Intervention can be directed toward individuals (including teachers and other adults working with the child), groups, environmental factors, and programmatic needs (see Table 3). According to Brannen et al. (2002), effective implementation includes consultation, collaboration, and teamwork. Throughout the intervention process, the occupational therapy practitioner works collaboratively with the client and other team members such as family members, instructional personnel, school administrators, and pri-

Table 3. Occupational Therapy Services and Supports for Students 3–21 Years Under IDEA Part B

IDEA Part B Performance Areas	Occupational Therapy Services and Supports
Academic	Provide consultation with curriculum planners to support academic achievement by identifying needed curriculum accommodations and modifications for standardized testing; suggest adaptations to curriculum materials, methods, processes, and production; identify and provide needed transition supports and services targeting post-secondary goals
Developmental	Foster development of pre-academic skills, including prewriting and pre-scissor skills, toileting skills, eating and drinking skills, dressing and grooming tasks, communication skills, management of sensory needs, social skills
Functional	Facilitate use and management of school-related materials; daily routines/schedule; written school work: task/activity completion; transitions among activities and persons; adherence to rules; self-regulation; interactions with peers and adults; participation in leisure and recreational occupations at home, school, and the community; use of adaptive and assistive technology to support participation and performance
	Assist school in locating driver education training for students with disabilities. Collaborate with family and school staff in the development and implementation of transition programs, including preschool and high school transition. Collaborate with school personnel in the design and implementation of positive mental health programs and positive behavioral support systems

vate practitioners who may serve the student. Interventions are respectful of the customs, beliefs, activity patterns, behavior standards, and expectations accepted by the society of which the client is a member. Along with the provision of strategies and techniques that assist the child with making progress, education and training of other team members also is an important service that occupational therapy practitioners provide. Interventions are provided in natural school environments (e.g., classroom, playground, cafeteria), occurring in the time and place that is most beneficial for the student. As noted in Hanft and Shepherd (2008), the primary setting for occupational therapy services incorporates daily routine and contexts important to the student.

Outcomes are measured by student achievement of the IEP goals and other educational objectives such as curriculum expectations. Outcome measurement for instruction may include participation on national, state, and/or district-wide assessments that are supported by services provided by the occupational therapy practitioner. Outcome measurement for occupations such as self-care, play, leisure, social participation, and work transition that typically are addressed by occupational therapy practitioners in the school setting is accomplished by monitoring progress on IEP goals focused on these areas. Data collected on identified outcomes is reviewed by the IEP team to assist with determining present levels of academic achievement and functional performance and is reported during the required annual review.

Section 504/Americans with Disabilities Act

Section 504 of the Rehabilitation Act prohibits discrimination on the basis of disability for any program receiving federal funds, including schools, early intervention, and Head Start programs. The Americans with Disabilities Act also prohibits discrimination on the basis of disability in education, employment, transportation, health care, and a host of other services and activities of state and local governments, including child care. Students with disabilities who are not eligible for services under IDEA may be eligible under Section 504 or the ADA if the disability is such that it significantly limits "one or more major life activities." Examples include students who have HIV/AIDS, asthma, arthritis, attention deficit disorder/attention deficit hyperactivity disorder, traumatic brain disorder, conduct disorder, or depression.

Occupational therapists may be asked to help local school district teams determine student eligibility under Section 504 and to assist in the identification of services and development of the 504 plan. If the 504 committee determines that an educational need for occupational therapy exists, services may be

provided directly to a child or as a necessary accommodation. While no additional federal funds are available for services under Section 504 or the ADA, compliance with the requirements are mandatory for early childhood and school settings.

Response to Intervention and Early Intervening Services

Two provisions in the 2004 reauthorization of IDEA provide additional opportunities for occupational therapy practitioners to contribute to the success of general education students who are struggling with learning or behavior. The first of these provisions, *Early Intervening Services (EIS)*, provides supports for students in kindergarten through 12th grade who are struggling with learning or behavior. School districts can use a portion of their IDEA funds to provide professional development for teachers and other staff and to provide direct services such as educational and behavioral evaluations, behavioral interventions, small group instruction, and instruction in the use of adaptive and instructional software for students who “need additional academic and behavioral supports to succeed in the general education environment” (see §613(f)(1)).

The second provision, *Response to Intervention (RtI)*, is a systematic process that closely monitors how students respond to different types of services and instruction. In the RtI process, increasingly intense levels of support are provided. Decisions about which supports to provide and at what level of intensity are made through progress monitoring and data analysis. At each step of the process, monitoring and record keeping provide critical information about the student’s ongoing instruction and intervention needs.

Both EIS and RtI are preventative, proactive strategies aimed at minimizing the occurrence of behavior and learning problems as early as possible, thereby reducing the need for more intensive services later. When these approaches are used, occupational therapy practitioners implement strategies that can be used throughout a school. For example, suggestions might include the use of wide-lined paper or a pencil grip to support improvements in handwriting, modification of the classroom environment to increase accessibility, use of elastic-waist pants for a child unable to fasten clothing after toileting, strategies to deal with a child who hits others on the playground when he or she becomes frustrated, or general strategies for breaking down steps for jumping rope so that a child struggling with this skill can be successful in physical education. In addition, occupational therapy practitioners may collaborate with other professionals to design school-wide positive mental health programs, positive behavioral support services, and anti-bullying campaigns.

The occupational therapy role in EIS and RtI will vary from state to state and from district to district depending on how these provisions are implemented. Because both initiatives are targeted toward general education, school-based practitioners may need to educate student support teams on how occupational therapy helps meet student’s learning and behavioral needs in those environments. In addition, practitioners should participate in state and district professional development activities related to EIS and RtI and become full participants on the local teams considering interventions and supports students need to succeed in school (Clark, 2008; Clark & Polichino, 2008; Jackson, 2007).

OT and OTA Partnerships

Occupational therapists and occupational therapy assistants work together in early childhood and school settings to deliver needed services. Occupational therapists are responsible for formal evaluation and also are accountable for the safety and effectiveness of the service delivery process, including intervention planning, implementation, outcome review, and dismissal/discharge. The occupational therapy assistant implements the intervention plan under the supervision of and in partnership with the therapist. State occupational therapy regulatory agencies determine supervision frequency, methods, and documentation.

Supervision of Other Personnel

Many early intervention programs, schools, or community agencies employ paraprofessionals to assist in the classroom or to provide direct support to some students. The occupational therapist may utilize these individuals, as allowed by state law and regulation, to carry out selected aspects of a service. Paraprofessionals must be properly trained and carefully supervised at all times to assist with the provision of selected activities or programming that will enhance the student's ability to achieve his or her IEP goals or IFSP outcomes. Paraprofessionals do not provide skilled occupational therapy, nor are they substitutes for the occupational therapist. Paraprofessionals perform only those tasks that can be safely performed within the child's routine and do not require the expertise of an occupational therapist or occupational therapy assistant.

The tasks delegated to a paraprofessional should be documented. A plan to train and supervise the paraprofessional must be developed by the occupational therapist. An occupational therapy assistant may train and supervise a paraprofessional in specifically delegated tasks; however, the occupational therapist is ultimately responsible for monitoring programs carried out by paraprofessionals and occupational therapy assistants.

Conclusion

Occupational therapists and occupational therapy assistants provide services to children and youth, families, caregivers, and educational staff within a variety of programs and settings. The ultimate outcome of occupational therapy services in early childhood and school programs is to enable the child to participate in ADLs, education, work, play, leisure, and social interactions.

References

- American Occupational Therapy Association. (2006). Policy 1.44: Categories of occupational therapy personnel. In *Policy manual* (2009 ed., pp. 33–34). Bethesda, MD: Author.
- American Occupational Therapy Association. (2008). Occupational therapy practice framework: Domain and process (2nd ed.). *American Journal of Occupational Therapy*, 62, 625–683.
- American Occupational Therapy Association. (2009). Guidelines for supervision, roles, and responsibilities during the delivery of occupational therapy. *American Journal of Occupational Therapy*, 63(6), 797–803.
- American Occupational Therapy Association. (2010a). Occupational therapy code of ethics and ethics standards (2010). *American Journal of Occupational Therapy*, 64(Suppl.), S17–S26.
- American Occupational Therapy Association. (2010b). Standards of practice for occupational therapy. *American Journal of Occupational Therapy*, 64(Suppl.), S106–S111.
- Americans with Disabilities Act of 1990, Pub. L. 101-336, 104 Stat. 327.
- Americans with Disabilities Act Amendments Act of 2008, Pub. L. 110-325, 122 Stat. 3553.
- Assistive Technology Act of 2004, Pub. L. 108-364, 118 Stat. 1707.
- Brannen, S. J., Cooper, E. B., Dellegrotto, J. T., Disney, S. T., Eger, D. L., Ehren, B. J., et al. (2002). *Developing educationally relevant IEPs: A technical assistance document for speech-language pathologists*. Reston, VA: Council for Exceptional Children.
- CAST. (2008). *Universal design for learning guidelines, version 1.0*. Wakefield, MA: Author.

- Clark, G. F. (2008). Getting into a collaborative school routine. In B. Hanft & J. Shepherd (Eds.), *Collaborating for student success: A guide for school-based occupational therapy* (pp. 105–137). Bethesda, MD: AOTA Press.
- Clark, G. F., & Polichino, J. (2008). *FAQ on response to intervention for school-based occupational therapists and occupational therapy assistants*. Bethesda, MD: American Occupational Therapy Association.
- Hanft, B., & Shepherd, J. (2008). *Collaborating for student success: A guide for school-based occupational therapy*. Bethesda, MD: AOTA Press.
- Improving Head Start for School Readiness Act of 2007, Pub. L. 110-134, 121 Stat. 1363, 42 U.S.C. 9801 *et seq.*
- Individuals with Disabilities Education Improvement Act of 2004, Pub. L. 108-446, 20 U.S.C. §1400 *et seq.*
- Jackson, L. (Ed.). (2007). *Occupational therapy services for children and youth under IDEA* (3rd ed.). Bethesda, MD: AOTA Press.
- Law, M., Polatajko, H., Baptiste, W., & Townsend E. (1997). Core concepts of occupational therapy. In E. Townsend (Ed.), *Enabling occupation: An occupational therapy perspective* (pp. 29–56). Ottawa, ON: Canadian Association of Occupational Therapists.
- No Child Left Behind Act of 2001, Pub. L. 107-110, 116 Stat. 3071.
- Nolet, V., & McLaughlin, M. J. (2005). *Accessing the general curriculum: Including students with disabilities in standards-based reform* (2nd ed.). Thousand Oaks, CA: Corwin Press.
- Rehabilitation Act Amendments of 2004, 29 U.S.C. §794.
- Social Security Act of 1965, Pub. L. 89-97, 79 Stat. 286, Title XIX.
- U.S. Department of Agriculture Food and Nutrition Service. (2001). *Accommodating children with special dietary needs in the school nutrition programs: Guidance for school food service staff*. Washington, DC: Author.

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APPENDIX C.

Occupational Therapy Services in Facilitating Work Performance

The purpose of this statement is to describe for external audiences the role of occupational therapists and occupational therapy assistants¹ in facilitating successful engagement of people in their chosen work activities and in meaningful work roles. The overarching goal of occupational therapy is to support people's "health and participation in life through engagement in occupation" (American Occupational Therapy Association [AOTA], 2008, p. 626). Work is one of eight areas of occupation² categorized with the domain of occupational therapy practice (AOTA, 2008). The *Occupational Therapy Practice Framework: Domain and Process, 2nd Edition* defines *work* as "activities needed for engaging in remunerative employment or volunteer activities . . . [and includes] identifying and selecting work opportunities, employment seeking and acquisition tasks, job performance issues, retirement preparation and adjustment, volunteer exploration and volunteer participation" (AOTA, 2008, p. 632). Work performance supports meaningful participation and attainable productivity, which are essential for people's health and well-being.

Occupational therapy practitioners³ provide services to clients at the individual, organizational, and population level who are experiencing problems or who have concerns for potential problems for engaging in work-related occupations. Difficulties or potential difficulties in work performance may arise from challenges the client is experiencing related to motor, sensory-perceptual, emotional regulation, cognitive, or communication and social performance skills or from those associated with performance patterns, the activity demands, or the context and environment. Occupational therapy practitioners provide work-related services in a variety of settings, including, but not limited to, business and industrial environments, acute care and rehabilitation facilities, psychiatric centers, sheltered workshops, schools, and community settings. Within these settings occupational therapy practitioners provide services that address work hardening/conditioning, pre-work screening, functional capacity assessment and ergonomics, pre-vocational assessment and training, sheltered employment, supported employment, and transition from school to work. The occupational therapy process includes evaluation; intervention planning, implementation, and review; and outcome monitoring. The key services include wellness and prevention services, restorative and compensatory interventions, consultation, education, advocacy, and case management.

Occupational Therapy Evaluation in Work Programs

Using a client-centered approach, the occupational therapist develops an occupational profile to understand the client's occupational history and reasons for seeking services. As part of the process, the occupational therapist gathers information about the client's capacities and needs, values and interests, priorities, and desired outcomes. The occupational therapist then analyzes information about the client's occupa-

¹Occupational therapists are responsible for all aspects of occupational therapy service delivery and are accountable for the safety and effectiveness of the occupational therapy service delivery process. Occupational therapy assistants deliver occupational therapy services under the supervision of and in partnership with an occupational therapist (AOTA, 2009).

²Areas of occupation include "Activities of daily living, instrumental activities of daily living, rest and sleep, education, work, play, leisure, and social participation" (AOTA, 2008, p. 630).

