

REVISED EDITION

Autism Spectrum Disorder

The Complete Guide
to Understanding Autism

Chantal Sicile-Kira

FOREWORD BY TEMPLE GRANDIN

OUTSTANDING
BOOK OF THE YEAR

AUTISM SOCIETY
OF AMERICA



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Praise for
Autism Spectrum Disorder

“This well-documented guide offers clear answers to difficult questions and recommends the important resources that parents will find the most useful. She’s done the research so the reader doesn’t have to! Her abundance of practical knowledge has been compiled into this user-friendly updated edition that both parents and professionals will want to keep on hand to refer to time and time again. Truly a must-have!”

—Ricki G. Robinson, MD, MPH, member of the Scientific Review Panel of Autism Speaks;
medical director of Profectum; and author of *Autism Solutions*

“A clearly written, well-organized, carefully documented compilation of important information and useful advice. It will provide invaluable help and guidance to parents and professionals alike, especially those who are new to the world of autism. This book is not merely highly recommended—it is indispensable.”

—Bernard Rimland, PhD, past director of the Autism Research Institute, founder of the Autism Society of America, and past editor of *Autism Research Review*

“This is an essential source of information and advice in plain everyday language that can help anyone who is affected by autism today, from the parent of a newly diagnosed child, to someone who has been in the trenches for years. Kudos to Chantal for providing us with this long overdue, user-friendly, how-to guide for dealing with autism.”

—Portia Iversen, cofounder of Cure Autism Now Foundation (CAN), member of Innovative Technology for Autism Advisory Board of Autism Speaks, and author of *Strange Son*

“The essential book that parents, health professionals, and a wide readership will reach for in order to fathom this confounding condition.”

—Douglas Kennedy, author of *Leaving the World*, *The Moment*, and *The Pursuit of Happiness*

“If I could recommend just one book to families and professionals, this is it! In *Autism Spectrum Disorder*, Chantal Sicile-Kira shares her immense

knowledge, personal experience, and insightful advice for families affected by autism. She guides readers along the journey from diagnosis through adulthood, including an extensive compilation of resources and ‘food for thought’ throughout. This isn’t a book that you’ll read once and place on a shelf; it’s an invaluable resource that you will continue to refer to for years to come.”

—Wendy Fournier, founding board member and president of the National Autism Association

“*Autism Spectrum Disorder* is a tremendous resource for families caring for children and adults with autism. While sharing her personal experiences of a parent of a child with autism, Chantal Sicile-Kira provides insights and resources that are often missing from many of the books on this topic. Quite simply *Autism Spectrum Disorder* simplifies many of the complications that families face in navigating systems of care, and in doing so, she gives families hope and great inspiration.”

—Areva D. Martin, Esq., cofounder and president of Special Needs Network Inc.

“For more than thirty years I have treated visual developmental delays for those with ASD; I think I have made a difference. But my contributions pale in comparison to what Jeremy has taught me through his work in Vision Therapy, and what Chantal has taught me as a mother and author. This book will become a lifelong companion for those who want to make a difference in a life—a life with autism or not.”

—Carl G. Hillier, OD, FCOVD, clinical director of San Diego Center for Vision Care

A u t i s m S p e c t r u m D i s o r d e r

The Complete Guide to Understanding Autism

REVISED EDITION

C H A N T A L S I C I L E - K I R A

A P E R I G E E B O O K

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For Jeremy, Rebecca, and Daniel, the stars of my universe.

I know of nobody who is purely autistic or purely neurotypical. Even God had some autistic moments, which is why the planets all spin.

—Jerry Newport, *Your Life Is Not a Label*

The history of man's progress is a chronicle of authority refuted.

—Author unknown

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MANY people have contributed in different ways to this book. I'm forever grateful to Bernard Rimland, PhD, and Temple Grandin, PhD, for their generosity of time and knowledge. Both Dr. Rimland and Dr. Grandin have, in different ways, shifted the paradigm in how the world looks at autism and how we can best help our children, whether they are toddlers, teenagers, or young adults. (Bernie passed away in November of 2006 and this was a great loss to all of us in the autism community.)

Thanks to all those on the spectrum who have shared their experiences. They are the real experts on autism. I'm grateful to the many parents and educators that I've met at conferences around the country; I'm continually learning from other people's experiences and knowledge base. Thanks to the many parent-driven organizations and professionals providing much-needed supports to families, and the researchers who continue to try to solve the mystery of autism and how to best help our children to reach their full potential.

Thanks, Lindsay Edgecombe and James Levine, for your support over the years, as well as Marian Lizzi, editor extraordinaire with whom I've had the pleasure of working on three books, and now this update.

Special thanks to my parents, Andre and Mathe Sicile. They did the best they could raising a neuro-diverse family of six children with no relatives around to help after moving to the United States from France in the 1950s. No easy task, yet we all survived!

To Rebecca and Jeremy, for being who you are. You were great children, and you've become wonderful young adults. I am so proud of both of you and am forever grateful I was chosen to be your mom. Raising you both—with your dad, of course!—has been my greatest and most important accomplishment. And lastly, to my husband, Daniel, thank you for your unwavering loyalty and constant support on this strange journey called life.

FOREWORD

THE autism/Asperger spectrum is very broad, ranging from a brilliant scientist to a person who remains nonverbal with a severe disability. There are many characteristics that are the same along the entire continuum. Two of the most important are problems with social situations, and sensory sensitivities. Sensory problems are often overlooked. When I was a child, a loud school bell was like a dentist drill hitting a nerve. It hurt my ears.

Chantal Sicile-Kira originally contacted me to discuss sensory processing issues. She told me she was writing a general reference guide to autism spectrum disorders. This led to a series of phone calls and faxes. Finally, we met at an autism conference in San Diego, where I had been asked to speak, and Chantal handed me her manuscript, asking me if I would read it and tell her what I thought.

I read her book on my plane trip back home, calling Chantal from two different airports to tell her how impressed I was with the thoroughness of her manuscript, as well as her ability to take complex information and simplify it, rendering it understandable to everyone. This book gives the general public, professionals, and parents a better understanding of the autism/Asperger spectrum, as well as providing lists of resources useful to those who are on the spectrum, and those who work and care for them.

I would like to give a word of advice to all people who work with children or adults on the spectrum: develop talents that can be turned into job skills or hobbies. Social interaction will develop through an interest that can be shared with other people. Special education teachers often put too much emphasis on deficits and not enough on building on areas of strength. As a visual thinker I was good at drawing, and my visual and drawing skills became the basis for my career as a designer of livestock facilities.

Skills tend to be uneven; an individual may be good at one thing and not another. I was good at drawing and building things, but algebra was

incomprehensible because I could not visualize it. The minds of people on the spectrum are usually specialized. I have observed that there are three basic types of specialized minds: the visual thinking mind; the music and mathematical mind; and the nonvisual numbers and language translator mind. Teachers and parents should work on utilizing these strengths.

Individuals with autism often become fixated on a single thing, such as trains or airplanes. Use the strong motivation of the fixation to encourage activities. If a child likes trains, use trains in mathematical problems, read a train book to teach literacy, or invent a game involving trains that can be played with other children. A good teacher takes the fixation and broadens it out. Many great scientists pursued a childhood interest.

The autism/Asperger spectrum is a continuum from normal to abnormal. In my book *Thinking in Pictures*, I profiled former scientists such as Einstein who had childhood autistic traits. The British researcher Simon Baron-Cohen has also written on the appearance of autistic traits in scientists and physicists. When does “computer nerd” become Asperger’s? There is no black-and-white dividing line.

Individuals who remain nonverbal will often have something they are good at. Many of them have fantastic memories. They may be good at jobs such as reshelving books in the library or taking inventory of the stock at a shop. They would be good at a job that most people would find boring. Develop these skills so they can be useful.

People on the spectrum who have a fulfilling life now often had four important assets earlier in their life: early education and treatment; medication or other treatment for severe anxiety, depression, or sensory sensitivities; development of their talents; and mentors and teachers to help them.

What I really like about Chantal’s book are the many references to and quotes from people on the autism/Asperger spectrum. This information from personal experiences will give both parents and professionals much-needed insight into how autistic people perceive the world.

—Temple Grandin, PhD, author of *Thinking in Pictures*, associate professor of animal science at Colorado State University, founder and president of Grandin Livestock Handling Systems Inc.

PREFACE

*My mom saved me from a life of despair.
Her attitude is the key to my achievements.
She made me feel I could be a success, no matter my challenges.*

—JEREMY SICILE-KIRA

SINCE this book was first published in 2004, much has changed in the world of autism, as well as in our son, Jeremy. When Jeremy was first diagnosed over twenty years ago, we were told that if we were lucky, we would find a good institution for him. I don't think the diagnostician meant the United Nations, but that's where Jeremy ended up—as the first Youth Representative to the United Nations for the Autism Research Institute at age twenty-three. He also graduated from his local high school at age twenty-one, with an academic diploma and a GPA of 3.78, despite having to type to communicate. He auditioned for and gave a commencement speech using voice output technology that is still inspiring many on YouTube (more on Jeremy later).

But Jeremy's achievements did not happen overnight. It took finding the right professionals to help him; taking care of medical challenges; advocating and negotiating for him when he was a child to ensure he had an appropriate education; working as a team with the great educators we found; and lastly raising and teaching him with the attitude that he was smart, and that one day we would reach him. It wasn't easy. But I left no stone unturned in finding the resources that could help him.

This updated edition of my first book will guide you in finding the courage and the resources you need to make the best possible choices in regard to treating, educating, and raising your child. Every child is different—what helps one child with autism may be ineffective for another.

Although there is a lot more information available now than when Jeremy was a baby, parents still need to become experts on their child and what could help him or her. This new edition has been completely updated with the latest information and the best websites to consult as new discoveries are made.

Although Jeremy is my inspiration for all the writing and training I do now, my first experience with autism was during my college years. In need of a full-time job to sustain me through college, I applied for a position at Fairview State Hospital for the Developmentally Disabled in Orange County, California, and was hired to teach adolescents self-help and social skills in preparation for community living. This was my first contact with the intriguing world of autism and some wonderfully unusual people (including the staff). I then worked for a short while as a case manager at Orange County Regional Center for the Developmentally Disabled, providing information and resources to families and their children.

Little did I know that my professional introduction and hands-on experience would serve me well when, twelve years later in France, I had my son, Jeremy, who was eventually diagnosed with autism. The only course of treatment offered there at the time was psychoanalysis. I was strongly reprimanded for using behavioral techniques in an attempt to teach my four-year-old son. Eventually, we moved to England before making our way back to California, where Jeremy is now a client of the same types of agencies I used to interact with on a professional level.

I could have used a book such as this one years ago, when I tried to learn whatever I could to help my clients, and then again after having my son. Having spent tens of thousands of hours learning about autism spectrum disorder (ASD), how to navigate through the different systems in different places, and how to create what my son needed, it seemed a waste to hoard all that I had learned for the benefit of just my family. That is why I wrote the original edition of this book, which won the Outstanding Literary Award from the Autism Society of America and a San Diego Book Award. Since then, I've gone on to write five more books and to speak around the world to provide parents and educators with the practical information they need. Everywhere I've been I've learned from other parents and educators, as well as from those on the spectrum who have shared their experiences. More recently, I've created autismcollege.com, so

that those who cannot get to conferences can still access my practical information and training online.

Educators and other professionals will find useful nuggets to help them with their students or clients. This book is written simply, with practical tips, in order to point the reader in the right direction for more information, if needed.

Adults who have been recently diagnosed will find information that is useful in different chapters. Hopefully, this book will provide some insight and support.

People who come across those who have ASD in their line of work can read the chapters they think will help them most. In Chapter 8, I have included a section that is helpful for the general public who may occasionally come across someone with autism: babysitters, recreation leaders, emergency responders, storekeepers, scout leaders, bus drivers . . . basically anyone who works with the public. With a diagnosis rate in the United States estimated to be as high as 1 in 50 schoolchildren, everyone knows someone whose life is touched by autism, and your clients, customers, and coworkers are some of them.

Back to Jeremy—today he is twenty-five. After graduation, he attended some community college classes and coauthored a book, *A Full Life with Autism: From Learning to Forming Relationships to Achieving Independence* (Macmillan, 2012). He became a Young Leader for the Autistic Global Initiative of the Autism Research Institute. In the last year, Jeremy began creating beautiful abstract paintings. In 2010, his therapists and I realized that Jeremy has synesthesia; he see letters and words in color, and he perceives and feels emotions as different colors. In 2012, Jeremy began to type out and describe his dreams, and his desire to learn how to paint. Recently, he created Jeremy's Vision to encompass his writing, painting, consulting, and advocacy work. As our children grow, it is important to find those areas of strength and interest to help them learn and enjoy life, and to find mentors to help them develop their areas of strength. Jeremy's story is an example of how people on the spectrum can always learn and discover new interests—just as neurotypicals do. It is important that they be given the opportunity to do so.

Yet, despite all of his accomplishments, life has not been easy for Jeremy. He still requires twenty-four-hour support. He has many sensory-

motor challenges. He is working toward moving out into supported living. He wishes he had more friends. But, all in all, life is good—he can communicate by typing and he is learning to be more interdependent—as well as independent. And now he has his painting, which is opening new doors for him.

Parents, this book was written with the goal of saving you countless hours of precious time and heartache. You have enough to do! Hopefully this book will also inspire you, inform you, and motivate you. Knowledge is power, so use this guide to empower yourself. Keep in mind that you are not alone. The autism community is here to help you.

ABOUT THIS BOOK

I have used the term “autism spectrum disorder” (ASD) throughout this book to mean anyone considered on the autism spectrum. If used, the word “autism” means autism spectrum disorder. When speaking specifically about people with Asperger’s syndrome, I have used “Asperger’s,” although I realize that the term technically no longer exists as a diagnosis. As there are more males diagnosed with ASD, I have most often used the pronoun “he.” I would ask the reader not to be put off by the third person construction, as in “the individual” or “the person.” Most resources are listed in the main text; others are in the Resources section.

This book has been compiled to serve an informational purpose. None of the information is meant to be diagnostic, legal, medical, or educational advice. Any treatments, therapies, or interventions should be discussed with a competent professional. Please consult your physician before changing, stopping, or starting any medical treatment. Laws and regulations change, and so the reader should get professional advice concerning matters of legal rights in terms of educational provision, health benefits, and any other benefits. The author and publishers disclaim, as far as the law allows, any liability arising directly or indirectly from the use, or misuse, of the information contained in this book.

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The Myths and History of Autism Spectrum Disorder

*Beyond the world of what and why
Beyond the reasons and the concrete,
The “abstract” lies with a richer glory
Somewhere in imaginations deep!*

—TITO RAJARSHI MUKHOPADHYAY, *The Mind Tree*

TWENTY-ONE years ago, we were in the local doctor’s office in a small village in England, where we had just moved. I was trying to explain to the receptionist why my three-year-old was obsessively walking around and around the waiting room, touching each chair he passed, whether it was empty or not, and obviously disturbing the other patients sitting in those chairs. We’d been waiting almost an hour to see the doctor. “My son is autistic. He can’t wait any longer,” I said. The receptionist replied, “Well, if he is artistic, have him draw. Here are some crayons to keep him busy.” As she walked away, she mumbled under her breath about how badly behaved some children were, and how impatient the parents.

Myths About Autism Spectrum Disorder

Sad but true, this type of misunderstanding still occurs in some places. However, as the number of people diagnosed escalates to epidemic proportions, most people today have come across autism spectrum disorder

(ASD). Still, as ASD is mysterious and has attributes that can be strange, awe-inspiring, and unexplainable, there are many myths that abound. Here are a few of them.

Myth #1: *The Rain Man Myth—Everyone with ASD Is an Autistic Savant*

In the movie *Rain Man*, Dustin Hoffman plays Raymond, a young man who has autism. He goes on a road trip with his brother, played by Tom Cruise. Raymond has an incredible gift with numbers. His brother discovers this, and takes him off to Las Vegas so Raymond can gamble and win some money. It is true that some individuals with autism have great skills in a particular area. Take Stephen Wiltshire, who can draw and paint accurate detailed representations of cities, sometimes after only having seen the city during a twenty-minute helicopter ride.

There are certainly individuals with ASD who have extraordinary talent. In fact, many may have talents yet untapped due to the challenges they face in communication, social relationships, or sensory overwhelm. Often what we see as an obsession is actually an indication of a talent that lies hidden and could be developed. Usually, those with autism have an inconsistent profile where they excel or do well in one area and have low performance in others. For example, years ago I worked with a young man who had a gift for memorizing and was infatuated with sports. On my first day of work at Fairview State Hospital, he came up to me and said, “I used to be a sports newscaster. Ask me any question about sports and I’ll fill you in.” He had memorized the pertinent statistics for all the World Series from the previous two decades. We talked sports and I did find him a bit odd. For a few minutes I entertained the thought that he was another employee, thinking what a dedicated person he must be to quit working for the media and join the staff at this hospital. Then I looked on my roster and realized he was one of my students for functional living skills. He definitely had a talent for sports statistics, but hadn’t yet learned how to dress himself independently or tie his own shoes. It is this discrepancy in ability level that can make life difficult for those on the spectrum. Yet, a person’s strengths can be used as the basis for helping him learn practical life skills as a child and identify possible employment opportunities as he grows older.

Myth #2: *Everyone Who Has ASD Is a Genius*

It is true that some people with ASD are geniuses, but not everyone is. Thomas Jefferson, it appears, had characteristics of Asperger's syndrome, within the range of modern diagnostic criteria. Others such as Beethoven, Isaac Newton, and Einstein have all been mentioned as famous people who could have been diagnosed as on the spectrum. However, for every person with ASD who is a genius, there are many more who appear to be mere mortals like ourselves. What is important is to give opportunities to all individuals to discover any hidden talents, or at least to reach their potential, whatever that may be.

Myth #3: *Those Who Are Nonverbal Are Unintelligent*

First of all, because of the nature of ASD, it is difficult to ascertain the cognitive level of people on the spectrum. Some or all of their senses are one hundred times more sensitive than others, and therefore they process the environment differently from neurotypicals (i.e., individuals considered to be "normal"). Secondly, more and more it is being recognized that many with autism have challenges with the "output"; that is, they may hear and understand what is being said (the "input"), but they are unable to respond verbally. Providing alternative means of communicating can be life changing for many.

People who are unable to speak, but have learned to type or write independently, express the difficulty they have in controlling their motor planning—that is, sending signals to their muscles—much like people who have had strokes. In his book *The Mind Tree*, Tito Rajarshi Mukhopadhyay explains, "Of course from my knowledge of biology I knew that I had voluntary muscles and involuntary muscles. I also knew that my hands and legs were made of voluntary muscles. But I experimented with myself that when I ordered my hand to pick up a pencil, that I could not do it. I remember long back when I had ordered my lips to move I could not do it."

Lastly, if you start with the perception that someone is unintelligent (considered "mentally retarded"), the expectations for that individual aren't going to be very high, and he will never be given the opportunity to reach as far as he can go. Better to hope he's a genius and be disappointed than

never to have given a person the benefit of the doubt. Always presume competence.

Myth #4: *Everyone Who Has a Symptom of ASD Has ASD*

If a person has one or two characteristics of ASD, it does not necessarily mean he has ASD. As explained in Chapter 2, it is the number and severity of deficits in the areas of social communication and social interaction, as well as restricted repetitive patterns of behaviors, interests, or activities that cause concern. That is why it is important to consult with a medical professional who is familiar with diagnosing ASD.

Myth #5: *All Individuals with Autism Need to Be Cured or Become Neurotypical*

There are many individuals who have the label of “autism” (or “Asperger’s syndrome”) who are brilliant and functional and clearly don’t need our help. In fact, many of these people are responsible for inventions that make improvements in all our lives or artistic creations that make the world a more enjoyable place to live. This is neurodiversity at its best. This book is not aimed at trying to change those individuals or to make them more neurotypical. This book is intended to help those who are suffering mentally, physically, or emotionally because of their autism or because of how they are treated due to their autism.

FOOD FOR THOUGHT

Even People with Autism Can Change

Over the years, I have read enough to know that there are still many parents, and professionals, too, who believe that “once autistic, always autistic.” This dictum has meant sad and sorry lives for many children diagnosed, as I was early in life, as autistic. To these people it is incomprehensible that the characteristics of autism can be modified and controlled. However, I feel strongly that I am living proof that they can.