³When the term *occupational therapy practitioner* is used in this document, it refers to both occupational therapists and occupational therapy assistants (AOTA, 2006).

tional performance gathered through formal evaluation, record review, interview, and observations related to the client's body functions, performance skills, performance patterns, the demands of the work activity, and the context and environment of the work occupation (AOTA, 2008). The occupational therapy evaluation may include data collection in the following areas:

- Job analysis to identify the required activity demands of the work tasks and possibilities for assistive technologies, job adaptations, or work accommodations;
- Evaluation of work and productive tasks, including work routines, tools and equipment, ergonomic considerations, and accessibility;
- Evaluation of work organizational culture, including psychological and social factors, and productivity expectations and job requirements both internal and external to the organization, including regulatory issues (Gupta & Sabata, 2010);
- The client's social and communication skills; functional abilities; potential for improvement; and need for adaptation, compensation, or occupational change; and
- The client's vocational aptitudes and interests necessary for development of transition plan from school to work preparation.

This information is synthesized to develop a plan of intervention that addresses the client's work participation needs, desired outcomes, and performance goals.

Occupational Therapy Intervention in Work Programs

Occupational therapy practitioners provide services to develop or increase the ability of the client to participate in and manage productive work, maintain health, adhere to safe work practices, and prevent work-related disability. Using the information gathered in the evaluation process, the occupational therapy practitioner collaborates with the client and other team members (e.g., employers, case managers, family members) or agencies (e.g., educational, local/state, vocational rehabilitation and social services departments and programs) to plan and implement intervention strategies. When developing these intervention strategies, occupational therapy practitioners consider the client's age, interests, values, beliefs, culture, skills and abilities, motivation, and psychological and social status. They address issues of worker role, task demands, work context, and work culture, as well as identify available resources. Intervention strategies are designed to identify, explore, and expand work options; enhance or develop work-related abilities (e.g., improve physical capacities, improve health and safety performance, develop skills and ability to participate); and obtain or retain employment. The following are some examples of occupational therapy interventions aimed at improving work performance and facilitating safe participation in work activities:

- Education related to health, safety and injury prevention, proper body mechanics, postural awareness, joint protection, ergonomic considerations, symptom awareness, and stress and pain management strategies applicable to work and productive activities;
- Adaptations to work activities, the work environment, and work demands and the use of assistive technologies that support the client's participation in the desired work activities;
- Strategies to improve social, communication, emotional regulation, and coping skills;
- Strategies to improve foundational work behaviors and work skills;
- Development of programs that incorporate graded activity, simulated activity, and work activity trials to allow for the gradual return to full work activity after illness or injury;
- Development of occupational activities to develop, increase, or improve productive work behaviors and skills;

- Development of work transition programs, job modifications, or job adaptations to facilitate successful work performance;
- Development of individualized plans for the transition of individuals with disabilities from school to work;
- Consultation and collaboration with clients about adaptations of work tasks, tools, equipment, and the work environment;
- Consultation with clients regarding injury management and prevention to reduce the incidence of disability-related injury;
- Collaboration with other team members, employers, services, and agencies to coordinate restorative and prevention services provided to the worker; and
- Case management services to assist in the coordination and planning for beginning or returning to work.

Table 1 provides examples of how performance related to work may be compromised and how occupational therapy practitioners may assist clients in participating in meaningful and productive work activities.

Funding Sources

Reimbursement for services related to occupational performance is dependent upon the type of services provided, the beneficiary of the services, and the setting where services are provided. Reimbursement may include, but may not be limited to,

- Direct reimbursement by employers or agencies for services to individuals or populations such as job analysis for a population; development of pre-work screens; ergonomic assessment of work, worker, and workplace; and educational programs for health, safety, and injury prevention.
- Local, state, or federally related program including workers' compensation, special education, Social Security Disability Insurance, and Medicare or medical assistance (see Appendix A for an overview of relevant legislation affecting rehabilitation services for the worker).
- Community agency resources using funds secured through federal or state monies, community or private grants, or other philanthropic donations. This often includes services provided to sheltered workshops, supported employment programs, and programs supporting individuals who are at a socioeconomic disadvantage (see Appendix B).

Table 1. Selected Case Examples

Descriptions of Client Work Performance	Occupational Therapy Evaluation	Occupational Therapy Intervention
Industrial Site—Strains and Sprains An employer in a heavy equipment manufacturing plant has recently noted a decrease in productivity and an increase in workers' compensation claims in the maintenance department. Further investigation revealed a high incidence of upper-extremity and low-back muscle strains and sprains among the maintenance crew.	<ul style="list-style-type: none"> • Conduct preliminary onsite inspection of department to identify triggers such as makeshift changes to equipment and signs of worker movement and positional discomfort that could be contributing to upper-extremity and back complaints. • Interview employees to gain their perspective on incidence of injuries, probable causes, and suggested remedies. • Perform a functional job task analysis, including identification of the physical job demands and ergonomic considerations for the different maintenance activities, including <ul style="list-style-type: none"> ◦ Materials handling, equipment operations, and tools usage; ◦ Postural considerations; ◦ Work environment; ◦ Stress factors such as force, repetition, hold time/rest time, angle/twist/body mechanics, impact, vibration, acceleration, and work time duration. • Analyze the data from the work site. • Determine areas requiring intervention. • Evaluate potential modifications to job, environment, tools, or client functions. 	<ul style="list-style-type: none"> • Collaborate with the employer to identify and implement ergonomic changes in specific work areas to minimize risk factors associated with equipment, required body positions, and the environment (Chiarello, 2003). • Develop an in-service education program for the maintenance department to address risk factor reduction strategies and body mechanics. • Develop a wellness program that includes daily flexibility and stretching sessions in addition to worker-centered lifestyle choice classes (e.g., smoking cessation, weight control, stress reduction; Gupta, 2008). • Cross-train workers to ensure adequate staffing coverage in the event of absenteeism as well as job rotation to allow a variety of positions, physical exertions, and equipment usage. • Institute an annual onsite evaluation to monitor modifications and programs.
Repetitive Strain Injury—Factory Worker Carla is a 43-year-old woman working as a sewing machine operator and fabric cutter in a garment factory. For the past several months, she has worked 8 hours per day, 5 days per week, plus 4 hours of overtime 2–3 days per week.	<ul style="list-style-type: none"> • Conduct a functional capacity evaluation to determine the physical and functional abilities of the client, including upper-extremity strength and overall endurance to perform work task. • Assess worksite, and offer employer suggestions to reduce risk to client. • Assess body mechanics and risk for repeated injury associated with <ul style="list-style-type: none"> ◦ Repetitive cutting through several layers of fabric and ◦ Static positioning of wrists and fingers when guiding material through an industrial sewing machine. 	<ul style="list-style-type: none"> • Instruct client with incorporating proper body mechanics and use of ergonomic scissors when cutting layers of fabric. • Provide employer with strategies regarding institution of job rotation program and incorporation of improved positioning and work techniques for all employees (Jaegers, 2008). • Implement a work conditioning program that includes education, flexibility and stretching, work simulation, and strengthening activities. • Collaborate with client and employer to identify ergonomic changes and accurate job placement for safe, productive, functional work performance (Sandqvist & Henriksson, 2004).
Developmental Disabilities Mark is an 18-year-old high school senior with Down Syndrome resulting in mild intellectual disability. Mark lives with his parents, who drive him to and from school. He wants to seek employment after graduation.	<ul style="list-style-type: none"> • Review Mark's records and interview Mark and his parents to learn about his occupational performance related to work, and identify his perceived needs as he moves forward (Sabata & Endicott, 2005). • Determine a work transition plan that addresses work behaviors, communication skills, and social interaction skills. 	<ul style="list-style-type: none"> • Educate Mark and his family about pertinent laws, community agencies, and resources available to assist him in seeking gainful employment (Sabata & Endicott, 2007; Vogtle & Brooks, 2005). • Collaborate with speech-language pathologist to incorporate peer buddy system to strengthen social and communication skills.

Table 1. Selected Case Examples (cont.)

Descriptions of Client Work Performance	Occupational Therapy Evaluation	Occupational Therapy Intervention
Developmental Disabilities (cont.)	<p>independence in daily living skills and the development of appropriate social behaviors. The goal was to maximize classroom learning and interaction with his classmates, ultimately affording Mark the skills to participate in his community (AOTA, 2008).</p> <p>Mark has not worked outside the home and has not had the opportunity to develop work skills or work behaviors. He has difficulty with time management, attention span, and sustained focus on a task.</p>	<ul style="list-style-type: none"> • Assess the level of difficulty he has with time management, especially with his morning routine. • Assess his pre-work skills, including concentration span, attention to task, and organizational skills; ability to follow written and verbal directions; and ability to communicate his ideas to others. • Determine performance skills in the area of community mobility and transportation usage (AOTA, 2008).
Mental Health—Schizophrenia	<p>Natalie, a 27-year-old woman with a history of schizophrenia, is a consumer at a community support day program. She lives in a subsidized apartment with two other individuals who also have been diagnosed with a mental illness. In the past Natalie has not been able to secure a job due to disorganized thinking, which affected her concentration and follow-through.</p> <p>Based on recent positive response to antipsychotic medication and success in volunteer work at the day program, Natalie has identified a goal of acquiring part-time office work and getting an apartment of her own.</p> <p>Natalie states that she lacks self-confidence related to working and that she is afraid she will not remember how to use a computer or be able to keep up with everyone else at a job.</p> <p>Her case worker has sought the services of an occupational therapist to assist in the work transition process.</p>	<ul style="list-style-type: none"> • Administer an occupational profile to determine Natalie's occupational history, work experiences, interests, patterns of daily living, and meaningful occupations (AOTA, 2008). • Assess Natalie's abilities in the following areas: <ul style="list-style-type: none"> • Problem-solving skills • Independence in daily living activities • Use of public transportation • Medication management • Seeking help and advocating for her needs. • Determine her work readiness skills development in task organization and time management.
Rheumatoid Arthritis	<p>Sarah, a 45-year-old woman with rheumatoid arthritis, is employed as a housekeeper at a hotel. She is unable to perform her work tasks due to exacerbation of her rheumatoid symptoms. She presents with decreased gross grasp, decreased pinch strength, difficulty reaching above shoulder height, and poor endurance for continuous work activity over 4 hours.</p> <p>Sarah uses her arms to lift bed linens and has difficulty grasping the material as she makes beds. She requires a rest period after cleaning each room.</p>	<ul style="list-style-type: none"> • The occupational therapist observes performance and analyzes activities to determine points of difficulty. In collaboration with Sarah, the therapist concludes that dusting and washing pictures, mirrors, and door frames above shoulder level are no longer possible without adaptation of the equipment used to perform these tasks. Grasp of smaller items (e.g., dusters with $\frac{1}{2}$" handles and mops with 1" handles) is particularly difficult for Sarah in her work. She demonstrates difficulty changing toilet paper roles that require lateral and three-point pinch. • Work with Sarah and her employer to identify and prioritize work activities. • Recommend adaptations and modifications in processes, approaches, and the contexts of required housekeeping tasks to support improved performance. • Recommend ergonomic changes to the tools and materials needed to do her job. • Train Sarah in work simplification and adapted techniques. • Work with Sarah to identify alternate work options, including training at a local community college in a career that requires less physical effort and stress upon the body.

(Continued)

Table 1. Selected Case Examples (cont.)

Descriptions of Client Work Performance	Occupational Therapy Evaluation	Occupational Therapy Intervention
<p>Older adults seeking volunteer activities</p> <p>A group of senior citizens who attend a weekly "Dine and Learn" lunch program at a local senior center were discussing their interest in volunteering in their community. They are interested in volunteerism as a way to stay physically and mentally active.</p> <p>The seniors have not had previous volunteer experience and are not certain where to begin to find a suitable venue and offer their services.</p>	<p>The occupational therapist uses a leisure activity check list to begin identifying areas of potential interest, such as woodworking, home repairs, working with adolescents, and financial consultation.</p> <p>As a result of an Internet search, the seniors identify local organizations and programs in need of volunteers that could benefit from their expertise. Settings include a Boys Club program teaching inner-city youth to make small furniture and decorative items, a service run by an area church to assist elders completing complex tax returns, and the local chapter of Habitat for Humanity.</p>	<ul style="list-style-type: none"> Establish a data bank and referral system that matches interests of group members with related volunteer opportunities. Organize a volunteer fair for the seniors to connect with and learn about the community organizations volunteer needs. Develop a training program within the senior center to prepare the seniors to match their skills with the specific needs and interests of the organizations.

References

- American Occupational Therapy Association. (2006). Policy 1.44: Categories of occupational therapy personnel. In *Policy manual* (2007 ed., pp. 33–34). Bethesda, MD: Author.
- American Occupational Therapy Association. (2008). Occupational therapy practice framework: Domain and process (2nd ed.). *American Journal of Occupational Therapy*, 62, 625–683.
- American Occupational Therapy Association. (2009). Guidelines for supervision, roles, and responsibilities during the delivery of occupational therapy services. *American Journal of Occupational Therapy*, 63, 797–803.
- Americans with Disabilities Act of 1990, P. L. 101-336, 104 Stat. 327.
- Chiarello, B. (2003). Does ergonomics improve productivity? An evidenced-based review. *Work Programs Special Interest Section Quarterly*, 17(4), 1–4.
- Gupta, J. (2008). Promoting wellness at the workplace. *Work and Industry Special Interest Section Quarterly*, 22(2), 1–4.
- Gupta, J., & Sabata, D. (2010). Older workers: Maintaining a worker role and returning to the workplace. In B. Braveman & J. J. Page (Eds.), *Work: Occupational therapy intervention to promote participation and productivity*. Philadelphia: F. A. Davis.
- Jaegers, L. (2008). Ergonomics, health, and wellness in industry. A holistic approach. *Work Programs Special Interest Section Quarterly*, 22(3), 4.
- Liu, K. W. D., Hollis, V., Warren, S., & Williamson, D. L. (2007). Supported-employment program processes and outcomes: Experiences of people with schizophrenia. *American Journal of Occupational Therapy*, 61, 543–554.
- Sabata, D., & Endicott, S. (2007). Workplace changes: Seizing opportunities for persons with disabilities in the workplace. *Work Programs Special Interest Section Quarterly*, 21(2), 1–3.
- Sandqvist, J. L., & Henriksson, C. M. (2004). Work functioning: A conceptual framework. *Work: A Journal of Prevention, Assessment, and Rehabilitation*, 23, 147–157.
- Vogtle, L. K., & Brooks, B. (2005). Common issues for adults with DD. *OT Practice*, 10, 8–12.

Additional Readings

- Aja, D. (2004, March). Using a functional capacity evaluation as a successful benchmark in the life care plan process. *Work Programs Special Interest Section Quarterly*, 18(1), 1–4.
- American Medical Association. (2008). *International classification of diseases* (9th rev., Clinical Modification, Hospital, Vols. 1–3). Chicago: Author.
- Gibson, L., Strong, L., & Wallace, B. (2005). Functional capacity evaluation as a performance measure: Evidence for a new approach for clients with chronic back pain. *Clinical Journal of Pain*, 21, 207–215.
- Glass, L. S. (Ed.). (2004). *Occupational medicine practice guidelines* (2nd ed.). Beverly Farms, MA: OEM Press.
- Gross, D. P., & Battie, M. C. (2003). Construct validity of a kinesiophysical functional capacity evaluation administered within a worker's compensation environment. *Journal of Occupational Rehabilitation*, 13, 287–295.
- Gross, D. P., Battie, M. C., & Cassidy, D. (2004). The prognostic value of functional capacity evaluation in patients with chronic low back pain: Part 1. Timely return to work. *Spine*, 29, 914–919.
- Haldorsen, E. M., Grasdal, A. L., Skouen, S., Risa, A. E., Skronholm, K., & Ursin, H. (2002). Is there a right treatment for a particular patient group? Comparison of ordinary treatment, light multidisciplinary treatment, and extensive multidisciplinary treatment for long-term sick-listed employees with musculoskeletal pain. *Pain*, 95, 49–63.
- Hayden, J., van Tulder, M., Malmivaara, A., & Koes, B. (2005). Meta-analysis: Exercise therapy for non-specific low back pain. *Annals of Internal Medicine*, 142, 765–775.
- Heymans, M., van Tulder, M., Esmail, R., Bombardier, C., & Koes, B. (2004). Back schools for non-specific low-back pain. *Cochrane Database of Systematic Reviews*, 3, CD000261.
- Howard, N., Spielholz, P., Bao, S., Silverstein, B., & Fan, Z. (2009). Reliability of an observational tool to assess the organization of work. *International Journal of Industrial Ergonomics*, 39, 260–266.
- Innes, E. (2006). Reliability and validity of functional capacity evaluations: An update. *International Journal of Disability Management Research*, 135, 135–148.
- Innes, E., & Straker, L. (2003). Attributes of excellence in work-related assessment. *Work: A Journal of Prevention, Assessment and Rehabilitation*, 20(1), 63–76.
- Jacobs, K. (2008). *Ergonomics for therapists* (3rd ed.). St. Louis, MO: Mosby.
- Kaskutas, V., & Snodgrass, J. (2009). *Occupational therapy practice guidelines for individuals with work-related injuries and illnesses*. Bethesda, MD: AOTA Press.
- Larson, B. A., & Ellexson, M. T. (2000). Blueprint for ergonomics. *Work: A Journal of Prevention, Assessment, and Rehabilitation*, 15, 107–112.
- Larson, B. A., & Ellexson, M. T. (2009). Industrial rehabilitation and work injury prevention. In I. Söderback (Ed.), *International handbook of occupational therapy interventions*. New York: Springer.
- Maher, C., & Bear-Lehman, J. (2008). Orthopaedic conditions. In M. V. Radomski & C. A. Trombly Latham (Eds.), *Occupational therapy for physical dysfunction* (6th ed., pp. 1106–1130). Baltimore: Lippincott Williams & Wilkins.
- Maloney, C. C. (2003, September). Work simulation strategies in work programs. *Work Programs Special Interest Section Quarterly*, 17(3), 1–3.

- Matheson, L. (2003). Functional capacity evaluation. In G. Andersson, S. Demeter, & G. Smith (Eds.), *Disability evaluation* (2nd ed.). Chicago: Mosby.
- Meyer, K., Fransen, J., Huwiler, J., Uebelhart, T., & Klipstein, A. (2005). Feasibility and results of a randomized pilot-study of a work rehabilitation programme. *Journal of Back and Musculoskeletal Rehabilitation*, 18, 67–78.
- Miller, D. M. (2004, February 9). Psychosocial issues and the return-to-work process. *OT Practice*, 9(3), 16–20.
- Moyers, P. A., & Dale, L. M. (2007). *The guide to occupational therapy practice* (2nd ed.). Bethesda, MD: AOTA Press.
- Musich, S., Napier, D., & Edington, D. W (2001). The association of health risks with workers' compensation costs. *Journal of Occupational and Environmental Medicine*, 43(6), 534–541.
- National Committee on Vital and Health Statistics. (2002). *Classifying and reporting functional status* (Report of the Subcommittee on Population). Retrieved February 8, 2009, from <http://ncvhs.hhs.gov/020211mn.htm>
- Sanders, M. J. (Ed.). (2003). *Management of musculoskeletal disorders*. Newton, MA: Butterworth Heinemann.
- Siporin, S., & Lysack, C. (2004). Quality of life and supported employment: A case study of three women with developmental disabilities. *American Journal of Occupational Therapy*, 58, 455–465.
- Soer, R., van der Scans, C., Groornoff, J. W. Ceenzen, J. H., & Reneman, M. E. (2008). Towards consensus in operational definitions in functional capacity evaluation: A Delphi survey. *Journal of Occupational Rehabilitation*, 18, 389–400.
- Stutzman, L. (2001, August). Evidence-based return to work guidelines. *CWCE Magazine*, pp. 36–38.
- U.S. Bureau of Labor Statistics. (2008). *Nonfatal occupational injuries and illnesses requiring days away from work, 2007* [Press release from the U.S. Department of Labor, No. 08-1716]. Washington, DC: Author.
- World Health Organization. (2003). *The burden of musculoskeletal conditions at the start of the new millennium* (WHO Technical Report Series). Geneva, Switzerland: Author.

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Appendix A. Selected Work Legislation

Legislation	Scope
Federal Employees Liability (FELA) Act, 1908 (45 U.S.C. 51 et seq.)	Established the no-fault insurance system that pays benefits to employees for accidental injuries or diseases that are work related.
Vocational Rehabilitation Act Amendments of 1943 (P.L. 78–113)	Changed the original provision of the Vocational Rehabilitation Act of 1920 (P.L. 66–236). Added people with physical disabilities, blindness, developmental delays, and psychiatric disabilities to those served. Established the Office of Vocational Rehabilitation. Put a new emphasis on activities of daily living and adaptation. Removed ceiling on appropriation.
Vocational Rehabilitation Act Amendments (Hill–Burton Act) of 1954 (P.L. 86–565)	Authorized greater financial support, research and demonstration grants, professional preparation grants, state agency expansion and improvements grants, and grants to expand rehabilitation facilities.
Vocational Rehabilitation Act Amendments of 1965 (P.L. 89–333)	Increased services for several types of people with disabilities and social handicaps. Made construction money available for rehabilitation centers and workshops.
Architectural Barriers Act of 1968 (P.L. 90–48)	Led the way to changes in access for people with disabilities.
Developmental Disabilities Services and Facilities Construction Act of 1970 (P.L. 91–517)	Gave states broad responsibility for planning and implementing a comprehensive program of services to people with developmental delays, epilepsy, cerebral palsy, and other neurological impairments.
Occupational Safety and Health Act of 1970 (P.L. 91–596)	Mandated that the employer provide employment free from recognized hazards that are likely to cause death or serious harm to workers.
Rehabilitation Act of 1973 (P.L. 93–112)	Expanded services to people with more severe disabilities. Provided for affirmative action in employment (Section 503) and nondiscrimination in facilities (Section 504) by federal contractors and grantees.
Rehabilitation Act Amendments of 1986 (P.L. 99–506)	Clarifications included that in evaluating rehabilitation potential, one must consider recreation, employability, and rehabilitation engineering needs.
Education of the Deaf Act (EDA) of 1986 (P.L. 99–371)	Extended statutory authority of the National Technical Institute of the Deaf to provide technical training and education to prepare deaf people for employment.
Omnibus Budget Reconciliation Act of 1987 (P.L. 100–203)	Permitted states to offer prevocational, educational, and supported employment services to people deinstitutionalized at any time before the waiver program.
Americans with Disabilities Act (ADA) of 1990 (P.L. 101–336)	Prevented discrimination against individuals with disabilities. Guaranteed equal protection for individuals with disabilities in employment, public accommodations, transportation, state and local government, and telecommunications.
Ticket-to-Work and Work Incentives Improvement Act of 1999 (P.L. 106–170)	Established to increase opportunities and choices for Social Security disability beneficiaries to obtain employment, vocational rehabilitation, and other support services from public and private providers, employers, and other organizations.
Americans with Disabilities Act Amendments Act (ADAAA) of 2008 (P.L. 110–325)	Focuses on the discrimination at issue instead of the individual's disability. Makes important changes to the definition of the term <i>disability</i> by rejecting the holdings in several Supreme Court decisions and portions of Equal Employment Opportunity Commission's (EEOC) ADA regulations. Retains the ADA's basic disability definition as an impairment that substantially limits one or more major life activities, a record of such an impairment, or being regarded as having such an impairment.

Appendix B. Internet Resources

American National Standards Institute	www.ansi.org
Board of Certification in Professional Ergonomics	www.bcpe.org
California Code of Regulations, Title 8, § 5110. Repetitive Motion Injuries	www.dir.ca.gov/title8/5110.html
California Department of Industrial Relations	www.dir.ca.gov
Canadian Centre for Occupational Health and Safety	www.ccohs.ca
Centers for Disease Control and Prevention	www.cdc.gov
Ergoweb	www.ergoweb.com
Foundation for Professional Ergonomics	www.ergofoundation.org
Health calculator page	www.halls.md/index.htm
Human Factors and Ergonomics Society	www.hfes.org
IIEE Applied Ergonomics Community	www.appliedergo.org
Institute for Work and Health	www.iwh.on.ca
International Ergonomics Association	www.iea.cc
International Society for Occupational Ergonomics and Safety	www.isoies.info
National Safety Council	www.nsc.org/Pages/Home.aspx
National Institute for Occupational Safety and Health	www.cdc.gov/niosh/homepage.html
Occupational Safety and Health Administration	www.osha.gov
The (Ontario, Canada) Workplace Safety and Insurance Board	www.wsib.on.ca/wsib/wsibsite.nsf/public/homepage
U.S. Department of Labor	www.dol.gov

APPENDIX D.

Occupational Therapy's Perspective on the Use of Environments and Contexts to Facilitate Health, Well-Being, and Participation in Occupations

Introduction

Occupational therapy practitioners¹ view human performance as a transactive relationship among the client (people, groups, or populations), the client's occupations (daily life activities), and environments and contexts. *Environments* are the external physical and social aspects that surround clients while they engage in an occupation. *Contexts* are the cultural, personal, temporal, and virtual aspects of this engagement; some contexts are external to the client (e.g., virtual), some are internal to the client (e.g., personal), and some may have both external features and internalized beliefs and values (e.g., cultural; American Occupational Therapy Association [AOTA], 2014b).

Using their expertise in analyzing these complex and reciprocal relationships, occupational therapy practitioners make recommendations to structure, modify, or adapt the environment and context to enhance and support performance. Both environment and context influence clients' success in desired occupations and are therefore critical aspects of any occupational therapy assessment, intervention, and outcome. This assumption is consistent with current education and health care laws and policies, which stipulate that assessment and intervention by providers take place in the natural and least restrictive environments (LREs) that support the client's successful participation. Table 1 reviews key legislation and court cases related to occupational therapy intervention and how they apply to practice.

Purpose

The purpose of this document is to articulate AOTA's position regarding how, across all areas of practice, occupational therapy practitioners select, create, and use environments and contexts to support clients as they achieve health, well-being, and participation in desired occupations.

Occupational Therapy Process

Occupational therapy practitioners collaborate with clients to identify both strengths and barriers to health, well-being, and participation. As part of this process, practitioners consider a variety of environmental and contextual factors to inform the clinical reasoning process that guides client evaluation, intervention, and targeting of outcomes.

Occupational therapy practitioners analyze the environment and context to understand how these elements can best support learning and performance. Solutions are then generated to reduce identified barriers or build on supports through modifications and adaptations.

¹When the term *occupational therapy practitioner* is used in this document, it refers to both occupational therapists and occupational therapy assistants (AOTA, 2006). *Occupational therapists* are responsible for all aspects of occupational therapy service delivery and are accountable for the safety and effectiveness of the occupational therapy service delivery process. *Occupational therapy assistants* deliver occupational therapy services under the supervision of and in partnership with an occupational therapist (AOTA, 2014a).