—Temple Grandin and Margaret M. Scariano, *Emergence: Labeled Autistic*

Myth #6: *There Are No Dramatic Improvements to Be Made in Individuals with Autism Who Are Suffering or Need Help*

Tremendous advances have been made in the field of ASD over the last decade. Granted, there is still no magic pill that “cures” everyone, and that shouldn’t be the goal for all on the spectrum. However, there are cases of children who were diagnosed as clearly having ASD, and who are now considered to be neurotypical or symptom-free by professionals due to therapies, treatments, and dietary interventions they have received. Some of these cases have been documented in books and in blogs and videos on the Internet. There are also accounts written by people who have recovered significantly from ASD (some of the classics are *Nobody Nowhere* and *Somebody Somewhere* by Donna Williams, *Emergence: Labeled Autistic* by Temple Grandin and Margaret M. Scariano, and *Thinking in Pictures* by Temple Grandin). Recovery means that they have overcome some of the symptoms they had that made it difficult for them to live full and successful lives in a world created by neurotypicals.

FOOD FOR THOUGHT

Does Autism Need to Be Cured?

Perhaps ethical consideration should be given to the concept of “curing” autism. Saying that autism needs to be cured gives credence to the idea that everyone has to be “normal,” that there is something wrong with being different. Granted, many people would find life a lot easier if they did not have ASD. But perhaps those who have extraordinary talents would not have those gifts, either. Would Beethoven have created his Ninth Symphony? Would Einstein have come up with his theory of relativity? Temple Grandin (who has designed one-third of all the livestock-handling facilities in the United States) believes that her talent for solving concept problems is due to her “ability to visualize and see the world in pictures,” which can be attributed to having ASD.

Jerry Newport is a fifty-two-year-old author with Asperger’s syndrome, and was a speaker at the 2001 National Conference on Autism hosted by the Autism Society of America. His speech was titled “Every Child with Autism Must Become a Success,” and was inspired by his concern about the “unrealistic and divisive notion in our community that becoming normal is the only and optimal goal for our consumers.” He said, “I will never be normal. I have become a success. I have acquired enough self-esteem to do my best in every endeavor. That is what former UCLA basketball coach John Wooden calls

success. I will focus on how we can teach all of our children to have self-esteem, make the most of who they are, and lead full lives, normal or not.”

Myth #7: *People with ASD Have No Emotions and Do Not Get Attached to Other People*

It is true that many people with ASD show emotions in a different way from neurotypicals. However, just because a person does not show emotions in the way we are used to seeing them exhibited does not mean that they don't have feelings. One only has to read accounts by people with autism to realize that some individuals may express emotions differently (*Look Me in the Eye* by John Elder Robison; *Nobody Nowhere* by Donna Williams) or are unable to show emotion because they are not in control of their muscles or motor planning (*The Mind Tree* by Tito Rajarshi Mukhopadhyay).

It is very clear from reading books by people with autism (*Asperger's from the Inside Out* by Michael John Carley; *Life and Love: Positive Strategies for Autistic Adults* by Zosia Zaks; *Your Life Is Not a Label* by Jerry Newport; *Pretending to Be Normal* by Liane Holliday Willey) that they are capable of forming attachments with other people, and do so. Some people with autism date, get married, and have children, just as we do. Perhaps they are less expressive than others about their feelings or express them differently, but that does not mean they are not attached to others. Many on the spectrum express the desire to have friends; they just don't know how to go about making them in the way neurotypicals do.

Myth #8: *Autistic People Are Violent*

Some individuals with autism have “meltdowns”—expressions of frustration at themselves or others. It's important to understand that all behavior is a form of communication, and trying to understand why a person is having a meltdown or participating in self-aggression is important. It could be that they are in pain and don't have any way of communicating this. They may be in sensory overwhelm, or in the throes of a PTSD flashback. Over time, individuals can learn to self-regulate. However, there

is no connection between planned violence and autism. In December 2012, an individual alleged to have Asperger's syndrome as well as mental health challenges shot and killed young students as well as educators at Sandy Hook Elementary School. It is important to realize that the shooter was mentally ill and had many problems. Asperger's syndrome itself is not linked to violence—underlying depression or mood disorders, conduct disorders, and paranoia can be.

The History and Future of ASD

The labels “autism” and “autistic” come from the Greek word *autos*, meaning “self,” and were coined in 1911 by psychiatrist Eugen Bleuler. He used the terms to describe an aspect of schizophrenia, where an individual withdraws totally from the outside world into himself.

The Early Days: Kanner and Asperger

In the early 1940s, both Leo Kanner and Hans Asperger, pioneers in the field of autism, used the term “autistic” in their publications (independently of each other), describing children with the characteristics we recognize today as being autistic; hence, the label “autism” was born. In 1943, Kanner, an Austrian psychiatrist based at Johns Hopkins University in America, was the first to identify autism as a distinct neurological condition, although he could not specify a cause. In 1944, Asperger, an Austrian pediatrician in Vienna, published a doctoral thesis using the term autistic in his study of four boys. Both professionals described children who developed special interests, but also had deficits in the areas of communication and social interaction. Kanner's description was of children with severe autism, with the conclusion that it was a disastrous condition to have. Asperger's description was of more able children, and he felt that there might be some positive features to autism which could lead to great achievements as an adult. For thirty years, Kanner's description became the most widely recognized.

The term “Asperger’s syndrome” was first used by Lorna Wing in a paper published in 1981, in which she described children much like the more able boys Asperger had described many years earlier. Unfortunately, Asperger died in 1980, and never knew that a few years later a condition named after him would become well known worldwide.

The “Refrigerator Mother” Days: Bettelheim

Meanwhile, Bruno Bettelheim, a Hungarian psychotherapist, reared his head in the mid- to late 1940s, claiming that the source of autism was “refrigerator mothers”: cold, unfeeling parents who pushed their children into mental isolation. Bettelheim had spent 1943 and 1944 in concentration camps, and he likened the mental isolation of autistic children to that of the prisoners of war released from such camps after World War II.

Bettelheim eventually moved to the United States and became director of the Sonia Shankman Orthogenic School in Chicago, where he was lauded for many years internationally. Sadly, his theories were widely accepted for two decades, though eventually his school fell into disrepute. Thanks to him, for many years autism was considered a mental illness (as opposed to a developmental disability), leading to limited treatment options for these children. Even as late as the early 1990s a few civilized nations (namely France and Switzerland) still considered autism a mental illness, offering psychoanalysis and psychiatric hospitals as the primary treatment.

In 1997, *The Creation of Dr. B: A Biography of Bruno Bettelheim* by Richard Pollack was published. Pollack, whose younger brother attended the Orthogenic School where Bettelheim was director, conducted extensive research for his book. He discovered that before emigrating to the United States, Bettelheim had worked in the family lumber business and earned a degree in art history, and in fact did not have any qualifications to run a school or theorize about the causes of autism. Pollack also revealed that as director of the Orthogenic School, Bettelheim was known for his volatile, sadistic nature. He terrorized and beat the children, and treated the parents with disdain, blaming them for their children’s problems and only allowing them infrequent visits.

FOOD FOR THOUGHT

Shades of Bettelheim

My son was born in Paris, France. Having worked with individuals with ASD in the United States, I recognized early on that he had autistic tendencies. We sought help and guidance, and although the professionals denied he had autism, they sent us to a psychoanalyst. The psychoanalyst had plenty of Bettelheim books on her shelves, yet was quick to explain that she did not subscribe to Bettelheim's "refrigerator mother" theory. However, after a few sessions of psychoanalysis, it was decided that my son had suffered separation issues from breast-feeding. This the analyst gleaned from watching him spin round objects (which reminded him of his mother's breasts) and chase after one that he had "lost" when it fell and rolled under a piece of furniture.

A Huge Step Forward: Rimland

We owe the dramatic change in psychiatry's perception of autism to Bernard Rimland, PhD, a psychologist and father of a son with ASD. In 1964, Rimland wrote *Infantile Autism: The Syndrome and Its Implications for a Neural Theory of Behavior*, insisting that autism was a biological disorder, not an emotional illness. This book influenced the choices that were made in treatment methods for autism. Rimland, who passed away in November of 2006, was the founder of the Autism Society of America (ASA) (autism-society.org), the first parent-driven organization to provide information and support to parents and professionals. He also founded the Autism Research Institute (ARI) (autismresearchinstitute.com) in 1967, creating a worldwide network of parents and professionals concerned with autism. ARI, now headed by Dr. Stephen M. Edelson, conducts research, and disseminates the results of research, on the causes of autism and on methods of preventing, diagnosing, and treating autism and other developmental disabilities.

Dr. Rimland was very concerned about the sudden rise of autism in the 1990s and was interested in research on any possible connection between autism and vaccines containing mercury. He tracked the increase of late onset (i.e., regressive type) autism. ARI helped many families with autism

in their quest to treat their children's medical and behavior challenges with biomedical interventions. Defeat Autism Now! (DAN!) started during those years, training clinicians in using biomedical interventions, which have helped many. Dr. Rimland was also interested in research on various dietary treatments, such as a ketogenic diet, vitamin/mineral supplementation, and a gluten-free/casein-free diet. (Note of interest: Rimland was technical adviser for the movie *Rain Man*.)

Increase in the Number of Books and Websites by Those with Autism

Another important development is the increase in the number of websites created, blogs written, books authored, and curriculum developed by those who have ASD (for example, Temple Grandin, John Elder Robison, Valerie Paradiz, Brian King, Daniel Tammet, Judy Endow, Lynne Soraya, Michael John Carley, Liane Holliday Willey, Donna Williams, Stephen Shore, Jesse A. Saperstein, Zosia Zaks, and Jerry Newport). The insights the authors share about what sensations they are feeling, why they act the way they do, and what has helped them in their struggles give us a glimpse of what it can be like to have ASD and how we can help children on the spectrum.

In recent years, there have been more published writings by individuals on the spectrum who are unable to speak but who still have a lot of information to share, such as Sue Rubin; Tito Rajarshi Mukhopadhyay; my son, Jeremy Sicile-Kira; Peyton Goddard; D. J. Saverese; and Ido Kedar. Such accounts and their advice are invaluable to us in trying to understand the behaviors of individuals who are unable to communicate about themselves. Although it must be borne in mind that these experiences are personal, there are many similarities that these writers share that can guide us in helping those unable to speak for themselves.

Increase in Numbers

Another change in recent years is the dramatic rise in the number of individuals diagnosed with ASD, now said to be reaching epidemic proportions in the United States and in other countries as well. In the 1980s,

autism prevalence was considered 1 in 10,000. In March of 2012, the Centers for Disease Control and Prevention (CDC) Autism and Developmental Disabilities Monitoring (ADDM) Network released estimates that 1 in 88 children had been identified as having ASD. These figures were based on data collected in 2008. Then, one year later in March of 2013, the CDC released newer estimates that 1 in 50 American schoolchildren have autism.

The dramatic rise in autism was first reported in the 1990s, and continued into the 2000s. A U.S. Department of Education study from 1992 to 1997 reported a 173 percent increase in the number of children with autism in public schools, compared with a growth of all non-autism disabilities in the same population of just under 17 percent. In California, between 1987 and 2002, there was an increase of 634 percent in the number of people with autism in California's Developmental Services System (California Department of Developmental Services, April 2003). A study conducted in Atlanta showed that 1 in 300 children in metro Atlanta had autism in 1996, a rate almost ten times higher than the rates from studies conducted in the United States during the 1980s and early 1990s, but consistent with those of more recent studies (*Journal of the American Medical Association*, January 2003). Figures from the California Department of Developmental Services from 1987 to 2007 indicate that the number of people with ASD grew 1,148 percent. During this same time period, California's general population grew 27 percent (State of California, 2007).

Studies in the UK, Iceland, and Japan have all recorded incidence rates of autism much higher than previously assumed. Studies done since 1985 in Europe and Asia have found that as many as 60 out of every 10,000 children have ASD (CDC, December 2003). In the UK, in 1979, it was estimated that 35 children in 10,000 would be diagnosed with autism; by 1993, the figure had risen to 91 in 10,000 children, according to the National Autistic Society. (For more on the prevalence of ASD, see pages 35–39.)

Dramatic Shift in the Age of Onset

Another recent development is a dramatic shift in the age of onset of autism. According to data compiled by the Autism Research Institute, regressive, or late-onset, autism cases (in which a baby develops normally and begins to regress during his second year) currently outnumber early-onset cases by about five to one. This is in contrast to the 1950s, '60s, and '70s, when late-onset cases were almost unheard of.

Though some of the unprecedented rise in numbers can be attributed to changing definitions and better diagnosing, ASD is clearly the fastest-growing disability of the past two decades.

Autism as a Brain-Gut Connection

A possible connection between gastrointestinal dysfunction and autism was first hypothesized by Andrew Wakefield, a British former surgeon and medical researcher, in a paper based on twelve children published in the *Lancet* in 1998. In his paper, Wakefield explained his hypothesis of a relationship between childhood gastrointestinal disorders and autism in those given the MMR vaccine, typically administered to children between age twelve and fifteen months. Wakefield's belief was that the three vaccines (measles, mumps, rubella), when given together, could change the child's immune system. This would allow the measles virus in the vaccine to penetrate the intestines, and certain proteins that escaped from the intestines could extend to and harm neurons in the brain. Wakefield did not claim he had proved that the MMR vaccine caused autism, but this is what was interpreted by many.

The role of gastrointestinal dysfunction in patients with autism continues to be an important topic of research. GI problems can worsen a child's behavioral issues—it's hard to be on your best behavior when you are in pain. More research is needed on the gut-brain connection, but clearly parents of nonverbal children need to be aware that their child's behaviors may be an indication of underlying gastrointestinal problems that ought to be looked into.

Autism as Neurodiversity

At about the same time as Wakefield's hypothesis was published, Judy Singer, a sociologist on the autism spectrum, invented a new word, "neurodiversity," to describe conditions like autism, dyslexia, and ADHD. Singer's goal was to shift the focus about atypical ways of thinking and learning from deficits and impairments to diversity, convinced that many atypical forms of brain wiring also convey unusual skills and aptitudes.

The word "neurodiversity" first appeared in print in a 1998 *Atlantic* article by journalist Harvey Blume. In the article, Blume likened neurodiversity to biodiversity—crucial for the advancement of the human race.

The difference in opinion about autism brings to mind the Indian parable about the blind men and the elephant. A group of blind men touch an elephant to learn what it is like. Each one feels a different part, but only one part, such as the leg or the tusk or the trunk. Each one describes and names the elephant based on his experience of the part of the elephant he is feeling. Such is the nature of autism.

The parent of a teenager who is nonverbal, not toilet trained, and experiences meltdowns will never be convinced that autism is just a brain difference to be accepted. The parent of a young child who appeared perfectly healthy and then regressed at age two and has terrible gastrointestinal problems with ongoing daily bouts of diarrhea or constipation may consider autism a disease. On the other hand, the parent of a child with Asperger's who is independent and academically brilliant may view autism as a gift. The point is, they are all correct, based on their experience.

Changes in Labels and Definition

Over time, changes in how autism is diagnosed and labeled have occurred. In the fourth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV), published in 1994, the labels autism, Asperger's, pervasive developmental disorder (PDD), and PDD Not Otherwise Specified (PDD-NOS) were used, among others. These syndromes, and others that share some of the same symptoms, were placed under the umbrella term "autism spectrum disorders." Though the different ASDs

varied in the number and intensity of the behavioral symptoms they shared, it was still the same three broad areas that were impaired: social relationships, social communication, and restricted, repetitive patterns of behavior.

In May 2013, the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-V) was published. Now, the above labels have been removed—including Asperger's—leaving only the label of “autism spectrum disorder,” or autism. Challenges in social relationships and social communication have been combined under social/communication deficits. Restricted interests and repetitive behaviors now include mention of sensory challenges for the first time. For a more in-depth explanation of the DSM-V, go to page 29.

What remains the same is that characteristics of autism can be present in a wide variety of combinations. Two people, both diagnosed with the same label of “autism,” can have varying skills, deficits, and aptitudes. One of them could be severely incapacitated, the other might appear to be only a bit odd and lacking in social graces. People with the label of “ASD” can present a wide spectrum of abilities and deficits. What it all boils down to is that there is no standard type or typical person with ASD, just as there is no standard type of non-autistic or neurotypical individual.

The Future

Although we still do not know the exact causes of autism, the last few decades have been encouraging in the wealth of knowledge that has been acquired. Since the mid-1990s there have been tremendous advances in the field of technology and medical science. The field of neuroscience has grown tremendously in the last decade, giving us a greater understanding of the brain, the spinal cord, and networks of sensory nerve cells, or neurons, throughout the body, and how these relate to behaviors, reasoning, and emotions—all important to the understanding of autism.

We are learning more about genetic susceptibility, environmental triggers, the gut-brain connection, and the timing of exposure during periods of vulnerability for the developing nervous system.

The growth of parent- and professional-driven ASD organizations, coupled with the ease of access to the Internet, has ensured a strong lobbying force aimed at encouraging scientists and politicians alike to devote resources to research into the causes of ASD and how to help those with the condition. There are many notable scientists and professionals worldwide who have done much to advance our knowledge of ASD and continue to do so.

In the last two decades, the number of nonprofit organizations dedicated to autism has increased dramatically. Cure Autism Now (CAN), cofounded by Portia Iverson and Jon Shestack in 1995, was one of the largest private funders of biological research in autism, providing more than \$20 million for research grants, education, outreach, and scientific resources since its inception in 1995. In 2007, CAN merged with Autism Speaks.

Since its inception in 2005, Autism Speaks, cofounded by Suzanne and Bob Wright, grandparents of a child with autism, has grown into the foremost organization in the United States. The National Alliance for Autism Research (NAAR), founded in 1994, merged with Autism Speaks in 2006. Thanks to the Autism Society of America (ASA), the Autism Research Institute (ARI), UC Davis's MIND Institute, the Organization for Autism Research (OAR), and many other organizations and selfless advocates too numerous to mention, research is being funded, findings shared, and information disseminated to help those with autism of different ages and ability levels, and their families.

Among the newer national nonprofits are Talk About Curing Autism (TACA), National Autism Association (NAA), and Autism One. There are more organizations founded and directed by individuals on the spectrum, such as the Autistic Global Initiative (AGI), the Global Regional Asperger Syndrome Partnership (GRASP), ASAN, and AUTCOM.

The Special Needs Network (SNN) has been very effective in impacting public policy in California and in providing resources and information to the underserved families in South Los Angeles. Community-based organizations such as SNN are necessary to respond to the needs of the disenfranchised communities of color that often fall between the cracks. Studies show these children are often diagnosed later than their non-minority peers, misdiagnosed at a higher rate, labeled emotionally

disturbed, and often overmedicated. Many are denied insurance benefits, medical care and treatment, directly impacting their prognosis.

Although more research is needed, it is important to note that the discovery of many successful treatments, therapies, and strategies has been due to a strong collaboration between parents and medical professionals. Together they have formed a strong partnership, widening the prism through which autism is viewed and treated from the medical perspective. To them we owe a resounding thank-you.

2

What Is Autism Spectrum Disorder and How to Know If a Person Has ASD

All people like to put things into categories. I do so with my buttons, ribbons, and bits of colored glass. As for people, I had only ever truly felt there were two categories: “us” and “them.” Most people see things in these terms, too, but with different and more value-laden definitions.

—DONNA WILLIAMS, *Nobody Nowhere*

THE day my son’s diagnosis was confirmed is indelibly etched on my mind. I was in the TV studio where I worked producing a soap opera when the operator announced that I had a call waiting from the hospital. Although I felt sure that my son was not developing properly, the medical professionals had up until now refused to listen to my concerns.

Somehow I held it together while the dramatic love scene was being taped, gave my nod of approval to the director, and headed for my office to take the call. When I was given the news about my son, I felt stunned, shocked, and unable to breathe. Although I had felt there was something amiss, I had wanted to be proven wrong. Now it was acknowledged and I had to deal with that reality.

I went back down to the studio floor to finish taping the day’s show. Somehow I got through it. Over the next few days, it was a relief to go to work and throw myself into the make-believe drama, which now seemed quite ordinary compared to the real-life emotional drama I was living. After many weeks and many tears of frustration and sadness I thought that perhaps now, with a diagnosis, we could move forward.

Why Seek a Diagnosis?

If you have any concerns about your child, it is important that you consult with a medical professional who is experienced in assessing ASD.

Hopefully, you will have worried needlessly. But if not, it is important that you have a diagnosis as early as possible, in order to access services.

Research shows that early and intensive treatment works best in helping these children make sense of their world. Research shows that the earlier a child is started on a course of treatment or therapy, the better the prognosis. However, research also shows that our brains have neuroplasticity, which means that they continue to reorganize themselves by forming new neural connections throughout life. So, no matter the age, learning can still take place, and parents of older children should not be discouraged from trying different approaches to help their child.