Table 1. Legislation and Court Cases Related to Occupational Therapy Practice

Federal Law, Court Case, or Movement	Key Constructs	Application to Occupational Therapy Practice
Section 504 of the Rehabilitation Act of 1973 (Pub. L. 93–112)	<ul style="list-style-type: none"> The Rehabilitation Act of 1973 is a civil rights law that states that no person may, on the basis of his or her disability, be “excluded from the participation in, or denied the benefits of . . . any program or activity receiving Federal financial assistance” (29 U.S.C. § 794(a)). In educational settings, this law requires that schools ensure equal educational opportunities for students with a qualifying disability through the provision of special education services, related services, modifications, or accommodations. 	<ul style="list-style-type: none"> Occupational therapy services can be used in any program funded with federal funds to ensure equal access for people with disabilities. In educational settings, occupational therapy practitioners can participate in developing a student plan under Section 504, help suggest and implement needed modifications and accommodations, and provide related services.
No Child Left Behind Act of 2001 (NCLB; Pub. L. 107–110)	<ul style="list-style-type: none"> NCLB is the most recent reauthorization of the Elementary and Secondary Education Act of 1965 (Pub. L. 89–313). It expands accountability standards for schools receiving federal funding. It includes children with disabilities in the accountability models developed to gauge student and school success. 	<ul style="list-style-type: none"> NCLB created increased motivation for schools to use all existing resources to improve the achievement of all students. It created broader opportunities for occupational therapy to be used by schools to benefit students with and without disabilities.
Individuals With Disabilities Education Improvement Act of 2004 (IDEA; Pub. L. 108–446)	<ul style="list-style-type: none"> IDEA is the law governing how early intervention services for children ages birth–3 years are provided; it addresses the provision of special education and related services to students ages 3–21. The purpose of IDEA Part B for students ages 3–21 is “to ensure that all children with disabilities have available to them a free appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment, and independent living” (34 C.F.R. 300.1[a]). The purpose of IDEA Part C for children ages birth–3 years and their families is to enhance and expand states’ capacity to provide early intervention services and to help maintain, implement, and coordinate interagency services for early intervention with children ages 0–3 years. Of note, IDEA requires that “removal of children with disabilities from the regular educational environment occurs only if the nature or severity of the disability is such that education in regular classes cannot be achieved satisfactorily” (34 C.F.R. 300.114[a][ii]). 	<ul style="list-style-type: none"> IDEA identified occupational therapy as a related service for eligible children under Part B for school-age children. It established occupational therapy as a primary service provider for children age birth–3 years under Part C. Under both programs, occupational therapy practitioners participate in evaluation and implementation, including analyzing and adjusting the context of and environment for learning and participation in school.

(Continued)

Table 1. Legislation and Court Cases Related to Occupational Therapy Practice (cont.)

Federal Law, Court Case, or Movement	Key Constructs	Application to Occupational Therapy Practice
Social Security Amendments of 1965 (Medicare and Medicaid; Pub. L. 89–97)	<ul style="list-style-type: none"> These amendments established a national public health care program, Medicare, to meet the needs of older Americans and people with disabilities (Social Security Disability Insurance) who qualify for services on the basis of disability status and a sufficient work history. They established an optional state–federal program to provide health and rehabilitation services for low-income people and certain people with disabilities. 	<ul style="list-style-type: none"> The amendments created a system of health care financing and insurance for older Americans and for people who would otherwise not have health and other services. It created a steady funding stream for health care, including occupational therapy. Social, community, and individual supports can in some circumstances be paid for by Medicare. Medicaid has many options for coverage of occupational therapy, including programs that provide community and home-based supports for long-term care.
Older Americans Act of 1965 (OAA; Pub. L. 89–73)	<ul style="list-style-type: none"> The OAA created a network of local and state entities, many called Area Agencies on Aging (AAAs), that are funded through OAA resources. Programs and services are focused on older people to plan and care for their lifelong needs. The goal of these programs is to keep older adults living independently in their own homes. A broad range of services are covered, based on local needs, and may address nutrition, caregiver support, community safety, and fall prevention. 	<ul style="list-style-type: none"> The OAA provides flexible funding options that support community health and social services programs for older adults, which may include occupational therapy. It increased focus and emphasis on community-based living resources and the promotion of aging in place.
Omnibus Budget Reconciliation Act of 1987 (Federal Nursing Home Reform Act; Pub. L. 100–203)	<ul style="list-style-type: none"> This act created a set of national minimum standards of care and a bill of rights for people living in certified nursing facilities. It requires nursing homes to develop individualized care plans for residents that focus on maintaining or improving the ability to walk, bathe, and complete other ADLs to the maximum extent possible. The act requires nursing homes to develop individualized care plans for residents and training of paraprofessional staff. It protects residents' right to be free of unnecessary and inappropriate physical and chemical restraints. 	<ul style="list-style-type: none"> This act created requirements as well as opportunities for occupational therapy practitioners to facilitate optimum function, attention to mental health, and maximum participation. Occupational therapy practitioners' care plans and interventions in nursing facilities, whether funded through Medicare or Medicaid, should be targeted to these goals. Occupational therapy practitioners may address environmental modifications and adaptations needed for maximum performance and safety, both in personal environments (e.g., wheelchairs, beds) as well as bedrooms, bathrooms, and common areas.
Americans With Disabilities Act of 1990 (ADA; Pub. L. 101–336)	<ul style="list-style-type: none"> The ADA built on previous civil rights legislation targeted at protecting the rights and enhancing participation of other minorities. It provides a clear mandate to end discrimination against people with disabilities in all areas of life. The ADA includes 5 titles that address employment, state and local government services, transportation, public accommodations (i.e., public places and services), and telecommunications. 	<ul style="list-style-type: none"> The ADA supports initiatives and interventions, including occupational therapy expertise, that promote function and participation for people with disabilities across the lifespan. Occupational therapy practitioners can support the end of discrimination through their knowledge of independent living, accessibility, environmental modifications, supported employment, competence-based evaluation for employment, and implementation of reasonable accommodations in all settings.

(Continued)

Table 1. Legislation and Court Cases Related to Occupational Therapy Practice (cont.)

Federal Law, Court Case, or Movement	Key Constructs	Application to Occupational Therapy Practice
Rehabilitation, Comprehensive Services, and Developmental Disabilities Amendments of 1978 (Pub. L. 95–602)	<ul style="list-style-type: none"> These amendments provide federal funding in cooperation with states to establish a national network of consumer-run community facilities and services. Independent living centers now exist across the country. The amendments advocate for the removal of architectural and transportation barriers that prevent people with disabilities from sharing fully in all aspects of society. 	<ul style="list-style-type: none"> The amendments support provision of occupational therapy evaluation and intervention in the natural environments in which people live, work, and play to help people adapt to the realities of their physical, social, attitudinal, and political contexts. Intervention includes consultation, program development, and advocacy with teachers in schools, supervisors in jobs, citizens' organizations, local governments, businesses, local media, and advocacy organizations.
<i>Olmstead v. L.C.</i> (1999)	<ul style="list-style-type: none"> In a 6–3 ruling by the U.S. Supreme Court against the state of Georgia, this case affirmed the right of people with disabilities whose living situation is supported by state or federal funds to live in their community. The ruling requires states to place people with mental disabilities in community settings rather than in institutions if at all possible. It dictates that community placement must be appropriate; that the transfer from institutional care to a less restrictive setting is not opposed by the affected person; and that the placement can be reasonably accommodated, taking into account the resources available to the state and the needs of others with mental disabilities. 	<ul style="list-style-type: none"> <i>Olmstead v. L.C.</i> established the precedent for the enforcement of a federal mandate for services to be provided in the LRE and in settings of choice for people with disabilities. The case created opportunities for occupational therapy practitioners to design accommodations, interventions, and related services to support community living for people with disabilities.

Note. ADLs = activities of daily living; LRE = least restrictive environment.

Practitioners can recommend environmental and contextual modifications and adaptations such as those in the following examples:

- Physical environment:* Improving accessibility of kitchens (lowering counter height and creating open floor plan) for clients using wheelchairs who want to engage in the occupation of cooking. Adding visual cues in the home environment to structure homemaking tasks to increase safety and organization for people with cognitive limitations.
- Social environment:* Encouraging a student on the autism spectrum to connect with a peer mentor to attend various activities on campus, including sporting events.
- Personal context:* Educating older adults on community mobility options.
- Temporal context:* Consulting with a newly retired business executive about volunteer options involving financial planning and entrepreneurship.
- Virtual context:* Collaborating with classroom teachers to provide appropriate technology.

Occupational therapy practitioners also recognize that specific interventions may need to begin outside the natural setting in which performance takes place and be completed in a setting in which components of occupations or underlying factors and skills can be targeted. For example, during inpatient rehabilitation, an adult with a spinal cord injury would practice community mobility in a simulated community environment in the rehabilitation facility to enable independent shopping on discharge to home.

Ultimately, interventions occurring in natural or modified environments support clients where they live, work, or play and wherever occupations take place (e.g., homes, classrooms, playgrounds, work, recreation or community centers). Providing appropriate intervention in the most appropriate environment is consistent with the values and purpose of occupational therapy. Practitioners also realize that many additional factors, such as limited financial, organizational, and personnel resources and the complexity of the client's condition, may inform various service delivery options. For example, although the most natural environment in which to address cooking difficulties for a client who is experiencing poststroke weakness in one arm may be the home, the client's medical status may dictate that training occur in a subacute rehabilitation facility.

Providing opportunities for all members of society to engage in health-promoting occupations through flexibility in the analysis of the environment and context in which clients thrive is essential. Table 2 provides additional examples of how occupational therapy practitioners use and modify the context and the environment to support health and participation in occupations.

Table 2. Case Studies

Case Description	Contextual and Environmental Focus of Occupational Therapy Service Delivery	Examples of Occupational Therapy Interventions Addressing Specific Environments and Contexts	Research Evidence and Related Resources Guiding Practice
A 15-month-old boy was born at 29 weeks' gestation. He has had difficulty sitting up, particularly during feeding, and achieving other developmental milestones. He is living at home with his family.	The focus of intervention is to support the entire family in sustaining their family life while addressing the child's developmental needs. Intervention is provided in the home with an emphasis on how to adapt the natural environment to support the child's occupational performance and development.	<ul style="list-style-type: none"> • After discharge from the NICU, provide direct intervention in the child's home to promote safety and establish the child's developmental skills. • Collaborate with the family to structure and modify the physical and social environments in the home to support occupational performance. • Educate the caregiver in developmental principles, positioning, and activities to facilitate feeding and development. • Consult with family and other members of the interdisciplinary team to support family goals. 	<ul style="list-style-type: none"> • Performing everyday activities in the natural setting provides reinforcement and support to achieve and enhance performance and competence (Dunst et al., 2001; Dunst, Trivette, Hamby, & Bruder, 2006). • Helping families accommodate to the demands of daily life with a child with developmental delays helps them develop appropriate and sustainable routines congruent with the family's values and the child's developmental needs (Keogh, Bernheimer, Gallimore, & Weisner, 1998). <p><i>Additional Resources</i> Frolek Clark & Kingsley (2013) Kingsley & Mailloux (2013)</p>
A 3-year-old girl with social and emotional regulation challenges attends a center-based preschool program.	The focus of intervention is to provide early childhood services in an inclusive classroom to enhance the child's opportunities for play with peers in naturally occurring situations that arise in the classroom. Occupational therapy intervention is integrated into the classroom activities.	<ul style="list-style-type: none"> • Structure play groups to promote peer social interaction skills. • Direct intervention with the child and parents to promote self-regulation and establish routines to facilitate the child's transitions throughout the day. • Consult with the early childhood team to analyze the demands of the preschool class and make recommendations for adaptations to support performance. 	<ul style="list-style-type: none"> • Center-based early intervention services have a positive effect on children's social functioning (Blok, Fukkink, Gebhardt, & Leseman, 2005). • Preschoolers with disabilities perform as well, if not better, when placed in quality inclusive classroom settings and play groups (Bailey, Aytch, Odom, Symons, & Wolery, 1999; Odom, 2000). • Parents of children with disabilities commonly report that they perceive inclusive classroom practices as contributing to their child's

(Continued)

Table 2. Case Studies (cont.)

Case Description	Contextual and Environmental Focus of Occupational Therapy Service Delivery	Examples of Occupational Therapy Interventions Addressing Specific Environments and Contexts	Research Evidence and Related Resources Guiding Practice
<p>A 7-year-old student with cognitive, motor, and speech delays participates in a special day class in a public school. He has difficulty processing sensory information, interacting with peers, focusing on academic tasks, using his hands for tasks, and maneuvering on equipment on the playground.</p>	<p>Guided by the child's needs, the IEP team, which includes the occupational therapist and the parents, determines that the child is having difficulty participating with typically developing peers and would benefit from a special day class for students with behavioral challenges. Although such placements are viewed as more restrictive, the regular classroom environment is currently overwhelming for the child.</p> <p>The goal of the tailored environment is to provide the structure necessary for the child to learn specific skills for participation in a less restrictive environment in the future.</p>	<ul style="list-style-type: none"> • Educate the IEP team about the effect of the environment on sensory processing and the relationship to behavior in a school setting. • Consult with the IEP team and teachers to structure, adapt, and modify the classroom and playground environments so that the child has opportunities to meet sensory needs by participating in vestibular, tactile, and proprioceptive activities throughout the school day. • Collaborate with the student to help him establish strategies and routines for sensory regulation, emotional and behavioral deescalation, and appropriate coping skills. • Develop a peer buddy system to promote appropriate social interactions with modeling and role-play during social group. • Provide direct intervention to facilitate integration of sensory systems in an environment rich in sensory experiences and equipment. 	<p>self-esteem, confidence, and happiness as well as reshaping their own expectations of their child's ability to develop and learn with others (Buysse, Skinner, & Grant, 2001).</p>
<p>A 28-year-old man with schizoaffective disorder lives alone. He has difficulty organizing his daily routines to manage his medications. He was recently admitted to the hospital because of an acute exacerbation of his illness. He wants to be discharged home.</p>	<p>The intervention focuses on developing medication routines to help the client return to his apartment. If he is unable to manage his medications, he might need to move to a group home with more structured supervision.</p> <p>By analyzing the social and physical environment in the client's home and community, the occupational therapy practitioner can identify external cues and resources to optimize the client's occupational performance.</p>	<ul style="list-style-type: none"> • Educate the medical team and case manager about performance deficits that affect medication routines. • Request that a pharmacist or nurse teach the client how to read labels and practice filling his medication box correctly. • Advocate for reminder calls for refills from the pharmacy or another entity. • Teach the client skills to establish habits and routines that support medication management, such as regular 	<p>Environmental supports are more likely to improve functional behavior for people with schizoaffective disorder when the supports are customized for the person and situated in the person's home (Velligan et al., 2000, 2006).</p>

(Continued)

Table 2. Case Studies (cont.)