If you are an adult and think you may be on the autism spectrum, just knowing there are others like you can bring an extra dimension to your life. There are now many nonprofit organizations run by adults on the spectrum. These are great places to get information or join online and in-person groups to meet others who may have some of the same strengths and challenges you experience.

In the past, people were hesitant about applying a label because the label of “autism” was permanent and signified that there was no hope or future for that person. This should no longer be the case. In the last two decades, there have been many improvements made in the field of autism with many new strategies and therapies available. Many children with autism can improve and even recover from any challenges that keep them from living productive and happy lives. We are also learning to identify the strengths that many on the autism spectrum have, and how to help each individual build on his or her talents.

Your Label to Use or Not

Having ASD diagnosed can open doors for you that would otherwise be closed. Your child may be eligible for early intervention services and

therapies from local agencies, treatment under medical insurance, and qualify for special education services. It will also allow the parent and professional to search out more knowledge on what to do, using the label as a starting point to gather information. However, you must remember that you, as the parent or the person with ASD, own the label. It is up to you to use it or disclose it when it is helpful, or not to use it if you are uncomfortable doing so, or if you feel it is not helpful or necessary. It is your information and your choice.

Be aware also that over time, the diagnostic criteria change, and the opinion of the experts as to what those criteria should be differs as well. So although a diagnosis is helpful and necessary to access services, as a parent you would do better to focus on the behavioral characteristics that tell you more about the child and how to help him than to get hung up on the diagnosis and what it means.

Sometimes it may take a long while for an official diagnosis to be reached. You will need the diagnosis to access services from government agencies; however, as a parent there are things you can be doing to help your child while you are waiting. Read Chapter 6, on family life, for suggestions in this area. This is also a good time to be doing your own research; see Chapters 3, 4, and 5.

Keep in mind that each person is unique, whether he or she has ASD or not, as Jerry Newport (an adult on the spectrum) reminds us with the title of his book, *Your Life Is Not a Label*.

Characteristics of Autism Spectrum Disorder

ASD is considered a neurodevelopmental disability, meaning that it affects the functioning of the brain. Autism typically appears during the first three years of life and is thought to be four times more prevalent in males than in females.

If the last two decades have been encouraging in terms of treatments and research findings, in the next decade we hope to know more about autism as the technologies used in neuro-imaging improve and more is understood about the brain–genetics connection. The diagnostic processes

of ASD are in a state of flux and constantly being improved as discoveries are made. What you have here is a road map of what is currently known and used.

At this point in time, there is no medical test to diagnose for ASD. Any diagnosis is based on observable characteristics, that is, the behavior that a person is exhibiting.

Because of the nature of the symptoms, ASD is sometimes difficult to diagnose at a very early age. If the child is their first, the parents have no experiences with which to compare. Seeing other toddlers and children develop differently, they may start to worry. When voicing these concerns to relatives, friends, or neighbors, the parent will often hear things like, “She’ll grow out of it.” Sometimes parents will talk to their doctor about their concerns regarding the child’s lack of verbal communication and eye contact, his failure to respond to his name, and his obsessive attachment to certain objects.

FOOD FOR THOUGHT

Getting Diagnosed

All the insecurities and frustrations I had carried for so many years were beginning to slip away. I had not imagined a thing. I was different. So was my little girl. Different, challenged even, but not bad or unable or incorrect. I understood my husband’s tears and his fear for our daughter’s future, but I did not relate to them. I knew my innate understanding of what the world of AS [Asperger’s syndrome] is like would help my daughter make her way through life. Together, we would find every answer either of us ever needed.

I had finally reached the end of my race to be normal. And that was exactly what I needed. A finish—an end to the pretending that had kept me running in circles for most of my life.

—Liane Holliday Willey, *Pretending to Be Normal*

In many cases, a baby will develop normally and then start to regress at around eighteen months. These children are usually easier to diagnose because of the obvious difference in past and present behaviors to which

parents and professionals can attest from looking at photos, watching videos, and comparing observations.

Some children have chronic ear infections, others may be showing allergic reactions. Many have intestinal issues—either chronic diarrhea or chronic constipation. Or a child may have constant rages and/or sleepless nights.

Often the parents may be concerned because their child is a walking encyclopedia on a particular topic (such as trains), plays obsessively in the same way with the same toy, or will eat only certain foods. Perhaps it is the kindergarten teacher who notices that he does not appear to engage in conversation with his classmates and has a difficult time with any change in routine. Or a child may be considered “naughty” at school because of certain behaviors, and perhaps the parents haven’t noticed anything amiss because he is an only child, or they think that boys mature less quickly than girls. This may be true, but it is better to be sure and investigate your concerns.

FOOD FOR THOUGHT

How I Got the Doctor’s Attention

When my son was a baby, I worried because he would sit rather floppily, content to play with the same toy in the same spot for hours, enabling me to get a lot of my pre-production work done. When I shared my fears with family and friends, they inevitably replied, “So he takes after his dad! Not everyone has to be as energetic as you. He’s a calm baby. Just be happy you can get your work done.” The pediatrician was not very supportive of my concerns, so I invited him to my son’s first birthday party. Seeing the contrast between my son and a room full of healthy babies, he was forced to face the fact that some tests might be in order.

The doctor may be hesitant to jump to any conclusions, because not all reported observations are necessarily objective and they can be interpreted in different ways. Everyone knows someone who was a late talker. On the other hand, a parent may not listen to concerns voiced by a child-care

worker, a teacher, or a neighbor. This is unfortunate because the earlier the diagnosis, the sooner the intervention, the better the prognosis.

Some people with ASD may reach adulthood without ever having been diagnosed. They may have always felt as if they were not on the same wavelength as others socially, emotionally, or sensorially. Perhaps they exhibit some of the characteristics listed on pages 24–27. In such a case, having a diagnosis would be useful in putting them in touch with information and organizations that may be able to help them.

FOOD FOR THOUGHT

Does This Person Have Autism?

Advice to parents: Follow your instincts. You are the expert on your child. Take notes on whatever behaviors (see below) are of concern by keeping a notebook or a document listing the behaviors and their frequency. Look at the CDC's Act Early website, cdc.gov/ncbddd/actearly/index.html. Check out the developmental milestones appropriate for your child's age range. You may want to print it out and use it as a checklist. This will be useful when discussing with your pediatrician. Another good site with a speech and language milestone chart is LD online, ldonline.org/article/6313.

If you have any concerns, voice them to your family doctor. You will need to have your child seen and evaluated by a good diagnostician in your area who is knowledgeable about autism. It is better to have your child checked out than to lose precious time waiting for him to "grow out of it."

Advice to medical practitioners, educators, and other professionals: Take care how you voice your concerns, but do voice them. See the website listed above for developmental milestones if you have concerns about a student. Find out who the local and experienced diagnosticians are in your area.

Behavioral Characteristics of ASD

A word of caution: This list is not meant to be a diagnostic checklist, but is intended to give you some ideas of the types of behaviors someone with autism may exhibit. Remember, it is the number and severity of these behaviors that may lead to talks with a professional about performing a diagnostic assessment (see "Diagnostic Criteria" on pages 27–31).

Some of these behaviors are seen on one end of the spectrum (e.g., classic autism), others on the opposite end (e.g., high-functioning autism, or what was labeled “Asperger’s syndrome” prior to the release of the DSM-V in May 2013).

IMPAIRMENT OF SOCIAL COMMUNICATION AND INTERACTION

As a baby, does not reach out to be held by mother or seek cuddling

Does not imitate others

Uses adult as a means to get wanted object, without interacting with adult as a person

Does not develop age-appropriate peer relationships

Lack of spontaneous sharing of interests with others

Difficulty in mixing with others

Prefers to be alone

Has an aloof manner

Little or no eye contact

Detached from feelings of others

Does not develop speech, or develops an alternative method of communication such as pointing and gesturing

Has speech, then loses it

Repeats words or phrases instead of using normal language (echolalia)

Speaks on very narrowly focused topics

Difficulty in talking about abstract concepts

Lack or impairment of conversational skills

SEEKING OF SAMENESS

Inappropriate attachment to objects

Obsessive odd play with toys or objects (lines up or spins continually)

Does not like change in routine or environment (going to a different place, furniture moved in house)

Will eat only certain foods

Will use only the same object (same plate or cup, same clothes)

Repetitive motor movements (rocking, hand flapping)

OTHER CHARACTERISTICS

Peculiar voice characteristics (flat monotone or high pitch)

Does not reach developmental milestones in neurotypical time frame or sequence

Low muscle tone

Uneven fine and gross motor skills

Covers ears

Does not respond to noise or name, acts deaf

Does not react to pain

Becomes stiff when held, does not like to be touched

Becomes hyperactive or totally nonresponsive in noisy or very bright environments

Eats or chews on unusual things

Puts objects to nose to smell them

Removes clothes often

Hits or bites self (hits head or slaps thighs or chest)

Whirls himself like a top

Has temper tantrums for no apparent reason and is difficult to calm down

Hits or bites others

Lacks common sense

Does not appear to understand simple requests

Frequent diarrhea, upset stomach, or constipation

Many of these behaviors are the person's responses to how he or she is processing the immediate environment. The typical meaning behind certain behaviors is discussed in Chapter 3.

Diagnostic Criteria

With the constant improvements in technology and advances in the field of science, screening for autism at an earlier age is possible. However, at this point in time there is not one specific objective or medical assessment that can be given to a baby, child, or adult to diagnose ASD. Rather, there exist different medical tests that can either rule out other conditions or help ascertain whether or not an individual might have autism.

Medical Tests

The following are suggested medical tests for the purpose of assessing a child with autism, eliminating other possible reasons for the person's behavior, or to see if other specific disorders and developmental disabilities exist. The medical professional you consult may suggest other tests as well. Keep in mind that after a diagnosis, other evaluations and assessments will be necessary to give you the information you need to form a plan of treatment.

- *Developmental screening.* During routine well-child visits, development screening is a way to tell if a child is learning basic skills when he or she should be. During developmental screening the doctor observes and interacts with the child, and asks the parent questions. The doctor is looking to see how the child learns, speaks, behaves, and moves and if the child has reached his developmental milestones or not. A delay in any area could be a sign of a problem. When such a screening—or a parent—raises concerns about a child’s development, the doctor should refer the child to a specialist in developmental evaluation and early intervention. These evaluations should include hearing and lead exposure tests as well as an autism-specific screening tool, such as the M-CHAT. Among these screening tools are several geared toward older children.
- *Magnetic resonance imaging (MRI).* Magnetic sensing equipment creates, in extremely fine detail, an image of the brain. Many advancements continue to be made in this technology. At the time of this writing, MRIs are not used for screening for autism, although some research indicates that MRIs may show differences in the brain resulting from autism.
- *Electroencephalogram (EEG).* An EEG can detect tumors or other brain abnormalities. It also measures brain waves that can show seizure disorders. At the time of this writing, there is research indicating that EEGs may become a useful tool for detecting autism.
- *Genetic testing.* There is a gene test that uses a cheek swab to screen infants and toddlers for sixty-five genetic markers associated with autism. This test was developed to be used by families who already have one child with autism. However, at the time of this writing, this test only identifies an estimated 10 percent of possible genetic markers. Technology is improving in this area.
- *Metabolic screening.* Blood and urine lab tests measure how a child metabolizes food and its impact on growth and development. In particular, these should be considered when a child appears to be regressing, or other clinical evidence shows there might be a problem.

- *Lead level test.* Children who have pica (eating nonnutritive substances, such as dirt) should have their lead levels checked.

Diagnostic and Statistical Manual of Mental Disorders (DSM-V)

The DSM, the medical diagnostic handbook, is in its fifth edition. The DSM is used to identify and diagnose mental disorders, and to code for insurance reimbursements. The professional assessing your child will be diagnosing—or not—depending on the criteria specified in the DSM.

The American Psychiatric Association (APA) released the latest version of the DSM, referred to as the DSM-V or DSM-5, in May 2013, after ten years of work on revising the criteria for the diagnosis and classification of mental disorders. In the DSM-V, changes have been made in the criteria needed for a diagnosis of ASD. The new criteria is considered more thorough and strict compared to the older diagnostic criteria, according to the APA. As well, a reorganization of criteria has taken place. In the DSM-IV, the domains for autistic disorder included impairments in communication, social interaction, and restricted interests and repetitive behaviors. In the DSM-V, the communication and social interaction domains are combined into one, social/communication deficits. Additionally, a delay in language development is no longer a requirement for a diagnosis of ASD.

Under the definition of “autism” in the DSM-IV, patients were diagnosed under four separate disorders: autistic disorder, Asperger’s disorder, childhood disintegrative disorder, or pervasive developmental disorder not otherwise specified. In the DSM-V, these separate disorders do not exist. This has created some controversy among parents and professionals in the autism community, especially with regard to removing Asperger’s syndrome as a disorder. Those involved with rewriting the DSM-V definition believe that the individuals diagnosed with one of the four pervasive developmental disorders (PDD) from DSM-IV should still meet the criteria for ASD in DSM-V or another, more accurate DSM-V diagnosis.

In the DSM-V, the diagnostic criteria for ASD is the following:

1. Persistent deficits in social communication and social interaction across multiple contexts in areas described below, that the individual currently displays or did in the past:
 - a. Deficits in social-emotional reciprocity (for example, failure to carry on a back-and-forth conversation, failure to initiate or respond to social interaction, not having appropriate social approach behaviors).
 - b. Deficits in nonverbal communicative behaviors used for social interactions (for example, abnormalities in eye contact and body language, lack of facial expressions).
 - c. Deficits in developing, maintaining, and understanding relationships (for example, difficulties in adjusting behavior to suit various contexts, difficulties in sharing imaginative play or making friends).
2. Restricted, repetitive patterns of behavior, interests, or activities as demonstrated by two of the following, that the individual currently displays or did in the past:
 - a. Stereotyped or repetitive motor behaviors, use of objects, or speech (for example, lining up toys, echolalia).
 - b. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal speech (for example, difficulties in moments of transition, insistence on same food).
 - c. Highly restricted, fixated interests that are abnormal in intensity or focus (for example, strong preoccupation with or attachment to unusual interests or objects).
 - d. Hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment (for example, does not appear to feel extreme cold or heat, excessive touching or smelling of objects).

It is important to recognize that for a diagnosis of ASD to be given:

1. The symptoms must be present in the early developmental period;
2. The symptoms must be severe enough to cause clinically significant impairment in social, occupational, or other important areas of functioning; and
3. The symptoms would not be better explained by intellectual disability or global developmental disability.

Comorbidity

A person may be diagnosed with ASD and still have other existing medical or psychiatric conditions. In medical terms, “comorbidity” is the presence of one or more conditions along with the primary diagnosis. Research indicates that 70 percent of individuals with autism also have one or more comorbid mental disorders, and 40 percent may have two or more comorbid mental disorders, according to the DSM-V. For example, an individual with a diagnosis of autism could well have ADHD, anxiety disorders, and depressive disorders. If an individual with autism is nonverbal or has low communication skills, observable signs, such as changes in eating and sleeping or increases in challenging behaviors, should be considered as possible signs of depression or anxiety.

FOOD FOR THOUGHT

Parents' Attitude Is Everything

BY MICHAEL JOHN CARLEY

No matter where your child is diagnosed on the spectrum—whether it's a nonverbal son or daughter, or a brilliant but awkward kid who doesn't understand social nuances—the attitude you have about your child's condition may actually play a far bigger role in their development than the diagnosis itself.

Children on the spectrum grow up hearing contrasting messages through the media, friends, family, etc., and by being in a behavioral minority they are beginning life at a psychological disadvantage. When they hear words like “cure,” “disease,” or other words that convey an impression that something is wrong with them, this only lessens their capacity for confidence and self-esteem. But when they hear messages of potential, words that talk about what they *can* do as opposed to what they can’t do, then there is hope and potential . . . as it would be for any of us.

This is not meant as feel-good, self-help spin or sociologically forced PC terminology—nor is it meant to invalidate the very real challenges that can often accompany the diagnosis. It is simply an indisputable notion that if an individual of any kind is surrounded by a community showing belief in them . . . they have a shot. Even the most significantly challenged children should be treated in this way because we still do not know how much they take in. They don’t communicate with us much so we don’t see any ability therein to hear what we say. But just because we don’t see it doesn’t mean it doesn’t exist. What parent would risk that?

So how do you accomplish this, especially if you see the diagnosis as tragic? First off, you find a parents support network. Whether in the form of a face-to-face monthly meeting organized by a local autism organization, coffee with a fellow parent of a child on the spectrum, or through an online support group, you will need to vent. You will need to unburden yourself, and maybe you’ll even need to denounce the very nature of remaining positive. But to vent as such in front of the child will do harm.

Second, take care of yourself. There’s a reason why, on airplanes, they tell you in the safety demonstration to put the oxygen mask on yourself first before putting it on your child. What this translates to is simply the old adage that you can’t help others until you first help yourself. Common wisdom applies herein as well: exercising regularly; eating healthy; not letting your job/daily duties get to you too much; and if you’re in a reciprocated romantic relationship, get away for a weekend every once in a while. If you’ve accomplished the first step of finding a community of fellow parents, such groups often arrange to trade babysitting services.

Third, study the history. What is a hard concept to grasp without some work is the notion that prognoses keep getting better. Amid all the political infighting that exists in the autism world, incredible progress has been made in our collective ability to educate young people on the spectrum. Few of the children diagnosed from the late 1990s to the early 2000s met their initial expectations: The vast majority well exceeded them because we all kept getting smarter. Odds are that your child will go beyond the first predictions, too.

Fourth, surround yourself with fellow positive thinkers. Other parents who lament, “My son/daughter will never . . .” are not thinking clearly. Other parents who say, “I love my child, but I hate what he has” are simply trying to justify their harmful attitudes (not to mention the mixed messages they may be inadvertently sending to their child). Loved ones who say hurtful things are simply not as educated as you, and fellow shoppers at the supermarket who cast critical eyes on your parenting are to be relegated to the mental trash bin.

But those with whom you can share the love and appreciation you have for your child are to be treasured. Life will be different for you, and life will be harder, not easier, for your child; but great, big-picture opportunity exists herein. Find your community.

*Michael John Carley is the founder of GRASP (grasp.org), the executive director of ASTEP (asperger-employment.org), and the author of *Asperger's from the Inside Out*. A former diplomat who worked in places such as Bosnia and Iraq, he and his then-four-year-old son were diagnosed with Asperger's syndrome in late 2000. He lives in Brooklyn, New York, with his wife and two boys.*

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What Causes Autism Spectrum Disorder and Why Do People with ASD Act the Way They Do?

Men and women are puzzled by everything I do. My parents and those who love me are embarrassed and worried. Doctors use different terminologies to describe me. I just wonder. The thoughts are bigger than my expressions to get a shape. Every move that I make interprets my helpless way to show how trapped I feel in the continuous flow of happenings. The happenings occur in a way that shows the continuity of cause and effect. The effect of a cause becomes the cause of another effect. And I wonder . . .

—TITO RAJARSHI MUKHOPADHYAY, *The Mind Tree*

IT used to be that autism was pretty rare. Eighteen years ago, if I mentioned the word “autism,” people would have heard of it, but nobody had ever encountered it except at the cinema by watching *Rain Man*. Now it seems everyone is related to or lives next door to someone with ASD. More recently I had to take my son to the emergency room at the local hospital. While we were sitting in the waiting room one woman looked at us and turned to her companion, saying, “Seeing that young man over there reminds me, how is your friend’s nephew doing, the one with autism?” Then we got called in for X-rays and the technician looked at Jeremy and said, “So, what school district do you live in? Were you happy with his program? My son’s ten and we finally got what he needed at school for him.” When we got home, I called the airline to confirm reservations for a summer family vacation. When I told the reservation clerk I would be

traveling with someone with autism and needed to make special seating arrangements, she said, “Don’t say another word, dear, I know just what you need. My cousin’s son has autism. . . .”

It’s an Epidemic

There has been much discussion over the past fifteen years about the reason for the rise in the numbers of those diagnosed with ASD in the United States, the UK, and other parts of the world. Some have argued that ASD is diagnosed better and earlier, resulting in higher figures than before. However, now it is generally agreed that there is a true increase in the number of children with autism. In order to have a better understanding of what is actually occurring, a close look at some official numbers and reports is in order.

Numbers in the United States

Figures from the California Department of Developmental Disabilities are often quoted because of the strict record-keeping necessitated by state laws. California is required under the Lanterman Developmental Disabilities Act to provide services to persons with developmental disabilities. These services are provided through regional centers that must keep accurate data on the number and type of clients they serve. The criteria for diagnosing cases are strictly adhered to, and have not changed over time.

The Department of Developmental Services is required (for budgetary reasons) to report to the legislature the incidence of autism and pervasive developmental disorders compared with other developmental disabilities. In March 1999, the department reported to the legislature that the numbers of persons entering the system and receiving services had jumped 210 percent between 1987 and 1998 (“Changes in the Population of Persons with Autism and Pervasive Developmental Disorders in California’s Developmental Services System: 1987–1998”). The California legislature was surprised and concerned by these findings.

Debate immediately started among autism experts, government officials, and parent-driven organizations on why such high figures were being recorded in California, as well as in the UK and other parts of the world. Some discounted the increasing rates of ASD, attributing the rise to better and earlier diagnosis, a change in definition that now encompassed the more able and those with Asperger's, and a migration to certain areas for better services.

The legislature therefore commissioned the University of California's Medical Investigation of Neurodevelopmental Disorders (MIND) Institute to investigate these findings. In October 2002, Dr. Robert S. Byrd and his colleagues reported back with results that made headlines all around the world.

Byrd and his colleagues found that the huge jump in autism rates from 2,778 in 1987 to 10,360 in 1998 could not be explained by changes in the criteria used to diagnose autism, or by an increased migration to California of children with autism. Nor could it be explained by statistical anomalies. The report also found that parents' reports of regression at an early age did not differ between the two different age groups studied; however, more parents of the younger group reported gastrointestinal symptoms in the child's first fifteen months of life.

Dr. Byrd's study clearly showed a tremendous increase in autism in California for some unknown reason.

Meanwhile, figures released by the California Department of Developmental Services show that the trend continues. From 1987 to 2007, the number of people with ASD grew 1,148 percent. This is significant when compared to increases of 66 percent for epilepsy, 73 percent for cerebral palsy, and 95 percent for mental retardation. During this same time period, California's general population grew 27 percent (State of California, 2007).

The federal government is also concerned about the increase of autism diagnosis and what it really means. This concern is reflected in time, money, and energy now being spent on finding out all we can on ASD. Some examples of what the government is doing:

- More and more money has been allocated to autism research by the government. The National Institutes of Health spent an estimated \$169 million on direct autism research in 2012, compared with \$81.3 million on autism research in fiscal year 2003 and \$9.6 million ten years earlier in 1993. However, \$169 million represents only 0.55 percent of the total national NIH budget of \$30.86 billion. In fiscal years 2007 and 2008, NIH began funding the eleven Autism Centers of Excellence (ACE). The ACEs are investigating different aspects of autism, including early brain development and functioning, social interactions in infants, rare genetic variants and mutations, associations between autism-related genes and physical traits, possible environmental risk factors and biomarkers, and a potential new medication treatment.
- In 1998, the Centers for Disease Control and Prevention included autism in the developmental disabilities surveillance program based in Atlanta and then began to monitor the prevalence of ASD in numerous states, and will continue to do so for many years. The Study to Explore Early Development (SEED) was designed to be a multisite collaborative study on autism and other developmental disabilities. SEED is looking at behavioral, physical, and medical conditions, as well as risk factors.
- The Coalition for Autism Research and Education (CARE), the Congressional Autism Caucus, was started in 2001 and it is still going strong. It is the first Congressional Member Organization to focus on ASD, and has members from most states. Its focus is to teach members of Congress about ASD and to improve research, education, and support services for people who have ASD.
- The Combating Autism Reauthorization Act, Public Law 112-32, signed into law in September 2011 by President Obama, continues important investments in research, early detection, supports, and services for children and adults on the autism spectrum. It also reauthorized the Interagency Autism Coordinating Committee (IACC), a federal advisory committee that includes both federal and public members. The IACC coordinates all efforts within the Department of

Health and Human Services concerning autism and advises the Secretary of Health and Human Services.

- The Institute of Medicine (IOM), a branch of the National Academy of Sciences, established an independent expert committee to review immunization safety concerns about a possible vaccine–autism connection

Elsewhere in the World

In Canada, the rate of ASD was 1 in 286 for the years 2000–2001, an average based on figures from the provincial departments of education. They also reported an average increase of 63 percent over a two-year period (Autism Society Canada). Findings from the National Epidemiologic Database for the Study of Autism in Canada (NEDSAC) published in March 2012 showed changes in the prevalence of ASD in Newfoundland and Labrador, Prince Edward Island, and southeastern Ontario. Data was taken between 2003 and 2008. The prevalence of ASD increased in all regions studied and in all age groups. The percent increases in prevalence ranged from 39 to 204, based on a comparison of the first and last years of the study period.

According to the National Autistic Society (NAS) in the UK, the indication from recent studies is that a prevalence rate of around 1 in 100 is a best estimate of the prevalence of ASD in children. No prevalence studies have been carried out on adults. This is in contrast to the 1993 estimate of 91 in 10,000 children and 35 per 10,000 in 1979.

What Causes Autism Spectrum Disorder?

In response to the question, “What causes ASD?” I am sorely tempted to reply, “We still don’t know,” and move on to the next chapter. However, there have been many advances made in research in recent years. Although we have no clear-cut answer, we have some plausible hypotheses, and

scientists, with the help of new technology, are beginning to make connections that will eventually help those seeking treatment.

What Does Not Cause ASD?

It is infinitely easier to talk about what we know does not cause ASD. It is known for a fact that ASD cannot be “caught” through osmosis, dirty doorknobs, or bad parenting. Other than that, nothing can be said for sure.

What We Think We Know

In the ten years since this book was first published, much research has been done regarding what causes autism, and how best to help those needing treatment. In one sense, it feels like *Plus ça change, plus c'est la même chose* (The more it changes, the more it stays the same), because we still don't know what causes autism and we can't prescribe one magic bullet for all.

It's becoming clearer and clearer that we should be talking about “autisms” and not one autism, because although people may share the same label, they can be completely different. Thus the reason there are discussions about whether or not autism is a disease that needs to be cured, or a brain difference—a neurodiversity—that should be celebrated as a gift. The answer is that it depends on the individual. As is often said in the autism community, “When you've seen one autistic person, you've seen one autistic person.”

However, advances are being made in neuroscience, genetics, and the study of environmental factors to help us better understand both causes and treatment options.

Where to Get Updates on the Latest Research

What follows is by no means an exhaustive look at the science behind the causes of autism. Research studies are being published often. The interested

reader can follow on a regular basis the latest discoveries and ongoing research. As mentioned earlier, it is best to read the actual study or report than to read summaries and news releases. In order to gain an understanding of this highly controversial topic, please consult a wide variety of websites and journals such as those listed below and form your own opinions:

- Use the National Library of Medicine Pubmed (nlm.nih.gov) search engine to find abstracts of any research articles you are interested in reading concerning autism. There are tutorials on the site with instructions for more advanced search techniques. Some abstracts will link you to the full article on the website of the journal where it is published. Some journals will provide full text for free, while others require a subscription or fee.
- Autism Speaks has information on its website (autismspeaks.org), and you can sign up to receive a biweekly science digest.
- The Autism Research Institute (ARI) website (autism.com) has information on various research studies. They also publish a quarterly newsletter with summaries of current research.

FOOD FOR THOUGHT

Developing a Critical Mind

The reader needs to be aware that, unfortunately, just as in every field, there are politics and money at stake in autism and science. Each organization and government body has its own interpretation of research studies and what they mean. Scientists are quick to point out flaws in studies by other scientists that do not report findings they agree with. Sometimes they are right. This means that we all need to develop critical thinking skills and an analytical mind-set.

Never rely on the media to tell you the full story on research findings. For example, in 2001, media reports and newspaper headlines and articles were saying that a report published by the Institute of Medicine (IOM) said that no link had been found between autism and vaccinations. Also stated in the report (but left unmentioned by the media) was that a possibility of a connection between the MMR (measles-mumps-rubella) vaccine and autism could not be disproved for a small number of children. However, when the media quoted that same IOM report in 2004, this possibility of a connection between vaccines

and autism was mentioned as one of the reasons why the IOM was again examining this issue.

To form your own educated opinion on any topic, always go straight to the horse's mouth. With the Internet, access to information is easy, cheap, and available to all. Unfortunately, it is also easy to spread misinformation. Make sure you are reading from websites that clearly state their sources, and make sure they are reputable ones. When looking at research studies, go to the original source. For those who are computerless, your library awaits you.

A Look at the Advances in Research over the Last Decade

It appears most likely that there is a genetic predisposition interacting with environmental factors that may play a key role in affecting the gastrointestinal tract, the immune system, the sensory nervous system, and the brain. There are differences in each case that can be triggers for some but not for all.

Neuroscience: The Brain

Autism, like many diseases including epilepsy, was at first considered a psychiatric challenge (in the mind) and is now viewed as a neurological challenge (in the brain). Advances in technology have increased our knowledge about brain structures. For example:

- Neuroimaging can't tell us everything, but it can tell us a lot, and the capability of technology has improved drastically in the last decade. Since 1970, structural magnetic resonance imaging (MRI) has provided us with views of the anatomical structures of the brain.
- Introduced in 1991, functional MRI (fMRI) has demonstrated how the brain functions in response to sensory stimuli. Over the past couple of decades, neurological research using fMRI has produced 20,000 peer-reviewed articles. In recent years, that pace has accelerated to eight or more articles a day.
- Since 2012, a new technology—high-definition fiber tracking (HDFT), developed at the Learning Research and Development Center at the

University of Pittsburgh—now does for brain injury what X-rays do for orthopedic injury. The focus of this new technology has so far has been on brain injury: It makes diagnosis more precise as well as more persuasive. Now, scientists are using this technology to research the autistic brain.

- In *The Autistic Brain*, Temple Grandin and Richard Panek ask the question, “What if some neuroanatomical finding or combination of them could serve as a reliable diagnostic tool?” A diagnosis based not only on behaviors but on biology as well would make a big difference in predicting deficits and targeting treatments. Doctors could:
 - Apply early intervention even in early infancy when the brain is most susceptible to being rewired
 - Target areas in the brain more locally, rehabilitating parts of the brain they think they can help
 - Test new therapies and monitor existing therapies more closely
 - Tailor a prognosis to an individual child on a case-by-case scenario

Genetics: What Do Genes Have to Do with It?

So, what is the connection of the genes to autism and to the brain?

- Like neuroimaging, the study of this science is in its infancy and scientists are beginning to understand the connections.
- In 1977, the first study of twins and autism was published and the gene connection was still open to question then. The DNA at conception might be identical at birth, but genes might work differently in each cell, or the genotype might not be identical at birth due to spontaneous mutations during the pregnancy. In 2007, a study published in *Science* concluded that de novo CNVs (copy number variants) pose a more significant risk factor for ASD than previously recognized. At first, scientists hoped to see patterns. But the picture remains hazy.

But How Are Our Brains and Our Genes Connected, and What About Environmental Impacts?

- It is widely accepted that there are multiple environmental factors that can trigger a genetic predisposition resulting in a condition or disease.
- In 2011, the first investigation by Childhood Autism Risks from Genetics and Environment (CHARGE), a research program of the MIND institute at UCSD, was divided into three areas—nutrition, air pollution, and pesticides. The results:
 - Combination of certain unfavorable genes and a mother's lack of vitamin supplementation in three months prior to conception and during first month of pregnancy significantly increased the risk for autism.
 - Children born to moms living less than two blocks from a freeway were more likely to have autism, presumably due to exposure to automotive exhaust.
 - Among the mothers of children with ASD or developmental delays, more than 20 percent were obese; in typically developing kids, 14 percent were obese.

And What About a Possible Connection to Vaccines?

- Some children have been known to get very sick and manifest severe symptoms consistent with autism shortly after receiving their eighteen-month vaccines. In many of these cases, the correct diagnosis could turn out to be mitochondrial disease, a condition whose symptoms can be consistent with autism.
- It's important to recognize that vaccines in and of themselves don't cause autism. However, as we are discovering with genetic research and neurology, we don't know which kids are susceptible to vaccines as an environmental impact.

NEVER UNDERESTIMATE THE POWER OF PARENTS

NAA: Making a Difference on a National Level

BY WENDY FOURNIER

In 2003, a small group of parents came together to form the National Autism Association (NAA). As I write this, we're approaching our tenth anniversary of service to families affected by autism.

Because NAA was founded—and has always been run—by parents, we know firsthand the struggles that families face. The moment my daughter was diagnosed is burned into my soul. I heard the doctor's words, delivered without compassion or a shred of hope, and cried the first of countless tears when he left the room. Grief and fear consumed me. As a mom, I just wanted to kiss my daughter and make everything all better, but I had no idea how to help her. I knew absolutely nothing about autism and the thought of failing her terrified me. I had to dig deep to find the strength that would carry us both through the uncertain journey ahead. I soon wiped away the tears, connected with other parents, and started learning everything I could to help my daughter.

Back then, we were all struggling to find information, resources, and treatment for our own children and saw the need for an organization that could advocate on a national level to make the journey a little easier for families like ours. NAA was started from home computers and living rooms, focused on the most important issues facing our community. We help families in many ways. Sometimes with information and guidance or financial assistance. Sometimes by simply lending an understanding ear to someone who feels alone and is having trouble coping.

We host our National Autism Conference each November, where families can connect with one another and learn about the latest trends in treatment, therapies, research, and advocacy. We've brought the issue of wandering and elopement to the national forefront and created extensive resources to help keep our loved ones safe. And we are always working on national advocacy efforts to help our children and adults with autism have the best future possible.

We've also learned some very tough lessons along the way. We lost our founder and dear friend Jo Pike to cancer at only forty-four years old. And I recently suffered a heart attack and went into cardiac arrest—staring my biggest fear in the face: *What will happen to my daughter when I'm gone?* So please remember as you embark on this journey that you must also take care of yourself. A great friend once told me that having a child with autism is a marathon, not a sprint. Truer words have never been spoken. Listen to your body, eat well, get enough rest, and schedule some downtime for yourself. Go have coffee with a friend, see a movie, read a good book—without the word “autism” in it—crank up your favorite music and dance around the kitchen, take a walk or a bubble bath. If only for a few minutes, rejuvenate and care for yourself.

An autism diagnosis can take an emotional toll on the entire family. Our lives can sometimes feel like a never-ending roller coaster. For many of us, it begins with denial and shock, and turns to grief, fear, anger, guilt, and constant worry. But even in the darkest of times, hope—or “hopeism,” as we call it—sustains us.

We experience pure joy in every milestone our children meet. We celebrate the wonderful little moments that many other parents simply can't appreciate in the same way. I'll never forget the first time my daughter grabbed a crayon and scribbled on the wall, the first Christmas that she was interested in opening gifts, the first time she blew out the candles on her birthday cake, or the first time she *really* hugged me back. I'm smiling now, as I think of those moments that will come for you—and they will!

Reach out to other parents and surround yourself with people who are positive and supportive. Always trust your gut and follow your instincts—you know your child better than any doctor, teacher, or therapist in the world. And remember, if a few moms were able to start a national organization from their living rooms, you should never, ever underestimate yourself. You are so much stronger than you might think. Christopher Reeve once said, “Once you choose hope, anything's possible.” Go grab a crayon and write that on your own wall!

Wendy Fournier is a mom of three and president of the National Autism Association (nationalautism.org). Her youngest daughter was diagnosed with autism in 2002. Wendy is committed to changing the perspective of autism from what was once considered a mysterious mental illness to a biologically definable and treatable medical disorder. She attends and speaks at conferences throughout the United States.

Vaccinations and Autism: Is There a Connection?

The possibility of a vaccination–autism connection is highly controversial, and the debate is ongoing. On one side, there is a growing tendency to blame the increased numbers of required or suggested vaccinations as well as the tendency to give multiple vaccines in one shot for all the cases of regressive autism in the past twenty years (regressive autism is autism that appears in a child at around the age of eighteen months, after a normal development, causing the child to regress). However, vaccinations in themselves do not cause autism, or millions more children would be autistic. Neither does thimerosal, an organic compound present in some vaccinations. But perhaps these are triggers for children who are genetically

predisposed to have autism and who have immune systems that are not functioning properly.

On the other side are the government and the vaccine manufacturers stating that vaccines are safe, and that those refusing to vaccinate their children are putting the public's health at risk.

NEVER UNDERESTIMATE THE POWER OF PARENTS

NFAR: Making a Difference in Our Community

BY SHARON AND JUAN LEON

When our oldest son, Michael, was diagnosed with autism in 1996, we knew very little about this disorder. At the time, we felt very alone. We never would have imagined that our son would be just one of the hundreds of thousands of children to be diagnosed with autism over the next decade.

Michael was diagnosed at a time when few treatment programs were available. Applied behavior analysis (ABA) types of programs were emerging and were not yet an approved treatment methodology for autism. As Michael's parents, we had to determine if we were going to create some sort of treatment program for him. After some investigation, we hired, trained, and set up an ABA-based home behavioral program. Luckily, it wasn't long before these types of treatments became more widely accepted and offered, and we were able to continue his program with funding assistance.

Throughout our son's development, we have learned how to advocate for services to get his needs met. But we have also realized that we have been fortunate. At the time, I was able to be a stay-at-home mother and could be there to manage Michael's treatments. We had the resources available to seek outside medical assistance, to try promising new therapies, and to hire legal counsel when needed.

As Michael grew, we watched the incidence rate for autism jump from 1 in 2,500 children to 1 in 110 children, and we kept wondering if anyone was paying attention to these staggering statistics. But the truth is, these aren't just statistics. They are young children and their families, whose lives have been dramatically changed by the effects of autism.

In December 2003, we founded the National Foundation for Autism Research (NFAR) because, as parents, we wanted more answers and resources for families and children in the autism community. We wanted to see effective treatments, resources, and opportunities made available to all families—regardless of income level. Our desire was to see a standardized practice of early detection and intervention programs made available across communities when treatment is most beneficial. And we wanted to see appropriate programs

and supports made available to teens and young adults that would allow them to reach their potential.

Through NFAR and our fund-raising efforts, such as our annual Race for Autism, we are funding community-outreach efforts, pilot treatment projects, and educational and transitional programs. NFAR is working to optimize the learning environment for children with autism during school-time hours through our grant programs. And we are providing funds for programs that work with the underserved communities in San Diego. But there is still much to be done.

Today, our son is continuing to make progress, and he has plans for his future. We want to give him those opportunities. And we want to help other families have multiple possibilities for their children with autism as well. We know that children with autism deserve a future, and by working together, we can make this possible.

Juan and Sharon Leon are cofounders of the National Foundation for Autism Research (NFAR) (nfar.org), a 501(c)3 nonprofit organization dedicated to the development of innovative treatment programs and options that improve the quality of life for children with ASD.

It is difficult for the average person to form an educated opinion just from reading the newspaper headlines. To be sure, there is valid concern about the serious risk to public safety if children are not immunized. Until recently, mumps and measles were practically nonexistent, and these diseases pose serious threats to children. In the UK, the number of cases of measles has been climbing.

To Learn More About Vaccines

Obviously, there is an urgent need for more research into vaccinations and a possible connection with ASD. Meanwhile, parents need to educate themselves by going to different sources and reading for themselves. As always, keep in mind each organization's or agency's mission when reading any articles or reports or analyzing research.

Any decisions regarding vaccinations should be discussed with your family physician. There are sources of information parents can look at to find alternative vaccination schedules, such as:

- The National Vaccine Information Center (NVIC) (909shot.com), a nonprofit educational organization founded in 1982, is the oldest and largest parent-led group in the United States advocating reformation of the mass vaccination system. NVIC is responsible for launching the vaccine safety movement in America in the early 1980s.
- SafeMinds (safeminds.org) is a nonprofit organization that works aggressively with government agencies and legislators to facilitate the removal of mercury from all medical products, as well as to create awareness campaigns for families and physicians.
- The Institute for Vaccine Safety (vaccinesafety.edu) was established in 1997 at the Johns Hopkins University School of Public Health (now the Bloomberg School of Public Health). Its goal is to work toward preventing disease using the safest vaccines possible. Visit this website for information concerning vaccine schedules for infants and children, as well as the amounts of thimerosal (if any) in the different vaccines.
- *The Vaccine Book: Making the Right Decision for Your Child* (Sears Parenting Library) by Robert W. Sears, MD, FAAP. Dr. Bob devotes each chapter in the book to a different disease/vaccine and discussion of what the disease is, how common or rare it is, and any possible side effects of the vaccines.
- *What Your Doctor May Not Tell You About Children's Vaccinations* by Stephanie Cave discusses the pros and cons of the different vaccines and offers a risk-benefit analysis, as well as an alternative vaccination schedule that may minimize exposure to any possible risks.

Why People with ASD Act the Way They Do

As mentioned in the previous chapter, a diagnosis of ASD is based on observable behavioral characteristics. We are beginning to have an understanding of why people have those observable characteristics, that is to say, why they behave the way they do.