Case Description	Contextual and Environmental Focus of Occupational Therapy Service Delivery	Examples of Occupational Therapy Interventions Addressing Specific Environments and Contexts	Research Evidence and Related Resources Guiding Practice
Clients living in a shelter for homeless people want to meet basic needs, remain safe, and reduce the potential for harm.	Using a consultative model, the intervention focuses on modifying the physical and social environments to promote safety and meet the clients' basic needs.	<p>sleep-wake times, use of an alarm clock and calendar to track when to take and refill medication, and storage of medication in a consistent location (e.g., on a nightstand).</p> <ul style="list-style-type: none"> • Provide visual cues such as a list of medications with pictures and their purpose or reminder signs. • Establish a connection with mental health support groups. 	<p>Life skills interventions have the potential to support the complex needs of people situated in the homeless context (Helfrich, Aviles, Badiani, Walens, & Sabol, 2006).</p>
A 52-year-old successful businessman had a right middle cerebral artery stroke 1 year ago, resulting in left-sided weakness and decreased balance. He lives at home and has tried to return to his job as a financial consultant but has struggled to maintain his productivity at work.	Because this client may not regain all performance skills, intervention focuses on designing environmental modifications in the home, work, and community settings that will support his health and participation in occupations.	<ul style="list-style-type: none"> • Establish defined areas and organize schedules within the shelter to enable clients to engage in self-care, education, work preparation, and play and leisure activities. • Design physically accessible spaces and equipment to enable clients to complete basic ADLs. • Educate clients in life skills interventions to address the environmental demands of homelessness. • Establish a self-governance and grievance committee to address safety in the shelter. • Post emergency procedures and community resources. 	<ul style="list-style-type: none"> • Specific strategies are effective in improving performance skills and participation in roles and routines after stroke (Ma & Trombly, 2002; Trombly & Ma, 2002). • Occupational therapists evaluate contextual factors of the work environment (e.g., work tasks, routines, tools, equipment) and use this information to plan interventions that facilitate work performance (AOTA, 2011). • Occupational therapy practitioners consult with community agencies, business owners, and building contractors, among others, to create environments that promote occupational performance for all (AOTA, 2000). <p><i>Additional Resources</i></p> <p>Wolf, Chuh, Floyd, McInnes, & Williams (2015)</p> <p>Wolf, Chuh, McInnes, & Williams (2013)</p>

(Continued)

Table 2. Case Studies (cont.)

Case Description	Contextual and Environmental Focus of Occupational Therapy Service Delivery	Examples of Occupational Therapy Interventions Addressing Specific Environments and Contexts	Research Evidence and Related Resources Guiding Practice
Older adults residing in an assisted-living facility are at high risk for loss of balance and falls.	The focus of intervention is to maintain the clients' occupational engagement through a multifactorial approach that includes elements such as strength and balance training; education; modifying activity demands; and creating a safe and supportive environment, including falls prevention.	<ul style="list-style-type: none"> • Consult with facility administrators, architects, and facility staff to design an environment that <ul style="list-style-type: none"> ◦ Reflects a noninstitutional character, ◦ Eliminates barriers to physical mobility, ◦ Provides lighting without glare, and ◦ Clusters small activity areas together. 	<ul style="list-style-type: none"> • The design of the social and physical environment influences the function and well-being of older adults (Day, Carreon, & Stump, 2000). • Occupational therapy practitioners advocate for and contribute to the creation of an environment in which the demands do not exceed the client's capabilities (Cooper & Day, 2003). • Occupational therapy practitioners identify and modify environmental barriers (Davidson, Bond, Dawson, Steen, & Kenny, 2005).
A 74-year-old woman with Alzheimer's disease lives in an apartment in the inner city with her husband of 45 years. She has become lethargic and no longer initiates activities. Her husband now does all the shopping, cooking, and cleaning. He is overwhelmed with the demands of caregiving.	The intervention focuses on supporting the caregiver's and the care recipient's health and participation in desired occupations and activities and enabling them to remain in their home as they age.	<ul style="list-style-type: none"> • Educate the caregiver about the disease process and the impact of the environment on the care recipient's occupational performance. • Recommend modifications to the home environment to manage daily care activities. • Provide emotional support and information on coping strategies and stress management to caregivers. • Facilitate use of community and family support. • Provide support and education on the uses of adaptive equipment in the home. 	<ul style="list-style-type: none"> • People with dementia or Alzheimer's disease can live at home, remaining in their roles and contexts for a longer period of time, if given enough support from caregivers (Haley & Bailey, 1999). • An in-home skills training and environmental adaptation program (Gitlin et al., 2003) improves the quality of life for both the caregiver and the care recipient with fewer declines in the care recipient's occupational performance and less need for caregiving (Gitlin, Hauck, Dennis, & Winter, 2005). • Home-based occupational therapy is effective and cost-efficient for community-dwelling older adults and their caregivers (Graff et al., 2008). • People with Alzheimer's disease perform better at home than in unfamiliar environments; it is harder for them to adapt to new environments (Hoppe, Davis, & Thompson, 2003).

Additional Resources
 Padilla (2011)
 Schaber (2010)

Note. ADLs = activities of daily living; AOTA = American Occupational Therapy Association; IEP = individualized education program; NICU = neonatal intensive care unit.

Summary

Occupational therapy practitioners work with a wide variety of clients across the lifespan. The goal of occupational therapy is to facilitate achievement of health, well-being, and participation in life through engagement in occupation (AOTA, 2014b). Practitioners consider current educational and health care laws and policies as they make recommendations to modify, adapt, or change environments and contexts to support or improve occupational performance. On the basis of theory, evidence, knowledge, client preferences and values, and occupational performance, they assess the intervention settings and the environmental and contextual factors influencing clients' occupational performance. In their interventions and recommendations, practitioners focus on selecting and using environments and contexts that are congruent with clients' needs and maximize participation in daily life occupations. Practitioners' expertise is essential to support clients' health and participation in meaningful occupations.

References

- American Occupational Therapy Association. (2000). Occupational therapy and the Americans With Disabilities Act (ADA). *American Journal of Occupational Therapy*, 54, 622–625. <http://dx.doi.org/10.5014/ajot.54.6.622>
- American Occupational Therapy Association. (2006). Policy 1.44: Categories of occupational therapy personnel. In *Policy manual* (2013 ed., pp. 32–33). Bethesda, MD: Author.
- American Occupational Therapy Association. (2011). Occupational therapy services in facilitating work performance. *American Journal of Occupational Therapy*, 65(Suppl.), S55–S64. <http://dx.doi.org/10.5014/ajot.2011.65S55>
- American Occupational Therapy Association. (2014a). Guidelines for supervision, roles, and responsibilities during the delivery of occupational therapy services. *American Journal of Occupational Therapy*, 68(Suppl. 3), S16–S22. <http://dx.doi.org/10.5014/ajot.2014.68S03>
- American Occupational Therapy Association. (2014b). Occupational therapy practice framework: Domain and process (3rd ed.). *American Journal of Occupational Therapy*, 68(Suppl. 1), S1–S48. <http://dx.doi.org/10.5014/ajot.2014.682006>
- Americans With Disabilities Act of 1990, Pub. L. 101–336, 42 U.S.C. §§ 12101–12213 (2000).
- Arbesman, M., & Logsdon, D. W. (2011). Occupational therapy interventions for employment and education for adults with serious mental illness: A systematic review. *American Journal of Occupational Therapy*, 65, 238–246. <http://dx.doi.org/10.5014/ajot.2011.001289>
- Bailey, D. B., Jr., Aytch, L. S., Odom, S. L., Symons, F., & Wolery, M. (1999). Early intervention as we know it. *Mental Retardation and Developmental Disabilities Research Reviews*, 5, 11–20. [http://dx.doi.org/10.1002/\(SICI\)1098-2779\(1999\)5:1<11::AID-MRDD2>3.0.CO;2-U](http://dx.doi.org/10.1002/(SICI)1098-2779(1999)5:1<11::AID-MRDD2>3.0.CO;2-U)
- Barnes, K. J., Vogel, K. A., Beck, A. J., Schoenfeld, H. B., & Owen, S. V. (2008). Self-regulation strategies of children with emotional disturbance. *Physical and Occupational Therapy in Pediatrics*, 28, 369–387. <http://dx.doi.org/10.1080/01942630802307127>
- Blok, H., Fukkink, R., Gebhardt, E., & Leseman, P. (2005). The relevance of delivery mode and other programme characteristics for the effectiveness of early childhood intervention. *International Journal of Behavioral Development*, 29, 35–47. <http://dx.doi.org/10.1080/01650250444000315>
- Brown, C. (2012). *Occupational therapy practice guidelines for adults with serious mental illness*. Bethesda, MD: AOTA Press.

- Buysse, V., Skinner, D., & Grant, S. (2001). Toward a definition of quality inclusion: Perspectives of parents and practitioners. *Topics in Early Childhood Special Education*, 24, 146–161. <http://dx.doi.org/10.1177/105381510102400208>.
- Case-Smith, J. (2013). Systematic review of interventions to promote social-emotional development in young children with or at risk for disability. *American Journal of Occupational Therapy*, 67, 395–404. <http://dx.doi.org/10.5014/ajot.2013.004713>
- Cooper, B. A., & Day, K. (2003). Therapeutic design of environments for people with dementia. In L. Letts, P. Rigby, & D. Stewart (Eds.), *Using environments to enable occupational performance* (pp. 253–268). Thorofare, NJ: Slack.
- Davison, J., Bond, J., Dawson, P., Steen, I. N., & Kenny, R. A. (2005). Patients with recurrent falls attending accident and emergency benefit from multifactorial intervention—A randomised controlled trial. *Age and Ageing*, 34, 162–168. <http://dx.doi.org/10.1093/ageing/afi053>
- Day, K., Carreon, D., & Stump, C. (2000). The therapeutic design of environments for people with dementia: A review of the empirical research. *Gerontologist*, 40, 397–416. <http://dx.doi.org/10.1093/geront/40.4.397>
- Dunst, C., Bruder, M., Trivette, C., Hamby, D., Raab, M., & McLean, M. (2001). Characteristics and consequences of everyday natural learning opportunities. *Topics in Early Childhood Special Education*, 21, 68–92. <http://dx.doi.org/10.1177/027112140102100202>
- Dunst, C. J., Trivette, C. M., Hamby, D. W., & Bruder, M. B. (2006). Influences of contrasting natural learning environment experiences on child, parent, and family well-being. *Journal of Developmental and Physical Disabilities*, 18, 235–250. <http://dx.doi.org/10.1007/s10882-006-9013-9>
- Elementary and Secondary Education Act of 1965, Pub. L. 89–313, 20 U.S.C. §§ 2701–3386.
- Fänge, A., & Iwarsson, S. (2005). Changes in ADL dependence and aspects of usability following housing adaptation—A longitudinal perspective. *American Journal of Occupational Therapy*, 59, 296–304. <http://dx.doi.org/10.5014/ajot.59.3.296>
- Frolek Clark, G., & Kingsley, K. (2013). *Occupational therapy practice guidelines for early childhood: Birth through 5 years*. Bethesda, MD: AOTA Press.
- Gitlin, L. N., Hauck, W. W., Dennis, M. P., & Winter, L. (2005). Maintenance of effects of the Home Environmental Skill-Building Program for family caregivers and individuals with Alzheimer's disease and related disorders. *Journals of Gerontology, Series A: Biological Sciences and Medical Sciences*, 60, 368–374. <http://dx.doi.org/10.1093/gerona/60.3.368>
- Gitlin, L. N., Winter, L., Corcoran, M., Dennis, M. P., Schinfeld, S., & Hauck, W. W. (2003). Effects of the home Environmental Skill-Building Program on the caregiver-care recipient dyad: 6-month outcomes from the Philadelphia REACH Initiative. *Gerontologist*, 43, 532–546. <http://dx.doi.org/10.1093/geront/43.4.532>
- Graff, M. J. L., Adang, E. M. M., Vernooij-Dassen, M. J. M., Dekker, J., Jönsson, L., Thijssen, M., . . . Rikkert, M. G. (2008). Community occupational therapy for older patients with dementia and their care givers: Cost effectiveness study. *BMJ*, 336, 134–138. <http://dx.doi.org/10.1136/bmj.39408.481898.BE>
- Haley, W., & Bailey, S. (1999). Research on family caregiving in Alzheimer's disease: Implications for practice and policy. In B. Vellas & J. Fitten (Eds.), *Research and practice in Alzheimer's disease* (Vol. 2, pp. 321–332). Paris: Serdi.
- Helfrich, C., Aviles, A., Badiani, C., Walens, D., & Sabol, P. (2006). Life skills interventions with homeless youth, domestic violence victims, and adults with mental illness. In K. S. Miller, G. L. Herzberg, & S. A. Ray (Eds.), *Homeless in America* (pp. 189–207). New York: Haworth Press.