From observation and written accounts by people with ASD, we can understand what some of the behaviors mean. This is helpful information for the general public so they can develop an understanding of why people with ASD might act a certain way, and understanding is a near neighbor of tolerance! It is invaluable knowledge for parents, caregivers, teachers, and other professionals who are trying to decide what therapies, treatments, and interventions could help a person with ASD.

Behaviors Are a Form of Communication

For the very young, and those who are nonverbal, behaviors can be the only way for them to communicate with us and the only way for us to understand what is going on with them. Some of these behaviors are avoidance behaviors. Other behaviors are indicative of the individuals trying to make sense of their surroundings, or movement differences as explained earlier. Still others are due to pain, anxiety, or panic attacks. The brain structure of many people with ASD is unlike ours, with some processing circuits wired differently, and it is important to realize that they cannot help what they are doing; they are not just “being difficult.”

Parents, caregivers, and teachers can observe a person’s behaviors and try to analyze the reason behind them. There is a certain amount of guesswork involved, but by systematically picking one behavior and writing down your observations, you will probably find a pattern.

For example, if a child keeps taking his clothes off, he is probably sensitive to the feel of fabrics on the skin. It would be helpful to observe and take notes on this particular behavior, such as whether he is doing it when he is wearing a certain type of fabric or a certain fit or cut of clothing. Identifying what he can wear will make it easier for him to be comfortable. Perhaps he can be desensitized by various sensory integration techniques known to be helpful.

FOOD FOR THOUGHT

On Being Sensitive to Touch

From as far back as I can remember, I always hated to be hugged. I wanted to experience the good feeling of being hugged, but it was just too overwhelming. . . . Being touched triggered flight, it flipped my circuit breaker. I was overloaded and would have to escape, often by jerking away suddenly.

—Temple Grandin, *Thinking in Pictures*

Still the best way to understand what certain behaviors may mean or how to help is to read first-person accounts by those on the spectrum. There are books written by some severely impacted nonverbal people, as well as many by those who are more able. We can understand our children more by reading what they have to say.

Striking a Balance Between Changing the Environment and Changing the Behavior

As parents and caregivers, we need to find the balance between trying to change the environment and changing the individual. Usually a bit of both will be in order. For example, if behaviors indicate possible food allergies, and tests indicate that that is so, a change in diet (the environment) is in order. However, the person may need to learn to tolerate (slowly, through desensitization) eating certain foods that perhaps he would not eat before if he is following a special diet to help his condition.

If a person has auditory and visual sensory processing difficulties, perhaps he can undergo auditory training or vision therapy and avoid spending too much time in noisy, bright environments. Classrooms should not be lit with fluorescent lighting, but the child also needs to learn an alternative appropriate behavior, such as requesting a break or permission to go for a walk, rather than having a temper tantrum.

Listed below are some behaviors and what they can mean. Keep in mind that these are generalizations and that everyone is different, so they may not be true for everyone. Nonetheless, this is a good place to start

trying to analyze a person's behaviors. Then, when looking at treatments and therapies, you will already have an idea of areas in which you can help this person. Remember, too, that some behaviors can be indicative of different causes, so you need to look at the total person.

Some Observable Characteristics and What They Could Mean

Finicky Eating

- Eating only from certain food groups can be indicative of food allergies. Sometimes the discomfort created by food allergies can cause other behavioral symptoms similar to sensory processing issues. Often, frequent diarrhea or constipation accompanies eating problems due to allergies.
- Eating only foods of the same texture, smelling the food before eating it, and not eating foods that produce a crunching sound can indicate sensory processing issues, as can chewing or eating unusual nonfood items.
- Eating only exactly the same foods, if accompanied by other examples of insistence on sameness, can show high sensory sensitivities or apprehension of the unknown.

Avoidance of Auditory Stimulation

- Covering the ears or appearing deaf (e.g., not responding when name is called) indicates auditory processing difficulties and a high sensitivity to sound. A person may cover his ears to try and block out the sound, or tune out completely.
- Leaving a room when people enter may be a way of avoiding too much auditory stimulation.
- Listening to and repeating TV commercials or songs could indicate that the person has gotten used to hearing those sounds, i.e., has

desensitized himself to them. Listening to people talk is more difficult because people don't usually say the same thing twice, and no two people speak the same way.

- People with autism often speak in a monotone or have peculiar intonations because they don't understand the concept of nuance, and that how you say something conveys an additional meaning to what you say.

No Reaction, or Else a Strong Reaction, to Touch

- Some babies become stiff when you pick them up; some children will fall and cut themselves and not cry. Usually this indicates that their tactile sense is out of whack. Perhaps a child's tactile sensors are overly sensitive and he does not like to be touched, or they are very dull and he doesn't feel sensations the way most people do.

Removes Clothes or Shoes Often

- A person may not like the feel of particular textures on their skin. Certain fabrics and shoes can make people with extremely sensitive tactile sensors uncomfortable.

Lack of Eye Contact

- People with visual processing problems find it hard to look at people straight on; usually they look from the side of their eyes. Many on the spectrum have expressed that they can use only one sensory channel at a time. For example, they can either visually process or auditorily process, but not both at the same time. So, if they want to process what the person is saying, they can't look them in the eye.

Unusual Body Movements

- Rocking in a chair, or back and forth from one foot to the other, could be a stress release from too much stimulation, or not enough.
- Flicking of fingers could also be a release from stress, but if doing it in front of the eyes, it could be a visual processing stimulation.
- Awkward movements and running into furniture can be a symptom of poor body mapping, not knowing where one is in space, or poor fine and gross motor skills.
- Difficulties with initiating movement, stopping movement, or following through with requests could be due to movement differences.

Does Not Play with or Imitate Others

- People with autism are often lacking in the social skills and interests, which the rest of us find so important. Also a child with sensory processing issues will have difficulty being near other children who are, in his eyes, noisy and unpredictable, and who have textures and smells associated with them that the child with ASD cannot tolerate.

Lines up Objects

- This can show a need for sameness. Usually children who line up toys are also the ones who do not like change in their routine, may have repetitive speech, and do not like to see the furniture moved into a different pattern in their home.
- They may have a hard time making sense of their world, and so the sameness in certain areas provides a predictability and security missing from an existence that they are having a hard time comprehending.

Temper Tantrums, Hyperactivity, and Aggression Toward Self or Others

- Keep in mind that all behavior is a form of communication. Trying to understand what the person is communicating is important. Temper tantrums or meltdowns in children can be a reaction to sensory overload, or to a change in the sameness that provides security.
- Places with a lot of light and noise, such as supermarkets and waiting rooms with fluorescent lighting, are really hard on people with sensory processing issues.
- Aggression toward others could be for any number of reasons, such as sensory overload (e.g., a sudden loud noise near someone's ear could cause them to jump up and strike out at the person making the noise, as it can be very painful), anxiety, or PTSD due to a past act of aggression toward the person on the spectrum.
- Self-aggression could be due to seeking sensory stimulation, feeling pain, anxiety, or frustration.
- Sudden changes in behavior can indicate possible mental or physical abuse toward the person on the spectrum.

4

Newly Diagnosed Adults and Parents of Children with ASD *After the Diagnosis*

The book was finished and now I had a word for the problems I had fought to overcome and understand. The label would have been useless except that it helped me to forgive myself and my family for the way I was. . . . I wanted to meet the other autistic people I'd been told about and was surprised to find out that they were few and far between, scattered across the country and across the world. I was even in a smaller category. I had become "high functioning." Nevertheless, I needed to meet others.

—DONNA WILLIAMS, *Nobody Nowhere*

When you are a parent of a child who is developing more slowly than typical children, you may feel alone, but you are not. Knowing that you are not alone is a big part of the cure for the worry and pain. Parents whose children are not developing typically can greatly benefit from understanding the similarities between themselves and others. A lot of healing occurs when you exchange stories with others in similar circumstances.

—ROBERT A. NASEEF, *Special Children, Challenged Parents*

IT WAS hard for me to go to my first autism support group meeting when Jeremy was little. I was taking another step toward acknowledging that my child had a disability and that it wasn't just going to go away. It felt as if I

was becoming a member of a club that I didn't really want to join. The only thing I had in common with the roomful of people was the label our children shared, but even so our children were so different from each other. But we helped one another. We shared resources, information, anger, tears, and advice. We gave each other energy and the courage to do what was needed. We shared stories about our children that were too embarrassing to tell anyone else, and we laughed at the absurdity of our situation. And most important, the group developed resources that were previously nonexistent. We created change in the status quo.

You Are Not Alone

Because of the epidemic rise in the numbers of individuals diagnosed with ASD, you are not alone. Whether you are a parent or you are an adult with autism, having access to others like yourselves is necessary, not only for the sharing of information but also for your mental health.

There Is Power and Comfort in Numbers

In this chapter, suggestions and resources will be provided for the parents of children with ASD and for the recently diagnosed individual. Professionals can also learn much by accessing the same sources. It is true that you are not alone: There are many organizations, associations, books, and websites ready to help you. Remember, too, that there is comfort to be had in meeting others experiencing the same situation as you. There is also power in numbers: the more people who get together, the more useful ideas float around. A word of warning: There are so many sources of information on the Internet to draw from that parents need to use caution and learn how to discern factual information from marketing hype. Autism has now, unfortunately, become a money-making business for many.

Adults who have a diagnosis of ASD may find support through online or local chapters of various nonprofits dedicated and run by adults on the autism spectrum, as well as parent- and professional-run organizations that

have an advisory board of adults on the spectrum. Some of these are listed below, others are listed in the Resources section at the end of this book.

Professionals who are new to the field of ASD would do well to read about the experiences of parents and to consult the resources available to parents in order to learn more about this disorder, as well as how it affects the family.

Parents and professionals alike would benefit and gain a greater understanding of autism and Asperger's by reading and viewing accounts by people with ASD, in books, on the Internet, and on TV.

Empower Thyself: Seek Knowledge

The first step in gaining an understanding about ASD is to gather knowledge. Here are some places to start:

Make contact with nonprofit organizations dedicated to ASD. The first step should be to make contact with other people in the same situation, that is, others who have ASD or other parents. The first place to start is your local support groups. Some are chapters run by national organizations and can be found on their websites. These are:

Autism Society of America (ASA): autism-society.org

Autism Speaks: autismspeaks.org

Talk About Curing Autism (TACA): tacanow.org

National Autism Association (NAA): nationalautismassociation.org

Those specific to adults on the spectrum include:

The Global and Regional Asperger Syndrome Partnership (GRASP):
grasp.org

Autism Women's Network: autismwomensnetwork.org

Autistic Self-Advocacy Network (ASAN): autisticadvocacy.org

FOOD FOR THOUGHT

Tips to Keep in Mind on Your Quest for Knowledge

- Make sure you are seeking information from reliable sources. Just because something is published on a website or in a magazine does not mean it is accurate. Stay away from websites that do not clearly state where the information listed comes from, who or what organization has created the website, and their connection to whatever products or treatment they are trying to sell you.
- Take it one step at a time and seek only what you are ready to assimilate. Focus on the present. Learn what you can that will help you today or over the next six months. At this early stage, if you try to think too far ahead, you may feel overwhelmed. Do only what you feel capable of doing, and read only what you are ready to digest.
- Learn the jargon. If someone uses a word you don't understand, look it up or ask for an explanation.
- Ask questions if you don't understand. Ignorance is not bliss, and life will become a lot easier if you get used to asking questions. Before going to any meetings or appointments, write questions down. Ask and ye shall receive.
- Stay away from treatments that are touted as being equally effective for everyone with autism. There is no such thing. What works for one child may not necessarily work for yours. Everyone is different; you need to find what is right for your child.
- Do not be intimidated by others. Some parents feel overawed by medical or educational professionals. There is no need to feel this way. They may be an expert in their field, but you are the expert on your child. ASD is very complex, and even educational and medical experts do not know everything. Together you can be a team.

There may also be local support groups in your area not affiliated with national organizations. These and local chapters of the national organizations will be able to give you more localized information. Because each state has different ways of providing federally mandated early intervention and education, you will need to know how to access these

services in your state. Also, local chapters often have guest speakers, and meeting other members can be a great way to get helpful information on local resources.

Local chapters may have a lending library of books you can borrow. This is a good way of filtering through the different books and only buying the ones you really will use over and over.

Make contact with other families or adults diagnosed with ASD.

Through your local association or websites, make contact with others in your situation. If you are an adult who has just been diagnosed, you might find it helpful to contact another adult who has ASD. This can be done on the telephone or online. Parents will find it helpful to talk to others who have been in the same situation or are going through it now.

Read reputable papers and books. Some suggestions are:

“Advice for Parents of Young Autistic Children” (2012, Revised) is on the Autism Research Institute website at autism.com/index.php/understanding_advice. There is other good information on this website regarding autism in general.

For a quick overview, read my book *What Is Autism?: Understanding Life with Autism or Asperger*. This is an easy read to share with your relatives and close friends so they can understand what you are going through.

The Autism Revolution: Whole Body Strategies for Making Life All It Can Be by Martha Herbert, MD, PhD, with Karen Weintraub.

Autism Solutions: How to Create a Healthy and Meaningful Life for Your Child—Innovative Strategies for Developing the Right Treatment Plan by Ricki G. Robinson, MD, MPH.

An Early Start for Your Child with Autism Using Everyday Activities to Help Kids Connect, Communicate, and Learn by Sally J. Rogers, Geraldine Dawson, and Laurie A. Vismara.

Read accounts written by adults with autism spectrum disorder.

For everyone, reading books and blog posts by people with ASD gives an

insight into what was helpful to them and explains some of their feelings and behaviors. For newly diagnosed adults, this may help you to understand that there are others out there with similar challenges, and perhaps their stories will hold tips to helping you live in a neurotypical world. See the Resources section for some recommendations.

Read accounts written by parents of children with ASD. There are many blogs and books written by parents of children on the spectrum. These can be very informative. Keep in mind that they have their own viewpoint and perspective depending on what their experience has been and what type of child they have.

Learn about any services or funding for which you or your child may be eligible. If you are not already, you and your child will soon be consumers of the various wonderful systems that are there to help you. This gives you certain rights as well as responsibilities (see “Where to Start Your Search for Services and Funding” on page 86). Your local parent support groups can provide you with the information you need to get started in your area. Educate yourself by talking to other parents who have been there before. Start the application process for anything you feel you are eligible for. Things take time.

Find out about any insurance coverage you may have. Many states now require insurance companies to provide coverage for autism-related therapies and treatments. Autism Speaks has the latest updates on their website at autismspeaks.org/advocacy/insurance/faqs-state-autism-insurance-reform-laws.

Get on waiting lists. If your child is very young, you need to find out about early intervention in your area. For any age, it is important that you get your name on any lists for services you feel you may need to access at some point. Who knows what the future holds? You may need to get on lists for speech evaluations, respite care, an assessment of special education needs, or other services. If you are investigating applied behavior analysis (ABA), it's best to call a few providers and get on their lists. You may not want or need it in the end, but remember, it is easier to get off a list than to get a service when you haven't been on one in the first place.

Start keeping good records. Start keeping a record of all medical visits and professional appointments. Keep track of telephone conversations as well. Filing papers in a three-ring binder in chronological order is the

best way to organize information. Do not separate papers by profession (e.g., speech assessment, psychological assessment), as a chronological order of all papers makes it easier to see a complete picture of the child at different ages.

Start keeping notes on your child. Make a journal about your child and start collecting data and making notes about developmental milestones, illnesses, bowel movement patterns, as well as health changes (if any) following vaccines, medications, and vitamins. Information recorded here about dietary habits; behaviors, including self-stimulatory ones; and the child's abilities and challenges can be useful in getting a full picture of your child and can help in identifying the best ways to help him.

Take videos of your child. Our memories may fade, but videos don't lie. This is a good way of seeing how a child develops and progresses. Also, if ever you need to prove a point on how a particular method is working, a video can illustrate that and make a strong visual impression about the difference in your child.

Do whatever you can to interact with and teach your child. You may be waiting on lists for some time. Do what you can to connect with your child: read to him, sing to him, play with him. Don't wait for someone else to do it. Connecting with this child may not be the same as connecting with his siblings (if any), but you will connect.

Take care of yourself. Most important, stay healthy. Remember that you still have a life outside this child. Take time for yourself and for your partner as well as any other children. There is a whole world out there, and you need to recharge your batteries to keep things in perspective.

Seek out positive people. Stay away from negative people who sap your energy. Later in this chapter, we will discuss the grief cycle and how it affects people. Sometimes, in support groups you will meet individuals who are constantly depressed or you may have relatives who are handling the diagnosis worse than you are. Everyone is entitled to a bad day here and there where they feel as if they have hit rock bottom. However, the whole point of having a good cry is to get it out of your system, and then get on with your day. You need to save your energy to help your child, your own family, and yourself; don't let others drain it from you.

Who Said What? Buyer Beware

You will meet people at support groups, visit many websites, read books, get advice from professionals. All these sources of information are helpful, but you must be able to sift through the information and analyze what is valid for you:

- *Information from other parents:* Parents will say that a particular treatment worked or didn't work for their child. They may say a certain therapy is the best thing on the market. Remember, they are talking from their point of view, based on their child. Your child may share a common diagnosis or label, but that does not mean the children have the same treatment needs. Keep in mind that just as people have certain political or religious beliefs, they also have particular beliefs when it comes to autism and treatment.
- *Information from websites:* As mentioned before, while many websites are valid, informative, and based on fact, others simply put out information based on the particular bias of the individual or company that has set them up. You need to read everything with a grain of salt and learn to develop analytical skills if you don't have them already.
- *Information from books:* Books are generally good sources of information, though again you need to bear in mind who is writing the book and what perspective they are writing from. Also, look at when the book was published. If you are preparing for a meeting with your school district and have questions about your rights and responsibilities, you want to make sure you are consulting a recent publication that takes into account any recent changes in the law, and not something written ten years ago.
- *Information from professionals:* Professionals are very knowledgeable people and can be experts in their field, but that does not mean that they are knowledgeable about the latest treatments and therapies for ASD. Neither are they experts on your child; you are. Again, you need to know more about a professional's experience and training, and what biases they have. On the other hand, keep in mind that autism has now

become big business, and unfortunately, there are some unscrupulous individuals who will try to sell all parents expensive tests and treatments for every child. Some children may benefit, but not all. It does not mean that what professionals have to say is not valid, just that, like all humans, they are shaped by their experiences. Perhaps they have not yet worked hands-on with a child of your age or functioning level. If they have, did the children they worked with progress, and to what extent? Did progress stabilize or regress when treatment was ended?

- *Information from autism organizations:* ASD organizations are wonderful sources of information. Just be aware that they have opinions, just as people do. Sometimes there can be the appearance of a conflict of interest. Unfortunately, autism is not free of politics. But remember that all organizations are doing their best to help people with ASD; you just have to be able to gather information and make your own decisions about what is best for your child and your family.

FOOD FOR THOUGHT

Loss of Expectation

What it comes down to is that you expected something that was tremendously important to you, and you looked forward to it with great joy and excitement, and maybe for a while you thought you actually had it—and then, perhaps gradually, perhaps abruptly, you had to recognize that the thing you looked forward to hasn't happened. It isn't going to happen. No matter how many other, normal children you have, nothing will change the fact that this time, the child you waited and hoped and planned and dreamed for didn't arrive.

—Jim Sinclair, *"Don't Mourn for Us"*

For Parents: Handling Your Own Emotions

Life is a series of choices. Granted, as a parent you did not choose for your child to have an autism spectrum disorder. However, you can choose how to react to it and what you are going to do about it. The first place to start is to learn about the emotions you are feeling, and to understand that they are real and unavoidable, and that all parents will go through them at some time or another. These emotions need to be addressed. A good place to start is to acknowledge them and accept that it is normal to have them.

The Moment Your Life Changes Forever

There are certain events that change the course of world history; dramatic events that are indelibly etched in all our memories. And along with the memory of the actual event, there is the memory of where you were or what you were doing when you got the news. The Boston Marathon bombing, the Sandy Hook Elementary School shooting, September 11, the *Challenger* exploding on takeoff, the day that John F. Kennedy was assassinated are all events that we as members of the human race shared collectively.

After disastrous events, all of society grieves together; and though we are all different, we can mourn together and acknowledge the feelings the event has provoked. The day a parent learns that his or her child has a disability is like one of those dramatic event days. For some, it feels as if they have just been hit in the stomach and had the wind knocked out of them. Even if the parent suspected that there was something wrong with the child, they can't believe this is happening. For every parent of a child with a disability, this moment is forever etched on their mind.

FOOD FOR THOUGHT

You Never Get Over It, You Just Learn to Deal with It

It was one of those beautiful Parisian spring days that makes you feel that all is right with the world. I decided to stop at the café after a walk with my four-year-old son.

At the next table, a mother and her ten-year-old boy were laughing at a joke he had just told her. She asked him about his school day and he talked about the games he played at recess. When the waiter came to take their

order, the boy grinned impishly at his mother and asked imploringly, “Maman, can I please have a pain au chocolat and a hot chocolate?” “It’s going to ruin your appetite for dinner, but go ahead,” she replied, ruffling his hair.

When the waiter came to take our order, I asked my son if he wanted a hot chocolate, as he stared at the speckles of dust in the air reflected by the light, his head cocked to one side, while spinning the spoon he had found on the table. He appeared not to hear me; it was as if I had not even spoken. I looked with envy at the other table, at that mother sharing an everyday ordinary moment with her child. And that now-all-too-familiar ache descended as I realized once again that I would never have a moment like that with my son; I would never sit and share a joke and have a conversation with him. I wondered if he would even ever look at me with the same interest he showed the spoon.

I reached for the spoon and started fidgeting with it. My son looked at the movement of the spoon. I picked it up and twirled it in front of my face. For an instant he looked into my eyes and smiled before fixating back on the spoon, melting my heart in the process. Perhaps, I thought, I will never be able to have a conversation with him about recess, but I know we will connect somehow; we will find a way, our way.

The difference is that no one else is sharing your pain. When the parent leaves wherever it is that he got the news and walks into the street or parking lot, his whole world has changed, but there is no comfort to be had, no collective reaching out to one another. The other people in the street or in the other cars have the same life they had an hour earlier. Only the parent’s has changed forever.

The Grief Cycle

In her book *On Death and Dying*, psychiatrist Elisabeth Kübler-Ross introduced her famous “stages of dying” or “stages of grief” model, in which she lists the five stages a dying person goes through when they are told about their terminal illness: denial and isolation, anger, depression, bargaining, and finally acceptance.

The emotions that a parent goes through when raising a child with a chronic health need or disability, including ASD, have been likened to Kübler-Ross’s five stages of grief. The difference is that instead of going through each stage chronologically, parents are on a continual cycle, going through different stages at different times. They never graduate completely

out of the grief cycle but do eventually learn to spend more time in the acceptance phase.

Why Do Parents Go Through the Grief Cycle?

First of all, parents are mourning the death of the child they never had, the death of the future they had envisioned sharing with their child. They have not actually lost their child, but they have lost their fantasy child, the one they had hoped for and dreamed about. As Jim Sinclair so rightly puts it in his article “Don’t Mourn for Us,” “Much of the grieving parents do is over the non-occurrence of the expected relationship with an expected normal child. This grief is very real, and it needs to be expected and worked through so people can get on with their lives—but it has nothing to do with autism. . . . It isn’t about autism, it’s about shattered expectations.”

Second, parents go through this grief process because until recently autism was considered incurable, and parents were told to go home and accept that there was no hope for their child and to plan on institutionalizing their child in the future when life with autism got to be too much. The medical professionals had nothing to offer but condolences.

Third, parents who have children with regressive autism (a child who developed normally and then started regressing at around eighteen months) may feel the very real loss of the child they did have, of seeing their child slip away into autism.

However, a diagnosis of autism is not a diagnosis of despair and hopelessness. There is a chance of dramatic improvements for some. And for the rest, there is much that can be done to help them reach their potential. There are so many new treatments, therapies, and educational strategies out there. Dedicated parents and professionals have fought hard (and are still fighting) to get research funded, discoveries made, services provided, laws enacted, and information shared so that all individuals with ASD can have a future. The grief cycle is still here, but the future looks brighter for all of us.

The Positive Aspects of the Grief Cycle

An important part of this grieving process is to realize that to grieve is normal and necessary. It is important for the well-being of the family that the parents recognize and acknowledge this grief as well as the emotions that will continually resurface. Each emotion on the grief cycle, if recognized, can be fuel for positive action. If you are at the anger stage, for example, you might use that anger to refuse to accept a third-rate educational program for your child and to request an appropriate placement. Parents need to learn to recognize where they are on the cycle, and how to use that emotion to gain knowledge and empower themselves. Then, on the days that they feel strong and capable, they will be ready for action.

Remember, when it comes to ASD, early intervention is the best intervention. The sooner you can use these emotions to help yourself, your child, and your family, the better off you all will be.

The Different Stages of the ASD Grief Cycle

Shock and disbelief. The first reaction a parent usually has when hearing the diagnosis, even if they suspected something was wrong, is disbelief. “There must be some mistake.” “This can’t be happening.” At this point, the parent usually does not process exactly what has happened or the enormity of what has just been said. They often go into automatic-pilot mode and sit through the rest of the meeting without really taking in any more information. Some parents may even feel physical pain, as if someone has torn them open. They may feel as if they have been smothered in a dark heavy blanket and are unable to see or hear or breathe.

Tip for parents: Leave the meeting and allow yourself time to react to what you have heard. React however you want to react. Don’t do anything or make any decisions until your body stops reacting. Make an appointment to come back another time, when you have had a few days to process the initial shock. Make a list of questions to ask. You may find it helpful to talk to close family and friends; you may wish to isolate yourself. Take time for yourself.

Denial. At this stage, parents think there is some mistake which will eventually be cleared up. Even though they may see the obvious and it has been confirmed by a professional, they still think, “There is nothing wrong

with my child. They must have mixed up the test results.” In denial, parents often seek second or third opinions, or some magical treatment that will “cure” their child.

Tip for parents: Use your denial positively. Gather information and learn more about autism. Some parents start “shopping” for services, looking for that one treatment that will cure their child. You know there really is not a magic pill out there, but denial can fuel you to get informed and learn all you can.

Anger or rage. Once a parent has gotten through the denial stage after the initial diagnosis, they will often be angry. “Why me?” “How come there are people out there with perfectly healthy children they don’t appear to care about, and our poor child, who is the light of our life, has the disability?” Often, the professional who gave them the initial diagnosis bears the brunt of their rage. The parents may feel anger toward their spouse, toward God (if they believe in one), toward the child, or maybe even toward the child’s sibling for being healthy and normal (which leads to feelings of guilt . . .). They will feel anger at the disability. At sensitive times, such as when seeking educational provision, this anger may flare up and be misdirected at representatives of the local educational authority.

FOOD FOR THOUGHT

Shame and Embarrassment

When my son was fifteen, he still found it difficult to be in certain environments at times and would start flapping one of his hands or rocking on the spot. I was so used to being stared at that I forgot that people were looking at me because of my son’s behavior, and I would think, “Is there food on my face?” “Are my buttons undone?”

My son was usually good at that age about keeping his hands to himself, but every once in a while he would get attracted to a pattern or a color or a shiny object and would touch someone’s bag or sweater while we were waiting in line at the supermarket. Obviously we worked hard at teaching him that this was inappropriate, but sometimes he saw something that was just too tempting. Of course I would immediately stop him, remind him of what we had said about doing that and apologize to the person in question. I often got them

laughing by saying something like, “He knows quality when he sees it, he only goes for the top designers.” Humor helped to put us all at ease.

Tip for parents: Feel angry! You have a right to be. But don’t misdirect your anger at the people who are trying to help you. Anger carries a lot of energy with it that can be focused to enable you to be an advocate for your child. Learn to refocus your anger and do something positive with it: perhaps write those letters asking for services or more assessments—just wait a few days and reread them once you have calmed down, then tone down the inappropriate parts before sending them off.

Confusion and powerlessness. You are now entering a world you know nothing about, hearing new words that sound foreign. You are confused: “What does this really mean about my child?” “I don’t understand what the doctor is talking about.” And this confusion leaves you feeling powerless. Powerlessness results from feeling that now you have to rely on the advice and expertise of others, people you don’t even know that well and have no reason to trust: “The specialist says this is the best method.”

Tip for parents: Of course you are confused and feel powerless; you have entered a territory you know nothing about. There is a solution: start learning the terminology and the subject, and little by little you will become knowledgeable. And knowledge is power. You will feel less and less confused and more in control once you have the knowledge to make informed decisions. It will take time, but you will get there.

Depression. Sometimes everything seems like a struggle. The struggles to try to cure or change the ASD lead to feelings of despair. The idea that this is not the life the parent had dreamed of, that this is not the family they had hoped for is more than can be borne. They realize that autism is 24/7, and that they are on a train they never wanted to board and there is no getting off. The lack of sleep does not help, either.

Tip for parents: This is when you need to take some time away from autism, even if it is only a few hours. Have a good cry and then pamper yourself. Call a friend and do something you really enjoy: meet for lunch, play some golf, go shopping. If talking to friends, family, or other parents is

not helping you get out of your depression, contact a counseling service or ask your doctor to recommend a therapist, perhaps even a bereavement counselor.

Guilt. Parents feel guilt about having a child with ASD. After the diagnosis, the guilt is typically expressed as, “What did I do to cause this to happen?” “Was it the glass of red wine I had at my birthday party when I was pregnant?” “I shouldn’t have allowed the doctors to give him those vaccinations.” “Am I being punished for something I have done?” Later on, when they revisit the guilt stage on the cycle, it revolves around, “I’m not doing enough for my child.” “I should have taken a second mortgage on the house so he could have more therapy and alternative treatments.”

Tip for parents: Don’t beat yourself up. All parents do what they think is best at the time. It is not a good idea to use hindsight to try to analyze and critique the past. Nobody’s perfect. Take the time to sit back and think about all the positive things you have done for your child, and how your child is growing and developing under your care. Pat yourself on the back for what you have done, and think about where you can go from here. The past is the past; focus on the present.

Shame or embarrassment. At some point parents will feel shame about not having a perfect child—“What will people think?” Later, as the child gets older, they are nervous about people’s reactions to the child’s behavior in public. They catch someone staring at their child. They think, “Gosh, I wish he wouldn’t flap his hand while he is walking.” “His lack of eating skills and his disruptive behavior is ruining everyone else’s dinner at this restaurant.” “People must think I’m a terrible parent when he acts this way.” And then, of course, they feel guilty about feeling shame, which puts them on another part of the cycle.

Tip for parents: Get over it. Do not worry about what others are thinking. In the big picture, it doesn’t matter. Think of it this way: Your child is different and interesting and your life with him will not be boring. Develop a sense of humor. Stand straight and tall, look confident. Just think about making this a positive experience for your child, not about the others. When people see that you are at ease with your child in public, or see that you are trying to cope with a challenging behavior, they will respect you.

Fear and panic. Parents will inevitably feel fear and panic: “What will happen to my child?” Times of transition can bring about these panic

attacks. “How will he adjust to the new school?” “Another new teacher! Is she going to understand his learning style?” “What will he do after high school?” and of course the biggest panic attack comes from the dreaded, “What will happen to him and who will look out for him when we are dead and buried?” or “I want him to live with us at home but we can’t handle it anymore. Is there a good safe place for my child?”

Tip for parents: Take some time for yourself, take a few deep breaths, or practice your favorite relaxation technique and then acknowledge that what you are feeling is fear of the unknown. Use the fear and panic to propel you toward gathering knowledge about the choices you have in regard to whatever issue you are feeling fear about. Write down everything you think the new teacher should know about your child and give her the letter with a smile, telling her you hope it is helpful information. Find out about his options after high school. Visit group homes or residential schools to see what they are really like. Just having the knowledge about the options will make you feel better. If you are not happy with the options, perhaps you will find yourself at the anger stage and that will propel you to organize with other parents and advocate for better choices or, better yet, create them.

Bargaining. After a while parents start to bargain with whatever higher intelligence or God they believe in. “If the forty hours of behavioral therapy per week for two years cures my son, I will adopt a poor family to send money to every week for the rest of my life.” “If it is only autism, I can accept it, but if it’s mental retardation as well . . .” “If he can learn to communicate in some way . . .” The process of bargaining is a way for the parent to accept a part of the problem without taking on the whole problem.

Tip for parents: As time goes on, you will find that you are bargaining less and less as you start to have more acceptance of your situation and get to know your child, his personality and potential, as well as the options out there.

FOOD FOR THOUGHT

Don’t Mourn for Us

This is an excerpt from an article published in 1993 in the Autism Network International newsletter, *Our Voice* (vol. 1, no. 3). It is an outline of the presentation Jim Sinclair gave at the 1993 International Conference on Autism in Toronto, and is addressed primarily to parents. Jim is autistic.

Autism is not death. Granted, autism isn't what most parents expect or look forward to when they anticipate the arrival of a child. What they expect is a child who will be like them, who will share their world and relate to them without requiring intensive on-the-job training in alien contact. Even if their child has some disability other than autism, parents expect to be able to relate to that child on the terms that seem normal to them; and in most cases, even allowing for the limitations of various disabilities, it is possible to form the kind of bond the parents had been looking forward to.

But not when the child is autistic. Much of the grieving parents do is over the non-occurrence of the expected relationship with an expected normal child. This grief is very real, and it needs to be expected and worked through so people can get on with their lives—but it has nothing to do with autism. . . . It isn't about autism, it's about shattered expectations.

I suggest that the best place to address these issues is not in organizations devoted to autism, but in parental bereavement counseling and support groups. In those settings parents learn to come to terms with their loss—not to forget about it, but to let it be in the past, where the grief doesn't hit them in the face every waking moment of their lives. They learn to accept that their child is gone, forever, and won't be coming back. Most importantly, they learn not to take out their grief for the lost child on their surviving children. This is of critical importance when one of those surviving children arrived at the time the child being mourned for died. . . .

That isn't the fault of the autistic child who does exist, and it shouldn't be our burden. We need and deserve families who can see us and value us for ourselves, not families whose vision of us is obscured by the ghosts of children who never lived. Grieve if you must, for your own lost dreams. But don't mourn for us. We are alive. We are real. And we're here waiting for you. . . .

Hope. Parents have moments when they feel hopeful. “We may make it through this.” “This diet/therapy/medication seems to be helping our child.” “He is getting this concept.” “He’s keeping his behaviors under control.” Just like any parents, there are times when we are encouraged by the accomplishments of our child or we meet professionals or treatments that are having a positive impact on him.

Tip for parents: Celebrate and cherish each and every one of these moments. Tuck them away and pull them out on the days when you feel bleak and could use some hope. These are the moments that make you feel

that life is good. Treasure them, and share them with those who have shared your sorrows so they can also share in your joy.

Isolation. Sometimes parents feel isolated—“My child is the only one who is not acting appropriately.” Or they seek isolation because they do not want to see the reminders that they have a different child or a different life from everyone else’s, or because they feel that they must protect their child.

Tip for parents: Sometimes you feel an overwhelming need to isolate yourself from others because the pain of seeing other parents interacting normally with neurotypical kids is too great. It is not a good idea to stay isolated, however. To get through this, use local associations to find other families who have children with ASD or other disabilities. You will feel more comfortable with them, as you will understand each other’s concerns. Eventually, over time, you will come to feel more comfortable spending time with other families who are not in the same situation as you.

Acceptance. Parents will feel acceptance of their child’s ASD only after having experienced and worked through some of the other emotions discussed above. Acceptance means that they are feeling some control over the situation and their feelings about it. The challenges may not be solved to the level that they wish, but they see that they are able to cope and live with the hand they have been dealt. Acceptance also means that they realize that there will be days filled with anger or grief, and days that they will have strength. On any given day they will be in one spot on the grief cycle or another, but it’s okay. The parent is learning to cope and knows it’s all right to have those emotions. Also, accomplishments that may seem ordinary and small to others will be moments they savor and cherish. Acceptance also means that they look at their child and see a person, not a disability.

FOOD FOR THOUGHT

Rethinking Normal

Liane Holliday Willey recognized that she had Asperger’s syndrome at the time her daughter was diagnosed. In her book *Pretending to Be Normal*, this is what she has to say about realizing she had Asperger’s as well.

Yet, no matter the hardships, I do not wish for a cure for Asperger's syndrome. What I wish for is a cure for the common ill that pervades too many lives; the ill that makes people compare themselves to a normal that is measured in terms of perfect and absolute standards, most of which are impossible for anyone to reach. I think it would be far more productive and so much more satisfying to live according to a new set of ideals that are anchored in far more subjective criteria, the fluid and the affective domains of life, the stuff of wonder . . . curiosity . . . creativity . . . invention . . . originality. Perhaps then, we will all find peace and joy in one another.

For Adults with ASD: Getting Diagnosed Later in Life

In the past, many individuals with ASD on the very able end, or with Asperger's syndrome, who were able to function pretty well, did not get diagnosed at all or not until later in life. However, many felt that they were in some way different and, once diagnosed, reported feeling relieved at knowing that there were others out there like them and that there was a reason why they never fitted in.

Knowing that there is a name or label for what you have gives you the option of looking up information and seeing what strategies are out there to help with some of the challenges you may face. Being diagnosed allows you access to support groups and information you did not know existed.

You may wish to read books by people with ASD who give suggestions on how they cope with some of the challenges they face, or look up information on the Internet. Some of the books listed in the Resources section were written by people who were diagnosed with ASD later in life. *The Complete Guide to Asperger's Syndrome* by Tony Attwood has a wealth of information as well.

There are many more resources you may find useful in Chapter 9. You may also find this next section helpful in your quest for more information.

Marshaling Your Resources to Get Support, Services, and Funding

Most parents or adults with ASD will need at one time or another to ask for support or advice. In this section, developing the survival skills that will make you an effective advocate is discussed, followed by some basic information on where to start looking for the services and funding that can help you.

How to Develop the Survival Skills You Need

Working through the educational systems in three different countries has provided me with untold opportunities for observing and learning about how systems work and don't work, the politics involved, and how to ask the right questions. This has been helpful in developing strong survival skills and enabled me to become an effective advocate for my son.

Think of the work you do, and about what skills you used to get and keep your job. Think of the skills used by other people working in the same company. All these skills are the kind you will need either as a parent of a child with ASD or as an adult with the condition. Applying the skills used every day in work situations will help you obtain the services you or your child needs and keep good relationships with all the people involved.

For example, the skills I developed while producing TV shows are the same skills I used to obtain my son's educational needs: gathering information, analyzing data, listening to consultants' and other team members' expertise, using good clear communication, learning to negotiate, preparing for meetings, deciding what was worth fighting for, working as part of a team, expecting professional behavior, monitoring progress, forgiving honest mistakes, and rewarding a job well done. Sometimes people had to be kicked off the team or there were major disagreements, but at the end of the day, there was a show in the can.

Communicating. Every job involves communicating, whether it is with the public, clients, or fellow workers and the boss. Even if you work the graveyard shift as a security officer, at some point you need to be ready to communicate in case of an emergency. Communication is the major building block of all relationships, and relationships are critical for you to develop in order to get the help you need or the educational program that is appropriate. Being effective at communicating means being able to listen as

well as to talk. It means being polite and respectful, and clear about what you are talking about.

Planning. Every company has a business plan, and every worker has a plan of action for what they will do that day, whether it is putting hamburgers together or marketing software. Whether you are dealing with the school district, the medical profession, or social services, planning should now be a part of your life. Planning means looking at what your needs are today and will be in six months, next year, five years from now, and so on. What do you envision for your child or for yourself? How are you going to make that happen? How can the services on offer help you reach your goals? All the decisions you make are about reaching the dream or vision you have for the future.

Researching and analyzing. Before making major decisions at work, you have to research your options and then analyze the information. If you are a chef, you may research where to buy the supplies you need to prepare certain meals, and then analyze the information you have uncovered to come up with the place that best suits your needs and your customers' requirements. If your company needs a photocopy machine, you research the different suppliers and analyze the various options. As a parent, or an adult with ASD, you need to research the different treatments and diets, education, and work opportunities available. You also need to research what funding options are open to you. Then, analyzing the information will help you decide what plan of action is best for you.

Marketing. If you have a new product to sell, you have to convince your clients that it is the best thing on the market since sliced bread. At work, when someone has a plan of action they want adopted, the whole team has to be convinced to jump on the bandwagon, or the plan will not fly. To sell the idea to colleagues, marketing needs to take place. The person with the idea goes around to his colleagues and persuades them of the benefits of his plan. The same needs to be done once you have developed a plan of action: You need to convince the other team members (e.g., the school district, your doctor) on the merits of your plan. In getting what you need, you will need to market your ideas (using those effective communication strategies) and present the information and analysis as to how you came up with this plan and why.

Negotiating. At work, you may have to negotiate time off with your boss. With clients, you may negotiate different prices or marketing plans. Either way, you have to be prepared to discuss your needs, and to know how far you are willing to go to get what you feel you need. When it comes to services, you may not have as much room for negotiation, but in some cases you may. With the school district, for example, you may be able to negotiate for an educational program they are hesitant to provide due to cost or lack of experienced personnel. Keep in mind that doing this is not easy, but it is possible.