- Hoppes, S., Davis, L. A., & Thompson, D. (2003). Environmental effects on the assessment of people with dementia: A pilot study. *American Journal of Occupational Therapy*, 57, 396–402. <http://dx.doi.org/10.5014/ajot.57.4.396>
- Individuals With Disabilities Education Improvement Act of 2004, Pub. L. 108–446, 20 U.S.C. §§ 1400–1482.
- Keogh, B. K., Bernheimer, L. P., Gallimore, R., & Weisner, T. S. (1998). Child and family outcomes over time: A longitudinal perspective on developmental delays. In M. Lewis & C. Feiring (Eds.), *Families, risk, and competence* (pp. 269–287). Mahwah, NJ: Erlbaum.
- Kingsley, K., & Mailloux, Z. (2013). Evidence for the effectiveness of different service delivery models in early intervention services. *American Journal of Occupational Therapy*, 67, 431–436. <http://dx.doi.org/10.5014/ajot.2013.006171>
- Ma, H. I., & Trombly, C. A. (2002). A synthesis of the effects of occupational therapy for persons with stroke, Part II: Remediation of impairments. *American Journal of Occupational Therapy*, 56, 260–274. <http://dx.doi.org/10.5014/ajot.56.3.260>
- No Child Left Behind Act of 2001, Pub. L. 107–110, 20 U.S.C. §§ 6301–8962.
- Odom, A. L. (2000). Preschool inclusion: What we know and where we go from here. *Topics in Early Childhood Special Education*, 20, 20–27. <http://dx.doi.org/10.1177/027112140002000104>
- Older Americans Act of 1965, Pub. L. 89–73, 79 Stat. 218, 42 U.S.C. §§ 3001 and 3058ff.
- Olmstead v. L.C., 527 U.S. 581 (1999).
- Omnibus Budget Reconciliation Act of 1987, Pub. L. 100–203, 101 Stat. 1330.
- Padilla, R. (2011). Effectiveness of environment-based interventions for people with Alzheimer's disease and related dementias. *American Journal of Occupational Therapy*, 65, 514–522. <http://dx.doi.org/10.5014/ajot.2011.002600>
- Parham, L. D., Cohn, E. S., Spitzer, S., Koomar, J. A., Miller, L. J., Burke, J. P., . . . Summers, C. A. (2007). Fidelity in sensory integration intervention research. *American Journal of Occupational Therapy*, 61, 216–227. <http://dx.doi.org/10.5014/ajot.61.2.216>
- Rehabilitation Act of 1973, Pub. L. 93–112, 29 USC §§ 701–7961.
- Rehabilitation, Comprehensive Services, and Developmental Disabilities Amendments of 1978, Pub. L. 95–602.
- Schaaf, R. C., & Nightlinger, K. M. (2007). Occupational therapy using a sensory integrative approach: A case study of effectiveness. *American Journal of Occupational Therapy*, 61, 239–246. <http://dx.doi.org/10.5014/ajot.61.2.239>
- Schaber, P. (2010). *Occupational therapy practice guidelines for adults with Alzheimer's disease and related disorders*. Bethesda, MD: AOTA Press.
- Schilling, D. L., Washington, K., Billingsley, F. F., & Deitz, J. (2003). Classroom seating for children with attention deficit hyperactivity disorder: Therapy balls versus chairs. *American Journal of Occupational Therapy*, 57, 534–541. <http://dx.doi.org/10.5014/ajot.57.5.534>
- Siebert, C., Smallfield, S., & Stark, S. (2014). *Occupational therapy practice guidelines for home modifications*. Bethesda, MD: AOTA Press.
- Social Security Amendments of 1965, Pub. L. 89–97, 42 U.S.C. §§ 1395 et seq. (Medicare) and 42 U.S.C. §§ 1396 et seq. (Medicaid).

- Stark, S. (2004). Removing environmental barriers in the homes of older adults with disabilities improves occupational performance. *OTJR: Occupation, Participation and Health*, 24, 32–40. <http://dx.doi.org/10.1177/153944920402400105>
- Stearns, S. C., Bernard, S. L., Fasick, S. B., Schwartz, R., Konrad, T. R., Ory, M. G., & DeFriese, G. H. (2000). The economic implications of self-care: The effect of lifestyle, functional adaptations, and medical self-care among a national sample of Medicare beneficiaries. *American Journal of Public Health*, 90, 1608–1612. <http://dx.doi.org/10.2105/AJPH.90.10.1608>
- Trombly, C. A., & Ma, H. I. (2002). A synthesis of the effects of occupational therapy for persons with stroke, Part I: Restoration of roles, tasks, and activities. *American Journal of Occupational Therapy*, 56, 250–259. <http://dx.doi.org/10.5014/ajot.56.3.250>
- Vaughn, S., Kim, A.-H., Sloan, C. V. M., Hughes, M. T., Elbaum, B., & Sridhar, D. (2003). Social skills interventions for young children with disabilities: A synthesis of group design studies. *Remedial and Special Education*, 24, 2–15. <http://dx.doi.org/10.1177/074193250302400101>
- Velligan, D. I., Bow-Thomas, C. C., Huntzinger, C., Ritch, J., Ledbetter, N., Prihoda, T. J., & Miller, A. L. (2000). Randomized controlled trial of the use of compensatory strategies to enhance adaptive functioning in outpatients with schizophrenia. *American Journal of Psychiatry*, 157, 1317–1323. <http://dx.doi.org/10.1176/appi.ajp.157.8.1317>
- Velligan, D. I., Mueller, J., Wang, M., Dicocco, M., Diamond, P. M., Maples, N. J., & Davis, B. (2006). Use of environmental supports among patients with schizophrenia. *Psychiatric Services*, 57, 219–224. <http://dx.doi.org/10.1176/appi.ps.57.2.219>
- Watling, T., Koenig, K., Davies, P., & Schaaf, R. (2011). *Occupational therapy practice guidelines for children and adolescents with challenges in sensory processing and sensory integration*. Bethesda, MD: AOTA Press.
- Whiteneck, G. G., Gerhart, K. A., & Cusick, C. P. (2004). Identifying environmental factors that influence the outcomes of people with traumatic brain injury. *Journal of Head Trauma Rehabilitation*, 19, 191–204. <http://dx.doi.org/10.1097/00001199-200405000-00001>
- Wolf, T. J., Chuh, A., Floyd, T., McInnis, K., & Williams, E. (2015). Effectiveness of occupation-based interventions to improve areas of occupation and social participation after stroke: An evidence-based review. *American Journal of Occupational Therapy*, 69, 6901180060. <http://dx.doi.org/10.5014/ajot.2015.012195>.
- Wolf, T. J., Chuh, A., McInnes, K., & Williams, E. (2013). *Adults with stroke: What is the evidence for the effectiveness of activity-/occupation-based interventions to improve areas of occupation and social participation after stroke?* (AOTA Critically Appraised Topics and Papers). Retrieved from <http://www.aota.org/practice/productive-aging/evidence-based/cats-caps/stroke.aspx>

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APPENDIX E.

Occupational Therapy in the Promotion of Health and Well-Being

The purpose of this statement is to describe occupational therapy's contribution in the areas of health promotion and prevention. It is intended for internal and external audiences. The American Occupational Therapy Association (AOTA) supports and promotes involvement of occupational therapists and occupational therapy assistants in the development and provision of programs and services that promote health, well-being, and social participation of all people.

Health Promotion

It is important to frame the discussion of occupational therapy's role in health promotion by first defining the term. The World Health Organization (WHO) provides the following definition in the *Ottawa Charter for Health Promotion*:

Health promotion is the process of enabling people to increase control over, and to improve, their health. To reach a state of complete physical, mental, and social well-being, an individual or group must be able to identify and realize aspirations, to satisfy needs, and to change or cope with the environment. Health is, therefore, seen as a resource for everyday life, not the objective of living. Health is a positive concept emphasizing social and personal resources, as well as physical capacities. Therefore, health promotion is not just the responsibility of the health sector, but goes beyond healthy lifestyles to well-being. (WHO, 1986, para. 2, italics added)

Trentham and Cockburn (2005) expand on this definition by stating that

health promotion is equally and essentially concerned with creating the conditions necessary for health at individual, structural, social, and environmental levels through an understanding of the determinants of health: peace, shelter, education, food, income, a stable ecosystem, sustainable resources, *social justice*,¹ and equity. (p. 441, italics added)

Since 1980, the U.S. Department of Health and Human Services (HHS) has established health promotion and disease prevention objectives to facilitate and measure improvement in health (HHS, 1980, 1990, 2000, 2010). The vision of Healthy People 2020 is the realization of "a society in which all people live long, healthy lives" (HHS, 2010, p. 2). Healthy People 2020 has four major goals:

1. "Attain high-quality, longer lives free of preventable disease, disability, injury, and premature death."
2. "Achieve health equity, eliminate disparities, and improve health of all groups."
3. "Create social and physical environments that promote good health for all."
4. "Promote quality of life, healthy development, and healthy behaviors across all life stages." (p. 5)

Active engagement in life and overall health status and not just longevity is emphasized. From an individual perspective, a healthy life means the use of capacities and adaptations across the life span, allowing people to enter into satisfying relationships with others, to work, and to play. From a national

¹Some italicized terms in this statement are defined in the glossary.

perspective, a healthy life means vital, creative, and productive citizens and residents contributing to flourishing communities and a thriving nation.

Health Disparities

It is important from a health promotion perspective to differentiate between the constructs of health and functional status. Many assessments of health status include items that measure function. As a result, these tools are negatively biased against persons with disabilities. It is possible to be physically and mentally healthy and have a high quality of life in spite of disability and functional limitations (Krahn, Fujiura, Drum, Cardinal, & Nosek, 2009). As noted earlier, one goal of Healthy People 2020 is to eliminate health disparities (HHS, 2010).

The term *health disparities* refers to population-specific differences in disease rates, health outcomes, and access to health care services. Addressing health disparities is consistent with the occupational therapy profession's official document on nondiscrimination and inclusion, which states, "Inclusion requires that we ensure not only that everyone is treated fairly and equitably but also that all individuals have the same opportunities to participate in the naturally occurring activities of society" (AOTA, 2009b, p. 819).

Persons with disabilities may be the largest population experiencing health disparities. "The differences in health status between people with disabilities and without disabilities are increasingly recognized as preventable and therefore unacceptable" (Krahn, Putnam, Drum, & Powers, 2006, p. 18). Persons with disabilities are at risk for developing secondary conditions that are physical and mental as well as social health problems that are the direct or indirect consequence of the disability. The five most frequent secondary conditions identified in a study by Kinne, Patrick, and Doyle (2004) are (1) chronic muscle and joint pain, (2) sleep disturbances, (3) extreme fatigue, (4) weight or eating problems, and (5) depression.

The prevalence of these conditions was 2 to 3 times higher among adults with disabilities than among adults without disabilities. In addition, persons with disabilities often have higher rates of diabetes, obesity, anxiety, social isolation, and unemployment (Drum, Krahn, Culley, & Hammond, 2005) and less satisfaction with care within the health system (Krahn et al., 2006) than their able-bodied counterparts. Secondary conditions, many of which are preventable, are often considered the primary cause of health disparities for this population.

Health promotion programs and services may target individuals, communities, and populations as well as policymakers. The focus of these programs is to

- Prevent or reduce the incidence of illness or disease, accidents, and injuries in the population;
- Reduce health disparities among racial and ethnic minorities and other underserved populations;
- Enhance mental health, resiliency, and quality of life;
- Prevent secondary conditions and improve the overall health and well-being of people with chronic conditions or disabilities and their caregivers; and
- Promote healthy living practices, social participation, *occupational justice*, and healthy communities, with respect for cross-cultural issues and concerns.

Prevention Strategies

A key purpose of health promotion is improved well-being, quality of life, and social participation for individuals and populations. Health management and maintenance for persons with or without disabilities require the implementation of prevention strategies. Prevention is generally categorized into three levels: (1) primary, (2) secondary, and (3) tertiary.

Primary prevention is defined as education or health promotion efforts designed to prevent the onset and reduce the incidence of unhealthy conditions, diseases, or injuries. Primary prevention attempts to identify, reduce, or eliminate risk factors for disease and injury. For persons with disabilities, primary

prevention may include modifying the physical and social environment to address the special needs resulting from the disability. Strategies for improving nutrition; increasing physical activities; smoking cessation; weight management; and screening for heart disease, diabetes, and cancer are important for persons with disabilities as well as the general population.

Secondary prevention typically includes screening, early detection, and intervention after disease has occurred; it is designed to prevent or disrupt the disabling process. For persons with disabilities, secondary prevention involves limiting the development of secondary conditions and their subsequent impact on function and quality of life.

Tertiary prevention refers to services designed to prevent the progression of a condition. Tertiary prevention for persons with disabilities should also include strategies to promote equal opportunity, full participation, independent living, and economic self-sufficiency (Patrick, Richardson, Starks, Rose, & Kinne, 1997).

Population Health Approach

Population health focuses on aggregates, or communities of people, and the many factors that influence their health. A population health approach strives to identify and reduce health disparities as well as enhance the overall health and well-being of a population (Finlayson & Edwards, 1997). In addition to providing occupational therapy interventions for individuals, occupational therapy practitioners can develop and implement occupation-based population health approaches to enhance occupational performance and participation, quality of life, and occupational justice.

Health Promotion and Occupation

Healthy People 2020 and the Ottawa Charter for Health Promotion parallel occupational therapy's belief that engagement in meaningful occupations supports health and leads to a productive and satisfying life. Wilcock (2006) stated that

Following an occupation-focused health promotion approach to well-being embraces a belief that the potential range of what people can do, be, and strive to become is the primary concern and that health is a by-product. A varied and full occupational lifestyle will coincidentally maintain and improve health and well-being if it enables people to be creative and adventurous physically, mentally, and socially. (p. 315)

According to Christiansen (1999), "Health enables people to pursue the tasks of everyday living that provide them with the life meaning necessary for their well-being" (p. 547). *Well-being* is a state of flourishing that consists of the following elements: positive emotion, engagement or flow, *meaning* (i.e., a sense of belonging to or serving something larger than oneself), positive relationships, and accomplishment or achievement (Seligman, 2011).

Occupational therapy services are provided to clients of all age groups, infants through older adults, from a variety of socioeconomic, cultural, and ethnic backgrounds, who possess or who are at risk for impairments, activity limitations, or participation restrictions. According to AOTA (2008), occupational therapy practitioners² recognize that health is supported when individuals are able to engage in occupations and activities that allow them to achieve the desired outcome of participation in their chosen environments. The essence of occupational therapy is "supporting health and participation in life through engagement in occupation" (p. 626). This focus on engagement in occupation is interwoven through the delivery of service, beginning with evaluation and continuing through the intervention phase. Health management and maintenance are included within the domain of occupational therapy as an instrumental activity of daily living; health promotion and prevention are identified as occupational therapy

²When the term *occupational therapy practitioner* is used in this document, it refers to both occupational therapists and occupational therapy assistants (AOTA, 2006).

intervention approaches; and health and wellness, quality of life, and occupational justice are potential outcomes of occupational therapy services (AOTA, 2008).

Occupations are purposeful and meaningful daily activities that fill a person's time and are typically categorized as self-care, work, play or leisure, and rest (AOTA, 1995; Meyer, 1922). A natural, balanced pattern of occupations is believed to be health enhancing and fulfills both the needs of the individual and the demands of the environment (Kielhofner, 2004; Meyer, 1922). This belief has been supported in studies with well elderly individuals in urban communities (Clark et al., 1997, 2001, 2012).

By engaging clients in everyday occupations, occupational therapy practitioners promote physical and mental health and facilitate well-being for persons with and without disabilities. Occupational therapy practitioners promote positive mental health through competency enhancement strategies, such as skill development, environmental supports, and task adaptations, and they prevent mental illness through risk reduction strategies, such as establishing healthy habits and routines and providing training in relaxation and coping techniques (AOTA, 2010).

Occupational imbalance, deprivation, and alienation are risk factors for health problems in and of themselves. They may also result from or lead to the development of other risk factors, which can in turn result in larger health and social problems. Causes are varied (e.g., unanticipated caregiving responsibilities, losses in employment or housing) and can lead to occupational imbalance, deprivation, and alienation, which can then lead to individual health problems such as stress, sleep disturbance, and depression (Wilcock, 2006).

Belle et al. (2006) demonstrated that caregivers of people with dementia experienced significant improvement in quality of life and a decrease in depression after intervention that included stress management; strategies for engaging in pleasant events; and teaching of healthy behaviors, communication skills, and problem-solving skills regarding behavior management of care recipients' difficult behaviors. Elliott, Burgio, and DeCoster (2010) similarly found that a caregiver intervention enhances health and decreases depression, resulting in a decrease in perceived burden. Occupational therapy practitioners are in a prime position to recognize the occupation and health problems inherent with caregiving and offer interventions such as those described in the cited research as well as additional interventions from an occupation lens, such as task analysis and modification to minimize the physical and emotional stresses of caregiving.

Role of Occupational Therapy in Health Promotion

Occupational therapy practitioners have three critical roles in health promotion and prevention:

1. To promote healthy lifestyles;
2. To emphasize occupation as an essential element of health promotion strategies; and
3. To provide interventions, not only with individuals but also with populations.

It is important that occupational therapy practitioners promote a healthy lifestyle for all individuals and their families, including people with physical, mental, or cognitive impairments. An occupation-focused approach to prevention of illness and disability has been defined by Wilcock (2006) as

the application of medical, behavioral, social, and *occupational science* to prevent physiological, psychological, social, and occupational illness; accidents; and disability; and to prolong quality of life for all people through advocacy and mediation and through occupation-focused programs aimed at enabling people to do, be, and become according to their natural health needs. (p. 282, italics added)

The roles of occupational therapy practitioners in evaluation and intervention in health promotion practice are based on the *Guidelines for Supervision, Roles, and Responsibilities During the Delivery of Occupational Therapy Services* (AOTA, 2009a). Occupational therapy practitioners possess the basic knowledge and skills to carry out health promotion interventions to prevent injury and maximize well-being. However, this area of practice is very broad, and practitioners need to continually expand their knowledge in health promotion to be effective and competent members of the team.

While recognizing the unique role of occupational therapy in health promotion and prevention, it is also important to acknowledge and respect the contributions of other health care professions in this arena. Occupational therapy practitioners should operate within their scope of practice and training and partner with other health promotion disciplines with specialized expertise such as in the areas of public health, health education, nutrition, and exercise science.

As in all other areas of practice, health promotion services should be based on the best available evidence. Law, Steinwender, and LeClair (1998) conducted an extensive review of the literature on the relationship between occupation and health. The longitudinal studies that were reviewed found that activity participation had a significant effect on perceived health. Maintenance of everyday activities, social interactions, and community mobility influenced self-reported quality of life.

A long-term benefit attributable to preventive occupational therapy was shown by Clark et al. (2001) when they reevaluated participants from the Well Elderly Study and found that 90% of therapeutic gain observed after intervention was retained at the 6-month follow-up. The Well Elderly Study was replicated through the Well Elderly Trial 2 with participants from a wider array of economic and ethnic backgrounds. Occupational therapy health promotion was once again found to be a cost-effective method to enhance health and well-being among older adults in an urban context (Clark et al., 2012).

Interventions With Individuals

The following are examples of occupation-based primary prevention intervention that target individuals:

- Musculoskeletal injury prevention and management programs
- Anger management and conflict resolution training for parents, teachers, and school-aged youth to reduce the incidence of bullying and other violence
- Parenting skills training to enhance family health and decrease potential for abuse
- Fall prevention programs for community-dwelling seniors
- Ensuring health literacy for non-English-speaking populations.

Examples of secondary prevention carried out by occupational therapy practitioners may include

- Education and training regarding eating habits, activity levels, and prevention of secondary disability subsequent to obesity;
- Education and training on stress management and adaptive coping strategies to enhance resilience for persons with mood disorders and posttraumatic stress disorder; and
- Osteoporosis prevention and management classes for individuals recently diagnosed with or at high risk for this condition.

Examples of occupation-based tertiary prevention intervention may include

- Transitional or independent-living skills training for people who have mental illness and those with cognitive impairments;
- Leisure participation groups for older adults with dementia to prevent depression, enhance socialization, and improve quality of life;
- Social participation activities at a drop-in center for adults with severe mental illness; and
- Stroke support groups for survivors and caregivers.

Occupational therapy practitioners have an opportunity to complement existing health promotion efforts by adding the contribution of occupation to programs developed by experts in health education, nutrition, exercise, and so forth. For example, when working with a person with a lower extremity amputation due to diabetes, the occupational therapy practitioner may focus on the occupation of meal

preparation using foods and preparation methods recommended in the nutritionist's health promotion program. This focus enables achievement of the occupational therapy goal of functional independence in the kitchen and reinforces the importance of proper nutrition for the prevention of further disability (Scaffa, 2001).

Interventions With Populations

To be effective, health promotion efforts cannot focus only on intervention at the individual level. Because of the inextricable and reciprocal links between people and their environments, larger groups, organizations, communities, and populations may also benefit from occupational therapy intervention (AOTA, 2008; Law, 1991; Wilcock, 2006).

Examples of interventions through the intermediary of organizations include

- Consultation to businesses to promote well-being of workers through identification of problems and solutions for balance among work, leisure, and family life;
- Consultation to schools regarding implementation of Americans With Disabilities Act of 1990 (ADA; Pub. L. 101-336) requirements;
- Education for day care staff regarding normal growth and development, handling behavior problems, and identifying children at risk for developmental delays; and
- Promotion of ergonomically correct workstations in schools and offices.

Community or population-level interventions may include

- Consulting with the local transportation authority regarding accessible public transportation;
- Consulting with contractors, architects, and city planners regarding accessibility and universal design;
- Implementing a community-wide screening program for depression at nursing homes, assisted living facilities, and senior centers for the purpose of developing group and individual prevention and intervention programs;
- Conducting needs assessments and implementing intervention strategies to reduce health disparities in communities with high rates of disease or injury, such as lifestyle management programs addressing hypertension, diabetes, and obesity;
- Addressing the health and occupation needs of the homeless population by eliminating barriers and enhancing opportunities for occupational engagement; and
- Training volunteers to function effectively in special needs shelters during disasters.

Governmental or policy-level interventions may include

- Promoting policies that offer affordable, accessible health care to everyone, including people with disabilities;
- Promoting barrier-free environments for all ages, including aging in place and universal design;
- Supporting full inclusion of children with disabilities in schools and day care programs;
- Lobbying for public funds to support research and program development in areas related to improvement in quality of life for people at risk and those with disabilities; and
- Promoting policies that establish opportunities for rehabilitation in the community for people discharged from inpatient psychiatric programs.

Opportunities for Occupational Therapy in Health Promotion

Funding for health promotion programs can come from governmental agencies, foundations, nonprofit organizations, insurance companies, and large corporations, among others. In addition, fee for service is

an option. Typically, health promotion and prevention programs do not rely on a single source of funding (Brownson, 1998; Scaffa, 2001).

Changes in health care brought about by the 2010 Patient Protection and Affordable Care Act (ACA; Pub. L. 111–148) have already and will continue to have an impact on health promotion, prevention, and public health service provision. Although the ACA is designed to improve individual health by increasing access to health insurance and health care, several provisions relate directly to health promotion. Specifically, Title IV calls for

- Increasing funding for prevention and public health programs;
- Providing education and outreach related to health promotion and disease prevention;
- Reviewing evidence related to preventive services and the development of recommendations;
- Providing Medicare coverage of annual well care visits and the development of personalized prevention plans;
- Improving access to preventive services for eligible adults in Medicaid;
- Eliminating patient copays for prevention services;
- Dispensing incentives for prevention of chronic diseases in Medicaid;
- Evaluating outcomes of community-based prevention and wellness programs for Medicare beneficiaries;
- Removing barriers and improving access to health promotion services for individuals with disabilities;
- Providing grants for employer-based wellness programs; and
- Funding for childhood obesity demonstration project (Kaiser Family Foundation, 2011; Network for Public Health Law, 2011).

Occupational therapy practitioners can seize opportunities to participate in the provision of health promotion and prevention services under the ACA by becoming a member of the primary care team and the patient's medical home. Failure to integrate occupational therapy into these arenas could severely limit the profession's future growth.

Case Studies

The following case studies provide examples of the role of occupational therapy in health promotion and prevention of disease and injuries.

Primary Prevention—Working With a Family

A retired couple consult an occupational therapist about a home safety assessment for the purpose of remaining in their home as they age.

Assessment

The occupational therapist develops an occupational profile (AOTA, 2008) using a semistructured interview format. She gathers information about the couple's goals, occupational history, health, occupational performance, and satisfaction level within the various performance areas, as well as social connectedness and overall life satisfaction.

Both spouses are healthy and able to perform daily tasks with a high level of satisfaction. They have a strong social support network and report being very satisfied with their lives. The occupational therapist also explores the health history of their parents and learns of a history of Alzheimer's disease and diabetes. She assesses the environment (i.e., home, yard, neighborhood) for accessibility and safety using the

Safety Assessment of Function and the Environment for Rehabilitation (SAFER) tool (Oliver, Blathwayt, Brackley, & Tamaki, 1993).

The occupational therapist notes that the living area is on three levels (several steps have no railings); rooms and hallways are generally poorly lit; and the rooms have too much furniture, leaving narrow or obstructed passageways. The yard has uneven and poorly defined walkways. The couple lives in a residential neighborhood with a distance of 3 miles to shopping. No public transportation is available, even for people with mobility impairments.

Intervention

For immediate consideration, the occupational therapist recommends that the couple install railings near all stairs, increase the level of lighting, and decrease the amount of furniture. She works with them to find the best configuration of furniture placement to maximize safety when walking in a room. She recommends that they consider changing the landscape to include clearly defined and level walkways that will also accommodate wheeled mobility, should that ever be needed.

A second set of recommendations includes how to retrofit the house if mobility impairments preclude climbing stairs in the future. The therapist describes optimal placement of an elevator from the first to the second floor. There is not an easy placement of an elevator from the basement to the first floor, so the therapist describes how the occupations now performed in the basement (e.g., exercise, laundry, computer use) may be transferred to the other two floors. The therapist works with the couple on problem solving around transportation, should driving become difficult.

Primary Prevention—Working With a Business

A commercial bakery contacts an occupational therapist to assess the various workstations in the bakery and make recommendations for improvements. Management goals include increasing productivity and decreasing sick days and worker compensation claims.

Assessment

The occupational therapist observes the work performed at the various workstations and interviews the workers. He notes body mechanics, repetitive motions, machine design, layout of workstations with travel distances, weights lifted and number of lifts per time unit, work speed and load, noise, temperature, air quality, clothing comfort, and length and frequency of rest breaks. He also notes worker-to-worker interaction and interaction among workers, supervisors, and management. In general, the supervisors and management seem approachable and open to suggestions from the workers.

The occupational therapist identifies a high frequency of lifting and repetitive motion done by the workers. Workstations require a significant amount of static standing, which can contribute to many musculoskeletal problems. Travel distances are long, work speed is rapid, noise level is high in certain parts of the factory, and the temperature is uncomfortably warm.