Acknowledging and rewarding. Once you have obtained what you wanted at work, or at least been given the opportunity to present your point of view, you need to reward the people involved by acknowledging the time they spent considering your proposal. The same holds true if you have negotiated and signed a deal with a client, or even if you didn't come to any agreement. A simple "Thanks for taking the time to listen to me" or "I appreciate your support," whichever the case may be, is in order. The same applies to the people you, as a parent or as an adult with ASD, have been "negotiating" with, even if you don't agree with the results.

FOOD FOR THOUGHT

On Taking Charge and Making a Difference

BY LINDA LANGE-WATTONVILLE

Early in my parenting and autism journey, when my two-week-old infant was hospitalized for seizures, I received vital advice from our neonatal nurse, a mother of a Down syndrome child. She handed me a book on seizures and urged me to educate myself to be my child's advocate and to make informed decisions. She explained that, although there are many dedicated professionals, no one will care about my child's outcome more than I do. Not only did I take her sage words to heart, I've met many other like-minded parents along the way, working to improve options for their kids and other persons with ASD.

Parents of autism face a maze of biomedical and educational treatment options. We bounce from one specialist to the next in search of answers and solutions. The process may be a necessary evil, but the end result can leave parents feeling at times helpless and ill-equipped to steer their child's treatment direction. A professional's role is to provide advice, assistance, and teaching.

But parents need not become subordinate to professionals to the extent that parents lose sight of their own child as a person, to know and understand at a deep level, as opposed to the child being simply a patient or subject for treatment.

Because my daughter Madison's seizures began at birth, I had the "benefit" of suspecting a challenging road ahead. I plunged into newly emerging biomedical information and options like Defeat Autism Now! At the same time, I read voraciously to Madison, and exposed her to a variety of music, while she also received early childhood intervention services in occupational therapy, physical therapy, speech therapy, and the National Association for Child Development home program.

I tried to start a supervised home-based ABA [applied behavior analysis] program when she was four, but Madison's admission to O. Ivar Lovaas's Wisconsin replication site was denied because of her low IQ test scores. That same month, I learned of the opening of a private applied verbal behavior school program for ASD kids opening in Austin, Texas, a two-hour drive from our home. I moved so that she could attend.

Madison was four and a half when she started the Horizon Program at Capitol School of Austin, which was started by parent Joyce Gruger. Madison, who remains nonverbal today, had some immediate success acquiring modified sign language to communicate some basic desires. Even so, I anxiously searched for an educational route to academic skills like spelling, reading, and writing, to lead to complex communication. I was also painfully aware that Madison, at eight years old, would age out of the program. I knew she still needed individualized teaching and that she was not ready for inclusion in a public school, so I chartered a nonprofit called the HALO (Helping Autism Through Learning and Outreach) School and began to stir up local interest in developing an educational option for older ASD students needing one-to-one academic instruction.

When *60 Minutes II* featured parent/teacher Soma Mukhopadhyay working at Carousel School in Los Angeles, I was encouraged to see her success teaching severely autistic kids who otherwise had been routed strictly to life-skills programs. I invited Soma to come to Austin to train teachers. She worked with students in Madison's school, and I extracted videotape footage to share during Soma's half-day workshop, attended by more than 240 professionals and parents from all over Texas, funded thanks to generous help from parents like Gwen and Frank Milano.

Soma's trademark Rapid Prompting Method (RPM) led to my daughter's educational and communication success, paving the way for her entrance into regular education classwork in public school. And in the fall of 2003, Soma and I collaborated our goals under the mission of HALO, offering organizational support for Soma to spread her RPM to as many persons with ASD as possible.

I guess the moral of this personal story might be that it pays off to become an expert in your own child, finding solutions and/or creating new ones that don't yet exist. Having the benefit of meeting hundreds of families of kids with ASD from all over the world, I've come to believe the ASD kids who fare the best are those with parents who dive into the effort of really knowing and

presuming competence in their child and working to cultivate the child's strengths.

In 2002, Linda Lange-Wattonville founded the nonprofit organization Helping Autism Through Learning and Outreach (HALO) for exemplary learning and innovative teaching techniques for persons with autism. Since her departure from HALO in 2008, she's continued her focus on creating educational, biomedical, and employment options for her daughter.

Perhaps, as an adult, you didn't get the results from a social worker you had hoped for; but remember, you may be asking that person for help again down the line. If you are a parent, you will be in touch with your local school district for many years, so it is better even in disagreement to acknowledge their efforts. "It looks as if someone took a lot of time out of their schedule to do this assessment and I appreciate the effort" is a good way of acknowledging the effort made before announcing that, unfortunately, the assessment did not address the real issue.

Monitoring. Every business has to have some form of monitoring put in place. The person making french fries has to monitor the amount of fries needed, the temperature of the oil, and how long the fries have been in the fryer. A doctor has to monitor the health of his patients postoperation. Even after your child has an individualized education program (IEP) and everyone leaves feeling satisfied that he is going to receive the support service he needs, monitoring must take place. This is where good communication skills are really necessary, as sometimes a gentle nudge is needed to get a service started.

For example, perhaps as an adult with ASD you have been assured a promised service or some funding to begin at a certain date. If it does not, you may need to make a few phone calls to find out what the status is, and what can be done to get the support in place.

FOOD FOR THOUGHT

The Importance of Becoming an Expert

When my daughter was diagnosed with Asperger's syndrome, her doctors gave me one outstanding piece of counsel. They told me that my husband and I would now become the experts on AS. We, in effect, would stand as her greatest advocates. The truth of their prophecy has been shown virtually every day. The general public is largely uneducated in AS. I have grown to believe that this is the single most damaging element to the AS cause, that is, understanding and acceptance. Without knowledge of the symptoms, outcomes and even confounding attributes, it is nearly impossible for others to recognize and support AS individuals.

—Liane Holliday Willey, *Pretending to Be Normal*

How to Get the Information You Need

In an earlier section, we talked about the need to find out about services and start the paperwork, as well as finding out about possible funding. Here are some other tips.

Find out what is available. All therapies cost money. Adults may need funds to supplement their wages. If you are not independently wealthy, someone in the family will need to become the designated expert on “how to get the treatment without it coming out of the family budget.” This person will need to learn about their rights in terms of education, social services, and the health system. If you have private insurance, find out what it will cover. Find out all you can about any financial support you may be eligible for.

Learn to ask questions. Do not suppose that social services, early intervention services, the school district, private insurance, or whatever agencies you are turning to for help will automatically tell you what you have a right to. Dare to ask questions. They have budgetary concerns. Sometimes they will tell you only what they are offering on a regular basis—what they wish to provide—not what you are entitled to. Most people have not been taught to think “outside the box.” You will need to learn to ask the right question to get the right answer. Think of it as playing detective. Often a case is cracked when the detective asks a question that

brings out information that people did not volunteer, as they felt it was unimportant or did not concern the case. The same can be true when looking for funding, employment support, or an appropriate education. As a parent, or an adult with ASD, you will need to be proactive, and learn to communicate in an assertive, nonaggressive manner. Always be polite. The people on the other end of the phone or the other side of the counter are only doing their job as they have been taught.

Talk to others in the same situation. Ask other parents or adults with ASD in your area for some ideas about what they have been able to obtain. There are many options for help out there. Each agency has a brochure explaining clients' rights and lists advocates to turn to for help if necessary.

Learn to ask for and accept help. When you are used to being selfreliant, it is difficult to ask for help or to accept help that is offered. My advice to you is: Get over it! Remember the times you have helped others and keep in mind that you will help others in the future. Now is not the time to have a stiff upper lip and be too proud to accept help.

Learn how to answer questions in a way that fully explains your situation. For example, at some point when answering questions on a form regarding your child's level of need, you may be asked, "Can your child walk?" Most people would reply "yes" if the child is not physically handicapped. However, some children with autism do not follow instructions and are not safety-conscious; some will run into the street, others may have a tantrum. The real question in your mind should be: "Is my child capable of getting somewhere independently without adult prompting of any sort?" If the answer is "no," the correct response to "Can your child walk?" is, "My child needs help to move safely from one place to another."

Where to Start Your Search for Services and Funding

Having ASD or having a child with ASD can be mind-boggling and expensive. Knowing what options are available medically, educationally, and financially is a great source of comfort. Knowledge is empowering, and gathering information is the first step toward making you feel that you are

in the driver's seat and that you have choices about which direction you want to go.

Although there are federal mandates, you need to know about how these are applied in your state, so check your local state agencies. Because each state is different, some more complex than others, various sources are listed below and some may be redundant. However, it is better to have too many places to look for the information you need than not enough. Here are some ways to start gathering information about services and funding:

Contact your local autism support group. Local autism chapters will be able to give you advice on a local level. To find out what chapters are in your area, visit the websites of national autism organizations.

Find out your rights and responsibilities. Contact the protection and advocacy agency in your state, and obtain a copy of whatever information they have in regard to your rights in the state where you live. You can find the protection and advocacy agency in your area by going to the website for the U.S. Department of Health and Human Services, Administration on Intellectual and Developmental Disabilities (acl.gov/Programs/AIDD/Programs/PA/Contacts.aspx).

Find out about possible medical and Medicaid benefits. It is best to contact your state agencies; however, if you wish other information you can contact the U.S. Department of Health and Human Services through its website (hhs.gov).

Find out if you or your child is eligible for other services by contacting your local State Council on Developmental Disabilities. Go to the National Associations of Councils on Developmental Disabilities website (nacdd.org/about-nacdd/councils-on-developmental-disabilities.aspx) to find your state council.

Find out if you or your child is eligible for Supplemental Security Income (SSI). Adults are eligible if considered disabled. For low-income families there may be some possible funding for children. Contact the Social Security Administration (ssa.gov, or call 800-772-1213) or your state agency for more information.

Find out your rights in terms of private insurance coverage. At the time of this writing, autism advocacy groups are lobbying for a federal law to require autism coverage in private insurance plans. Meanwhile, there are many states that have voted on insurance coverage. To find out the latest

updates and see if your state requires autism coverage, visit autismspeaks.org/advocacy/states.

Treatments, Therapies, and Interventions

“Therapies,” “techniques,” and “treatments” used with people with “autism” present themselves like shops along the High Street; they have little relationship to one another and each shop will encourage you to shop at their store and tell you why their product is the product.

But each of these shops sells something quite different from the next. Some deal with behaviors, some with brain development, some with biochemistry, some with cognition or with the mind and some with the soul—and some don’t deal with anything but make a good job of appearing to.

The problem with services behaving like High Street shops is that people with “autism” don’t just have problems with behavior or communication or perception or their senses or with brain development or with biochemistry, or with stress levels or with troubled souls. Because people with autism are whole beings, most of them have trouble with the whole lot, which all interconnect and feed into each other at some point.

To get any all-round service, people with autism don’t need a High Street of competing shops, they need a department store where each department is aware of what the others offer and points people in the direction of other services which complement their own.

—DONNA WILLIAMS, *Autism: An Inside-Out Approach*

WHEN Jeremy first stood up and walked on his own, his first steps were not toward me. He got up and followed the patterns in the rug. We were living in Paris at the time, and psychoanalysis was the treatment on offer to cure Jeremy’s autism. When my husband was offered the opportunity to work on Legoland in Berkshire, we jumped at the chance to move to England, where

at least Jeremy could attend a special needs school. Soon after arriving in England, I read *Let Me Hear Your Voice* by Catherine Maurice, and I also met Cathy Tissot, whose autistic son attended the same school as mine. Neither of our children were progressing at school and so we decided to try the Lovaas program, a home-based applied behavior analysis (ABA) program. At that time, ABA programs were still relatively new and we were one of the first families in the UK to go this route.

I remember going to Cathy's house one evening, trying to get up the nerve to call the Life Institute, the Lovaas center in California, to find out if there was a consultant who could come and put on a workshop to train us and students to work with our children.

Making that phone call changed my life. That was the moment when I stopped being a victim of the systems in place, took control, and realized I was not powerless to help my son.

As a child, Jeremy had many challenges, and he continues to have some. We have tried different biomedical, dietary, and homeopathic treatments; different educational strategies; sensory therapies; occupational, physical, and speech therapy—anything that made sense to help Jeremy, based on his needs. Some have been very helpful, others have not. As he learned to communicate and type, he was able to tell us what the therapies felt like for him and what he felt was useful. Now that he is a young man, he decides what he would like to try or continue to help him in becoming more independent and reaching his goals.

How to Know What Will Help

In the past, there were practically no options for people with ASD in terms of treatments, therapies, and interventions, and this was the source of much anguish and stress. Nowadays, although we still don't know the cause of autism, we know more about what can help people, depending on the symptoms they are showing. Options abound, and the challenge is more about getting the right information and trying to decide what best fits the needs of the person with ASD, before figuring out how to access that treatment or therapy.

In Chapter 4, where and how to get information was discussed. In this chapter, you'll learn more about how to know what can help a particular person with ASD, and about some of the different treatment and therapy options that are available.

Knowing About the Person with ASD

Although there are more therapies and strategies now than ever before, there is still no magic bullet, and every person is different. If you are a person on the spectrum who is fully functional and has no health, emotional, or relational issues: Congratulations! You can skip the rest of this chapter.

Other adults with some challenges may find some useful information here. Many very able people on the spectrum suffer from sensory challenges, gut issues, allergies, anxiety, and panic attacks.

Parents and educators, the first thing you need to do is to look at the person with ASD whom you are trying to help, no matter how young or old he or she is. As discussed earlier in this book, autism is now generally accepted to be a whole-body expression, as a result of genetic predisposition with an environmental impact coming into play. For years, scientists focused only on teaching or psychological strategies and not medical or dietary interventions. As more is discovered about autism, including the gut and brain connection, the more options a parent should consider. Being a parent means becoming an expert in what can help your child.

Here are some things to consider:

- *The age of the person.* A person who is diagnosed at age ten or sixteen or twenty-five or even forty-five will have different therapy and treatment needs from a child diagnosed at eighteen months or three years of age or five years of age. For example, a toddler may need intensive early intervention to learn to speak or develop a system of communication. He or she may be showing some medical challenges, such as immune system problems, allergies, stomach problems, diarrhea, and constipation issues. An older child may have language

skills but limited social skills. Adults may have sensory processing issues that could be helped through physiologically oriented therapies. Remember that although for a long time people have been talking about the early years as the “window of opportunity” for learning, recent research has shown that brains have neuroplasticity, which means that they continue to reorganize themselves by forming new neural connections throughout life.

- *What medical or health issues the person has.* Does your child suffer from constant diarrhea or constipation? Is he overly sensitive to noise and light? Does he bang his head? Is he a finicky eater who will only eat a few specific items? Does she have temper tantrums? These are not part and parcel of autism, but they are clues to health issues your child might be experiencing. Some possible medical challenges may be apparent, others may not.
- *What the person is like in terms of functioning level or ability.* ASD covers a wide range of functioning in terms of behavioral characteristics, communication and social awareness, and sensory integration issues. If a formal diagnosis has been made, any assessments made at that time may give you more information about yourself or the person you’re helping. There are many different assessments that are used, depending on the age and ability of the person: speech and language, occupational therapy, functional behavior analysis, neuropsychiatric tests, and developmental, intelligence, and academic tests. A parent of a child with ASD has a good knowledge base of what their child is able or unable to do, just from living with him and observing his capabilities and deficits.
- *The person’s behaviors.* A diagnosis of autism is still based on observable characteristics, and it is important to look at a child’s behaviors and try to understand what they indicated earlier. Is the child covering his ears frequently when there is a lot of activity in the room? Does he have tantrums when you change his routine? Is he always trying to remove all his clothes? Does he appear clumsy and uncoordinated?

- *Whether the person is a visual, auditory, or kinesthetic learner.* Many people assume that all people with ASD are visual learners and therefore that visual strategies will work with everyone. This is not the case, as some people are auditory learners. It is helpful to establish which sense you or your child uses best.
- *What the person's strengths and weaknesses are.* Every person has strengths, and if you can identify them, you can build on them to fortify the weaknesses. It is important to focus and build upon the child's strengths to motivate him to learn, to create opportunities to learn social skills, and to explore possible work options for the future.
- *What goals this person has, or you have for your child.* Each person needs to think about what their overall goal is. Perhaps it is a general goal of "recovering" a child from autism; perhaps it is to have the child reach his potential. Perhaps it is addressing one particular area of a person's life or skill area where he needs to learn practical or coping skills.
- *What treatments the person has already had (if any).* Looking at what has been helpful and what has not can be useful at times in analyzing whether or not a particular treatment is worth pursuing.
- *Whether or not it is time to reevaluate.* Is the person changing, growing? Perhaps a treatment appropriate at one time is no longer the case. Every once in a while it's a good idea to step back and decide whether the current treatments are still useful or appropriate. It may be time to change or "tweak" a current treatment.

As Donna Williams suggests in the quote taken from her book *Autism: An Inside-Out Approach* at the beginning of this chapter, all these therapies, treatments, and interventions truly need to be looked at with a department-store mentality, rather than a High Street approach. ASD is all-invasive, and rarely does one therapy alone provide all the help a person needs. Therapies or treatments are not exclusive of others, and a visit to different departments or types of therapies is often needed.

What to Consider When Looking at Treatment Options

After looking at the needs of the person with ASD, there are other factors to consider before deciding on what treatments and therapies to pursue at this particular time. Here are some things to consider when looking at treatment options:

- *The potential risk to the individual.* “First, do no harm” should be your mantra. Does the therapy have side effects? Is it risky to mental or physical health? Do the possible risks outweigh the possible gains? Does it use any form of punishment?
- *The family.* ASD is a family thing, as they affect everyone in the household either directly or indirectly. But so does the treatment. The parents have to think about how the treatment or therapy fits into the family. What kind of involvement is expected from others? How will this treatment affect any siblings? Is the family going to be able to follow through with whatever the professional deems necessary (e.g., giving supplements on a regular basis, sticking to a diet, generalizing skills learned)? Can the family commit to the prescribed treatment or therapy for whatever time it takes or is recommended? Are all responsible adults in the household in agreement about the particular treatment and supportive of seeing it through? If the treatment fails, how will it affect the family?
- *The financial cost of the therapy.* Money does not grow on trees. Do you have to sell your home to provide this therapy or intervention? Why is the therapy so expensive and who is benefiting financially from the high cost of this therapy? Is insurance going to cover it? Are you asking for the school district or private health insurance to fund the treatment? If yes, do you have the tenacity to advocate effectively to obtain the appropriate type of service?
- *Where did the information about the therapy come from?* Is the person or organization suggesting the therapy benefiting financially? Unfortunately, autism has become a big business for many.

- *How will the treatment be integrated into whatever existing program the child already has?* For example, in the case of a special diet, how will it be carried over to all of the child's environments? Will the treatment's inclusion be at the expense of other equally important aspects of the child's program?
- *What evidence exists to validate this method of treatment?* Is the therapy being touted as a miracle cure for everyone? Is there scientific validation of this treatment? What does the anecdotal evidence have to say?
- *Is this treatment or therapy autism-specific and, if not, has it proved effective with individuals with ASD?* Some treatments may not be specifically created with ASD in mind, but can be very beneficial. However, it is important to verify how others with ASD have done with this treatment. For example, early intervention is a great concept. Yet some programs do not work well with all children with autism, because most children with ASD do not imitate or tune in to social cues the way other developmentally delayed children do, and therefore need first to be taught how to imitate or understand those social cues.
- *How is the effectiveness of the therapy going to be measured?* With any treatment or therapy, there should be record-keeping in order to track effectiveness. Parents need to ask who is responsible for taking data, how data is taken, how often it is recorded, and how often it is reviewed.
- *What is the track record of the provider of the therapy or treatment?* How long have the practitioners been doing this therapy and with what age group? What level of ability has this person worked with? If it is dietary supplements, is it a reputable company that is making them?
- *Does the person prescribing the treatment or supervising the course of treatment have all pertinent information about the person being treated?* Make sure the person knows as much about the individual in question as possible. It's a good idea to write down anything you think the provider should know, especially if she is dealing with a young

child or someone who is unable to communicate independently about himself. Information that is helpful includes other treatments that may have been tried, the person's likes or dislikes, and particular behaviors the practitioner should know about. Any allergies to food or medication, phobias, chances of seizures, special diets, and so on are all valuable information.

- *What do lab tests show?* Some lab tests can help in understanding if the child has medical challenges or nutritional deficiencies and would benefit from some treatments over others. However, it is important to ensure that the labs used and doctors consulted are reputable and knowledgeable about treating autism.