Intervention

The occupational therapist recommends ergonomically designed workstations that can decrease the amount of static work, time standing, travel, or lifting and that can improve working positions. Because some jobs involve repetitive motions that may not be avoided, the therapist instructs the managers in the benefits of rest breaks and instructs the workers in stretching exercises. Each worker is also instructed in proper body mechanics at his or her workstation. The therapist works with the management to design a daily schedule that allows for an even workflow to decrease times of high stress. The therapist is asked to return every 6 months to reassess and instruct new employees.

Primary Prevention—Working With a School

An elementary school is planning a new playground, which must be accessible to every child in the school. An occupational therapist is consulted for input on design features that will make the playground aesthetically pleasing, fun, and challenging to use for children of all abilities.

Assessment

The occupational therapist surveys the area where the school is planning to locate the playground. He uses the guidelines for play areas developed by the U.S. Access Board (2007) to ensure minimum requirements are met. He then researches commercially available playground equipment to find equipment that will be fun and challenging to use for all populations in the school as well as encourage interaction among the children.

Intervention

The occupational therapist provides the school with a report detailing his recommendations for important features in the playground equipment and the layout of the playground. He is careful to identify all safety issues and suggests ways to make the playground as safe as possible. The report also includes recommendations for landscaping so that children using wheeled mobility can easily navigate around the playground. The therapist remains on the design team for consultation until the playground is completed.

Secondary Prevention—Working With a Local Governmental Agency

An occupational therapist working in home health has noticed that her elderly clients who no longer drive because of a variety of functional limitations have no other means of transportation to go grocery shopping, run errands, and visit friends. The therapist reviews the literature for evidence and locates the special issue of the *American Journal of Occupational Therapy* that includes several systematic reviews on the relationship between occupation and productive aging (Leland & Elliott, 2012), and she commits to taking action.

Assessment

To determine the need for alternative means of transportation, the occupational therapist conducts a needs assessment, gathering existing data from several sources, including state and local census data and information from community organizations that provide services to older adults.

Intervention

The occupational therapist contacts the county office on aging to discuss her findings and concerns. She conducts a brief presentation, including data she collected about the local community and evidence from the systematic reviews. A joint task force is formed with local senior centers to further study the transportation experience of elderly county residents and make recommendations. Cognizant of the need to balance the fiscal resources of the county with the needs of aging county residents, the task force develops a proposal for extending one bus route and including three additional stops on two other bus routes during the weekday non-rush hour time period. The proposal emphasizes the importance of transportation and social participation to the health and well-being of elders.

Tertiary Prevention—Working With a Group

A rehabilitation unit in a hospital decides to offer health promotion classes to former patients with chronic conditions. An occupational therapy assistant is chosen to lead a class for patients with chronic obstructive pulmonary disease.

Assessment

The occupational therapy assistant researches information on the disease, existing programs, and their content and outcomes. He researches optimal group size, length of each session, session frequency, and number of sessions.

Intervention

Using the assessment information, the supervising occupational therapist works with the occupational therapy assistant and a respiratory therapist to develop the health promotion class, including number of participants, length of session, and topics offered. It is decided that a maximum of 15 participants will meet monthly for 1½ hours for a total of 12 sessions. Topics include self-management, assertive communication, information-seeking, and problem-solving skills. The group will also function as a support group. The occupational therapist collects data to determine the effectiveness of the program in preventing secondary conditions associated with chronic obstructive pulmonary disease and promoting independent living and quality of life.

Summary

Through this statement, the AOTA described the role of occupational therapy in the promotion of health and well-being among individuals, families, communities, and populations. Three levels of prevention services were defined, and potential contributions by occupational therapy practitioners were detailed at each level.

The examples provided are just a few of the extensive, rich, and varied occupation-based approaches that can facilitate the achievement of the national goals outlined in Healthy People 2020. These approaches include, but are not limited to, the creation of health-promoting social and physical environments, improved quality of life, healthy development, and health equity for all.

References

- American Occupational Therapy Association. (1995). Occupation: A position paper. *American Journal of Occupational Therapy*, 49, 1015–1018. <http://dx.doi.org/10.5014/ajot.49.10.1015>
- American Occupational Therapy Association. (2006). Association policies: Policy 1.44: Categories of occupational therapy personnel. *American Journal of Occupational Therapy*, 60, 683–684. <http://dx.doi.org/10.5014/ajot.60.6.681>
- American Occupational Therapy Association. (2008). Occupational therapy practice framework: Domain and process (2nd ed.). *American Journal of Occupational Therapy*, 62, 625–683. <http://dx.doi.org/10.5014/ajot.62.6.625>
- American Occupational Therapy Association. (2009a). Guidelines for supervision, roles, and responsibilities during the delivery of occupational therapy services. *American Journal of Occupational Therapy*, 63, 797–803. <http://dx.doi.org/10.5014/ajot.63.6.797>
- American Occupational Therapy Association. (2009b). Occupational therapy's commitment to non-discrimination and inclusion. *American Journal of Occupational Therapy*, 63, 819–820. <http://dx.doi.org/10.5014/ajot.63.6.819>
- American Occupational Therapy Association. (2010). Specialized knowledge and skills in mental health promotion, prevention, and intervention in occupational therapy practice. *American Journal of Occupational Therapy*, 64(6, Suppl.), S30–S43. <http://dx.doi.org/10.5014/ajot.2010.64S30>
- Americans With Disabilities Act of 1990, Pub. L. 101–336, 42 U.S.C. § 12101.

- Belle, S. H., Burgio, L., Burns, R., Coon, D., Czaja, S. J., Gallagher-Thompson, D., . . . Zhang, S. (2006). Enhancing the quality of life of dementia caregivers from different ethnic or racial groups. *Annals of Internal Medicine*, 145, 727–738. <http://dx.doi.org/10.7326/0003-4819-145-10-200611210-00005>
- Brownson, C. A. (1998). Funding community practice: Stage 1. *American Journal of Occupational Therapy*, 52, 60–64. <http://dx.doi.org/10.5014/ajot.52.1.60>
- Christiansen, C. H. (1999). Defining lives: Occupation as identity: An essay on competence, coherence, and the creation of meaning. *American Journal of Occupational Therapy*, 53, 547–558. <http://dx.doi.org/10.5014/ajot.53.6.547>
- Clark, F., Azen, S. P., Carlson, M., Mandel, D., LaBree, L., Hay, J., . . . Lipson, L. (2001). Embedding health-promoting changes into the daily lives of independent-living older adults: Long-term follow-up of occupational therapy intervention. *Journals of Gerontology, Series B: Psychological Sciences and Social Sciences*, 56, 60–63. <http://dx.doi.org/10.1093/geronb/56.1.P60>
- Clark, F., Azen, S. P., Zemke, R., Jackson, J., Carlson, M., Mandel, D., . . . Lipson, L. (1997). Occupational therapy for independent-living older adults: A randomized controlled trial. *JAMA*, 278, 1321–1326.
- Clark, F., Jackson, J., Carlson, M., Chou, C., Cherry, B. J., Jordan-Marsh, M., . . . Azen, S. P. (2012). Effectiveness of a lifestyle intervention in promoting the well-being of independently living older people: Results of the Well Elderly 2 randomised controlled trial. *Journal of Epidemiology and Community Health*, 66, 782–790. <http://dx.doi.org/10.1136/jech.2009.099754>
- Drum, C. E., Krahn, G., Culley, C., & Hammond, L. (2005). Recognizing and responding to the health disparities of people with disabilities. *Californian Journal of Health Promotion*, 3, 29–42.
- Elliott, A. F., Burgio, L. D., & DeCoster, J. (2010). Enhancing caregiver health: Findings from the Resources for Enhancing Alzheimer's Caregiver Health II Intervention. *Journal of the American Geriatrics Society*, 58, 30–37. <http://dx.doi.org/10.1111/j.1532-5415.2009.02631.x>
- Finlayson, M., & Edwards, J. (1997). Evolving health environments and occupational therapy: Definitions, descriptions, and opportunities. *British Journal of Occupational Therapy*, 60, 456–460.
- Kaiser Family Foundation. (2011). *Summary of new health reform law*. Retrieved from www.kff.org/healthreform/8061.cfm
- Kielhofner, G. (2004). *Conceptual foundation of occupational therapy* (3rd ed.). Philadelphia: F. A. Davis.
- Kinne, S., Patrick, D. L., & Doyle, D. L. (2004). Prevalence of secondary conditions among people with disabilities. *American Journal of Public Health*, 94, 443–445. <http://dx.doi.org/10.2105/AJPH.94.3.443>
- Krahn, G. L., Fujiura, G. T., Drum, C. E., Cardinal, B. J., & Nosek, M. A.; RRTC Expert Panel on Health Measurement. (2009). The dilemma of measuring perceived health status in the context of disability. *Disability and Health Journal*, 2, 49–56. <http://dx.doi.org/10.1016/j.dhjo.2008.12.003>
- Krahn, G. L., Putnam, M., Drum, C. E., & Powers, L. (2006). Disabilities and health. *Journal of Disability Policy Studies*, 17, 18–27. <http://dx.doi.org/10.1177/10442073060170010201>
- Law, M. (1991). The environment: A focus for occupational therapy [Muriel Driver Memorial Lecture]. *Canadian Journal of Occupational Therapy*, 58, 171–179. <http://dx.doi.org/10.1177/000841749105800404>
- Law, M., Steinwender, S., & LeClair, L. (1998). Occupation, health, and well-being. *Canadian Journal of Occupational Therapy*, 65, 81–91. <http://dx.doi.org/10.1177/000841749806500204>
- Leland, N. E., & Elliott, S. J. (2012). Special issue on productive aging: Evidence and opportunities for occupational therapy practitioners. *American Journal of Occupational Therapy*, 66, 263–265. <http://dx.doi.org/10.5014/ajot.2010.005165>
- Meyer, A. (1922). The philosophy of occupation therapy. *Archives of Occupational Therapy*, 1, 1–10.

- Network for Public Health Law. (2011). *Public health provisions of the Patient Protection and Affordable Care Act: Issue brief*. Retrieved from www.networkforphl.org/_asset/x4mc6h/ACA-chart-formatted-FINAL.pdf
- Oliver, R., Blathwayt, J., Brackley, C., & Tamaki, T. (1993). Development of the Safety Assessment of Function and the Environment for Rehabilitation (SAFER) tool. *Canadian Journal of Occupational Therapy*, 60, 78–82. <http://dx.doi.org/10.1177/000841749306000204>
- Patient Protection and Affordable Care Act, Pub. L. 111–148, § 3502, 124 Stat. 119, 124 (2010).
- Patrick, D. L., Richardson, M., Starks, H. E., Rose, M. A., & Kinne, S. (1997). Rethinking prevention for people with disabilities, Part II: A framework for designing interventions. *American Journal of Health Promotion*, 11, 261–263. <http://dx.doi.org/10.4278/0890-1171-11.4.261>
- Scaffa, M. E. (2001). *Occupational therapy in community-based practice settings*. Philadelphia: F. A. Davis.
- Seligman, M. (2011). *Flourish: A visionary new understanding of happiness and well-being*. New York: Free Press.
- Trentham, B., & Cockburn, L. (2005). Participatory action research: Creating new knowledge and opportunities for occupational engagement. In F. Kronenberg, S. Simó Algado, & N. Pollard (Eds.), *Occupational therapy without borders: Learning from the spirit of survivors* (pp. 440–453). Philadelphia: Churchill Livingstone.
- U.S. Access Board. (2007). *Accessible play areas: A summary of accessibility guidelines for play areas*. Retrieved from www.access-board.gov/play/guide/guide.pdf
- U.S. Department of Health and Human Services. (1980). *Promoting health/preventing disease: Objectives for the nation*. Washington, DC: U.S. Government Printing Office.
- U.S. Department of Health and Human Services. (1990). *Healthy People 2000*. Washington, DC: U.S. Government Printing Office.
- U.S. Department of Health and Human Services. (2000). *Healthy People 2010: Understanding and improving health* (2nd ed.). Washington, DC: U.S. Government Printing Office.
- U.S. Department of Health and Human Services. (2010). *Healthy People 2020* [Brochure]. Retrieved from www.healthypeople.gov/2020/TopicsObjectives2020/pdfs/HP2020_brochure_with_LHI_508.pdf
- Wilcock, A. A. (2006). *An occupational perspective of health* (2nd ed.). Thorofare, NJ: Slack.
- World Health Organization. (1986). *The Ottawa Charter for health promotion*. Retrieved from www.who.int/healthpromotion/conferences/previous/ottawa/en/
- Zemke, R., & Clark, F. (1996). *Occupational science: The evolving discipline*. Philadelphia: F. A. Davis.

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Appendix. Glossary of Health Promotion Terms

Occupational alienation—“Sense of isolation, powerlessness, frustration, loss of control, and estrangement from society or self as a result of engagement in occupation that does not satisfy inner needs” (Wilcock, 2006, p. 343).

Occupational deprivation—“Deprivation of occupational choice and diversity because of circumstances beyond the control of individuals or communities” (Wilcock, 2006, p. 343).

Occupational imbalance—“A lack of balance or disproportion of occupation resulting in decreased well-being” (Wilcock, 2006, p. 343).

Occupational justice—“The promotion of social and economic change to increase individual, community, and political awareness, resources, and equitable opportunities for diverse occupational opportunities that enable people to meet their potential and experience well-being” (Wilcock, 2006, p. 343).

Occupational science—“An interdisciplinary academic discipline in the social and behavioral sciences dedicated to the study of the form, the function, and the meaning of human occupations” (Zemke & Clark, 1996, p. vii).

Social justice—“The promotion of social and economic change to increase individual, community, and political awareness, resources, and opportunity for health and well-being” (Wilcock, 2006, p. 344).

Well-being—A state of flourishing that consists of the following elements: positive emotion, engagement or flow, *meaning* (a sense of belonging to or serving something larger than oneself), positive relationships and accomplishment or achievement (Seligman, 2011).



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