FOOD FOR THOUGHT

She Had Experience, Just Not the Right Kind

My son is very challenged by sensory integration issues and has many fine and gross motor problems. One year he came home from high school with rug burns on his chest and back, the result of an inexperienced occupational therapist's attempts to perform sensory integration on him. After a few phone calls (and I must say no apology from the therapist or the school district in question), two individualized education program (IEP) team meetings, and a sensory integration (SI) and occupational therapy (OT) assessment, another occupational therapist was brought into the picture. At this point, concerned not only about the quality of my son's educational experience but also for his safety and comfort level, I asked the proposed therapist specific questions about her experience. The therapist said she had a few years of experience with sensory integration, as well as working with adolescents with autism. All seemed well with the world.

After a few months, I received reports from the school that the therapist was concerned about the occupational therapy goals for my son. She felt the goals were unrealistic, and that he was not progressing on any of them. The goals the IEP team had identified were fastening buttons and snaps on his pants and learning to cut with a knife. I met with the therapist to ask how I could help. After chatting with her, I realized that though she had worked with adolescents with ASD, they had been able students who could follow instructions and did not have the same level of motor difficulties as my son. The therapist had not needed to teach these skills before and was unable, in spite of her professional training, to figure out a way to teach my son these basic tasks. I had not thought before to ask about the ability level of the

children she had worked with, thinking that as a professional she could figure things out for varying levels of ability.

The therapist was at a loss about how to teach my son, even though he had a well-trained school aide who was more than willing to help. Needless to say, my son learned to fasten the snaps on his pants after the aide analyzed the different steps, identifying which ones were creating difficulty for him, and then wrote up a task analysis and worked on teaching him this skill in a systematic manner.

So, the moral of the story is, ask the right questions. No matter how long my son has been in the system, I am always learning a few more questions that I should have asked.

Treatments, Therapies, and Interventions

This is not meant to be an in-depth overview of all the treatment options, but rather a brief explanation about the most well-known or currently popular ones. Resources are included for those who want more information. Therapies and interventions are listed here for informational purposes only, and this does not mean that they are endorsed by the author or that they are prescribed for any particular person. The reader should investigate further the treatments that interest them and make an informed decision with professionals and others who may be concerned.

General Resources

If you are a parent, you'll have to become an expert in treatments and educational strategies. In this chapter, I've outlined some basic information. Keep in mind that there are more treatments and therapies available than are listed here. This chapter covers the most widely known and recognized treatments to give you the basic knowledge you need to start your understanding and search for help. Again, remember to keep your child in mind, as well as who you are getting the information from. Remember that the treatment of autism is a growing and changing field, and new discoveries are continually being made. Make sure you are getting the most

current information. In the end, you will have to decide how to best help your child.

Here are some websites and books for a more in-depth understanding of options to consider. Following each treatment section are more specialized resources.

- “Advice for Parents of Young Autistic Children” by James B. Adams, PhD; Stephen M. Edelson, PhD; Temple Grandin, PhD; Bernard Rimland, PhD; and Jane Johnson. Available on the ARI website at autism.com/index.php/understanding_advice.
- *The Autism Revolution: Whole-Body Strategies for Making Life All It Can Be* by Dr. Martha Herbert and Karen Weintraub. Dr. Herbert is a Harvard Medical School researcher and clinician. Her website is autismrevolution.org. The companion website to her book with complementary information is autismwhyandhow.org.
- *Autism Solutions: How to Create a Healthy and Meaningful Life for Your Child* by Ricki G. Robinson, MD, MPH (drrickirobinson.com). Dr. Robinson is the medical director of the Profectum Foundation (profectum.org), was a founding board member of Cure Autism Now (CAN, now Autism Speaks) and the Interdisciplinary Council on Developmental and Learning Disorders (ICDL), and currently serves on the Scientific Review Panel of Autism Speaks. There is training available on the Profectum website.

Healthy Bodies

Effective teaching methods are extremely important, but so is physical and neurological health. In Chapter 3, possible causes of autism were discussed, as was the brain–gut connection. If a child is experiencing pain or if the body is not absorbing needed nutrients, learning can be difficult, if not impossible. Remember that behavior is a form of communication. If a person often has tantrums for no apparent reason, it could be that he or she is in pain of some sort. Some children’s digestive systems are not working

properly, making it impossible to digest essential nutrients needed for brain development. If a child has sensory challenges, this will impact everyday life. Scientists are hard at work discovering all the secrets the brain has to offer, and much is still unknown. However, as there is a definite connection between the body and the brain, a healthy body is a priority.

Before starting any of these interventions, data should be taken over at least a two-week period on all of the person's negative (tantrums, hyperactivity, bedwetting) and positive (communication, interactive play, staying on task, eye contact) behaviors. This will give a baseline of the behaviors before treatment. During and after treatment, the same types of notes should be taken. This will enable you to judge whether or not the treatment is having any effect.

Dietary and Nutritional Approaches

It's a given that a nontoxic environment is best for all, and that we are what we eat. Many on the spectrum are particularly sensitive.

What follows is a basic overview of some of the dietary and nutritional approaches that are being used to treat ASD. Some of these approaches have empirical research to back them up. Some have much anecdotal testimony. Some of these approaches are noninvasive and worth trying; others should only be done under the care of a knowledgeable health professional.

These approaches can be effective in helping people whose metabolic systems may not be functioning properly. It may be that their systems are not processing essential nutrients properly, possibly because of a food allergy or intolerance, a "leaky gut" (where the wall of the intestine does not do its job of keeping its contents separate from the bloodstream), or high levels of mercury or other toxic metals. It is possible to check for food allergies by adding or removing the suspected culprit from the person's diet and taking data on their behavior before and after. Essential nutrients can be tested in the same way. However, there are specific tests and analyses that can be done that are more indicative of what is going on in the metabolic system.

Dietary and nutritional interventions can be confusing for anyone who is not medically inclined. Please keep in mind that what follows is not a complete analysis of all the possible interventions, and that interventions are constantly being improved upon.

Eating Healthy

The general public over the last ten years has learned more and more about the importance of making good food choices, from eating organic foods to consuming less sugar and fewer additives. As humans, we need certain fundamental nutrients for our bodies to function well and these include certain vitamins and minerals, essential fatty acids, and amino acids (from protein). These essential nutrients can be found in a balanced diet rich in fruits and vegetables, protein, and certain fats.

FOOD FOR THOUGHT

The Power of Sharing Knowledge

Thirty years later, Dr. Rimland and I had lunch down the street from my home and office in Connecticut. I expressed how inadequate I felt in understanding the digestive and immune system problems of the autistic children I was seeing in increasing numbers. I asked Dr. Rimland if he could gather some smart people to brainstorm the problems. I knew one smart person, Jon Pangborn. Bernie knew dozens around the world. Within a few months he had organized and named the first DAN! meeting, an extraordinary gathering of thirty practitioners, researchers, and parents who found common ground in a new map of the landscape that emerged from the mirage that once simply cast blame on mothers.

—Sidney MacDonald Baker, MD, *from the Defeat Autism Now! 2002
Conference Presentations Book*

Eating healthy is a good starting point. Some guidelines:

- Reduce or avoid:
 - additives such as artificial colors, artificial flavors, and preservatives
 - junk food (e.g., fried chips)
 - added sugar (e.g., candy, soda)
 - fried foods or foods containing trans-fats
- Eat three to four servings of vegetables and one to two servings of fruit each day. Corn is not considered a vegetable; it is a grain. Potatoes have limited nutritional value, especially when fried. It's better to eat whole fruits than to drink fruit juice, but fruit juice is a better choice than soda.
- Eat at least one to two servings per day of protein (meat, chicken, eggs, nuts, beans). Some children may need smaller protein snacks eaten more frequently. This could be the case if your child is irritable between protein feedings.
- Eat organic foods whenever possible, as they contain lower levels of pesticides. As well, organic milk and chicken have higher levels of essential omega-3 fats.

The Feingold Diet

This diet was developed by Dr. Ben Feingold to treat hyperactivity in children. In his book *Why Your Child Is Hyperactive*, he recommends removing artificial colorings and flavorings, salicylates, and some preservatives from children's diets. Salicylates are a group of chemicals related to aspirin and found in certain fruits and vegetables. His hypothesis was that more and more children were being seen and treated for hyperactivity at the time the book was published due to the increase in artificial ingredients being added to our food and the increase in the

consumption of processed foods. The Feingold Association of the United States (feingold.org) can provide further information.

Gluten-Free/Casein-Free (GFCF) Diet

The GFCF diet has been developed for individuals who have allergies or a toxic response to gluten (found in wheat, oats, rye, and barley, among others) and casein (found in dairy products).

Responses to gluten and casein can include diarrhea, constipation, hyperactivity, red face or ears, breaking wind frequently, and pale skin. (However, it is important to note that these symptoms can be an indication of other problems.) Basically, peptides that are derived from an incomplete breakdown of certain types of food are affecting neurotransmission within the central nervous system. Research studies as well as hundreds of anecdotal reports have shown dietary intervention as a useful treatment for alleviating some of the symptoms of autism in children. Out of 3,593 reports on the GFCF diet submitted to Autism Research Institute (ARI) Survey of Parent Ratings of Treatment Efficacy, 69 percent of children fared better and 28 percent saw no change. It is less clear what the effect is on adults. This type of treatment, though constraining in terms of diet, is not harmful, and it may be worth removing gluten and casein from your child's diet to see if it has an effect on his behavior. It is recommended to remove 100 percent of dairy for one month and gluten for three months. There are lab tests that can be done as well. Some individuals have challenges with corn, soy, and other foods. To follow this diet accurately and to ensure that all products are GFCF, it is important to carefully read product labels.

For practical information and support from other parents who have experience in this area, visit tacanow.org/tag/gfcf.

RESOURCES

Autism Network for Dietary Intervention: autismndi.com

Special Diets for Special Kids by Lisa Lewis

Nourishing Meals by Alissa Segersten and Tom Malterre

The Kid-Friendly ADHD and Autism Cookbook by Pamela Compart, MD; Dana Laake, RDH, MS, LDN; Jon B. Pangborn, PhD, FAIC; and Sidney MacDonald Baker, MD

Digestive Wellness by Elizabeth Lipski

The Specific Carbohydrate Diet (SCD)

The SCD is based on the diet that early man ate before agriculture began and consists of meat, fish, eggs, vegetables, nuts, and low-sugar fruits. The SCD consists basically of avoiding all carbohydrates and most sugars (except monosaccharides in fruit). Some individuals with autism have low levels of digestive enzymes for certain sugars and carbohydrates. It makes sense to consider the SCD in patients who do not respond well to a GFCF diet. To insure proper implementation of the SCD, it is recommended to find an experienced nutritionist to help you.

RESOURCES

Breaking the Vicious Cycle by Elaine Gottschall

breakingtheviciouscycle.info/home

pecanbread.com

The Ketogenic Diet

This diet has been developed for people who have seizures. It is high in fat, low in protein and carbohydrates. When the body burns fat instead of carbohydrates for energy, it creates ketone bodies, which in turn suppress seizure activity. This is not a healthy, balanced diet; it is difficult to undertake, and it has to be tailored specifically for each person. It is usually considered to be a last-ditch effort when medications are no longer effective, and should not be attempted without the supervision of a neurologist and a knowledgeable dietician.

RESOURCES

epilepsyfoundation.org/aboutepilepsy/treatment/ketogenicdiet

Ketogenic Diets by Eric H. Kossoff, MD; John M. Freeman, MD;
Zahava Turner, RD, CSP, LDN; and James E. Rubenstein, MD

Vitamin and Mineral Supplements

As explained earlier, proper nutrition is necessary. However, the typical U.S. diet is lacking in needed vitamins and minerals. One way to get more vitamins and minerals is by juicing vegetables and fruits. Another way is by taking supplements. Not all supplements are created equal. Some manufacturers of supplements voluntarily participate in the Dietary Supplement Verification Program (DSVP) of the U.S. Pharmacopeia (USP). The USP is a program that verifies that the contents of a supplement match the label. Check for a USP or DSVP label, or go to usp.org/USPVerified to check a product.

Vitamin B6 and Magnesium

This is one of the most studied nutritional supplements, with twenty studies published since 1965. These studies have shown benefits to taking vitamin B6 (often combined with magnesium), and none have shown harm. In fact, almost all of these studies found that 30 to 40 percent of children and adults with autism benefited from high-dose supplementation of vitamin B6 with magnesium. Some of the benefits reported have been improved eye contact, improved language, reduced self-stimulatory behavior, reduced aggression, and reduced self-injurious behavior.

Essential Fatty Acids

It has been recognized that EFAs are critical nutrients that have a very important role to play in the metabolism and development of the body. However, due to the way our foods are now processed plus the fact that we do not swallow a daily spoonful of cod liver oil the way our grandparents

did, it has become apparent that most of us are not getting the fatty acids our bodies need.

Two general categories of essential fatty acids are omega-3 and omega-6. There are many scientific studies showing that people need EFAs, and that most in the United States do not consume enough. Four published studies have found that children with autism have lower levels of omega-3 fatty acids than the general population. To date, there have been nine treatment studies for children/adults with autism on the effects of EFAs, six positive and three inconclusive or negative.

Other Vitamin and Mineral Supplements

For more information on research, and the importance of the many other different vitamins and minerals, read “Summary of Dietary, Nutritional, and Medical Treatments for Autism—Based on Over 150 Published Research Studies” by James B. Adams, PhD

(autism.asu.edu/Docs/2012/Summary_dietary_nutritional_medical_treatments9-30-12.pdf).

Other Nutritional and Medical Treatments

There are other important nutritional and medical treatments that have been effective for some, and ineffective for others, and parents need to figure out what could be useful for their child. These treatments include probiotics, digestive enzymes, amino acids, carnitine, melatonin, thyroid supplementation, sulfation therapies for methylation/glutathione/oxidative stress, immune system regulation, and hyperbaric oxygen therapy (HBOT). There is not space here for an in-depth discussion of the treatments, but there are resources below with specific information on each treatment.

As a parent, you are an expert on your child. As a parent of a child with autism, you'll need to do the homework on what could help your child. Reading studies and discussing with knowledgeable professionals and parents is necessary. Below are good resources for parents to consult for a more in-depth understanding of the options available.

RESOURCES

“Summary of Dietary, Nutritional, and Medical Treatments for Autism —Based on Over 150 Published Research Studies” by James B. Adams, PhD
(autism.asu.edu/Docs/2012/Summary_dietary_nutritional_medical_treatments9-30-12.pdf). This is a clear summary of the rationale and research on dietary, nutritional, and medical treatments, and should be read by anyone considering the above approaches.

Nutritional Supplement Use for Autistic Spectrum Disorder by Jon B. Pangborn, PhD. This is published by the Autism Research Institute, founded by Dr. Bernard Rimland. Dr. Pangborn is not a medical doctor, but has been associated with the Autism Research Institute for over thirty years and practiced as a licensed and certified nutritionist (in Illinois).

Talk About Curing Autism (tacanow.org), founded by Lisa Ackerman, is a very supportive resource for families. The website has lots of information including an autism journal to help understand about possible treatments, and support groups around the country. Again, as a parent you will need to choose what makes sense for you and your child.

Medical Academy of Pediatric Special Needs (MAPS) (medmaps.org): Practitioners are listed here as well as training opportunities for medical professionals.

—To find practitioners by geographical area, visit the websites of MAPS, Autism Society of America, and Autism Speaks.

—For a list of what to consider when searching for practitioners, go to the ARI website (autism.com/index.php/treating_finding).

Conventional Medications

Medications can be used to treat some of the behaviors associated with autism. Certain drugs are used to control seizures. For some people, drugs can be helpful for reducing anxiety, obsessive-compulsive behaviors, hyperactivity, self-injurious behaviors, attention deficits, and depression. Medications used include anticonvulsant drugs, stimulant medications, tranquilizers, antidepressants, and opiate antagonists. No medication should be tried without the advice of a knowledgeable physician familiar with ASD and the person being treated. As well, these medications should be part of an overall treatment program, as these medications may help with symptoms but do not always address the cause. Most of these medications should be tried in very tiny doses, less than the manufacturers' recommendation. Care should be given especially when treating young children, as many of these medications have only been researched for use in adults.

For more information on particular drugs, read the section on psychiatric medications in "Advice for Parents of Young Autistic Children" (2012, Revised) available at the ARI website at autism.com/index.php/understanding_advice.

Addressing Sensory Processing Challenges

Jean Ayres, an occupational therapist, first described sensory integration dysfunction as a result of inefficient neurological dysfunction. The auditory, visual, tactile, taste, and smell senses are what give us information about the world around us. Individuals with sensory disorders have senses that are inaccurate and send false messages. Children and adults with hypersensitivity overreact to stimuli, while others have hyposensitivity, which prevents them from picking up information through their senses. Sensory malfunction can also be an inability to understand and organize sensory information when it is received. Sensory integration dysfunction symptoms are many and varied, depending on which sense or senses are perturbed. When he has auditory sensitivities, a child may cover his ears, overreact or underreact to noise, or try to escape from groups. Tactile sensitivities can be indicated by a seemingly high tolerance for pain, refusal

to keep socks and shoes and sometimes clothes on, difficulty in brushing teeth and hair, or dislike of having hair washed. Visual issues may be apparent if a child is sensitive to light, likes to watch things spin or move (tops, hands on a clock), spins himself or other things, or turns lights on and off. These are just a few examples of behaviors that display sensitivities in certain areas.

Sensory issues are not autism-specific, and therefore the methods below were not specifically developed for people with autism. Many children and adults who have sensory disorders do not have ASD.

There is a strong connection between sensory processing and learning. If a child cannot visually or auditorily process information correctly, it will be difficult for him to learn. For some it will be hard to function in certain environments. There is a connection between visual processing and how we move in space, and hand-eye coordination. This impacts emotional development as well. Sensory processing challenges are significant for many on the spectrum, impeding their ability to learn and to function on a daily basis.

Some sensory challenges may be improved by dietary and nutritional approaches discussed earlier in this chapter. It is important that you choose therapy providers who have experience with ASD and the age group of the person seeking treatment.

Sensory Integration (SI)

This is practiced by occupational therapists, who contend that many behaviors exhibited by children and adults with autism are an attempt to avoid certain types of sensations or seek preferred stimuli in order to balance out their nervous system. Occupational therapists who are well trained in sensory integration behavior and skills use various strategies to assist individuals with ASD to process and use sensory information. Data from patient records show these improvements. SI can be a valuable intervention, integrated into a child's program, depending on the person's sensory issues.

RESOURCES

The Out-of-Sync Child and *The Out-of-Sync Child Has Fun* by Carol Stock Kranowitz (out-of-sync-child.com)

Raising a Sensory Smart Child by Lindsey Biel, OTR/L, and Nancy Peske ([Sensory Smarts: sensorysmarts.com](http://SensorySmarts.com))

Auditory Integration Training (AIT)

These methods, developed by Dr. Guy Berard and Dr. Alfred Tomatis, are based on the theory that some people have hypersensitivity toward certain sound frequencies, making some common sounds painful to hear. In AIT, individuals wear headphones and listen to modulated sounds and music, with certain frequencies filtered out. This is done over a period of time. It is not known exactly how it works, physiologically speaking; however, individuals have reported benefits from these listening methods. An ARI review of twenty-eight reports of studies undertaken between 1993 and 2001 on AIT developed by Dr. Berard favors this method as a useful intervention. Other listening programs have been developed that can be used at home without any special equipment, and some are listed below.

RESOURCES

Dr. Berard: berardaitwebsite.com/index.htm

Dr. Tomatis: tomatis.com

The Sound of a Miracle by Annabel Stehli (about her daughter's recovery from autism through AIT)

Listed below are two programs that have been developed for home and school use. For more information, read about the different types of programs and ask professionals and parents who have used them about the benefits and drawbacks of each of the different methods.

Samonas Auditory Intervention: listening-ears.com/samonas.html

The Listening Program: advancedbrain.com/the-listening-program/the-listening-program.html

Vision Therapy

Vision processing is important for learning, for making sense of the world around us. As Dr. Carl Hillier puts it, “Eyesight is the ability to discriminate the differences between the small things. Vision is the ability to derive meaning from the world, and to guide the intelligent movement of the body.” A regular eye exam will tell you if your child has 20/20 vision, but it won’t tell you if your child is having visual-processing difficulties. An assessment should be done by a developmental optometrist. If needed, vision therapy will be recommended. Vision therapy is an individualized treatment program designed to correct visual-motor and/or perceptual-cognitive deficiencies.

RESOURCES

To find a developmental optometrist, go to covd.org.

To learn more about vision versus eyesight, read “Vision and Its Valiant Attempt to Derive Meaning from the World” by Carl G. Hillier, OD, FCOVD, at visionhelp.com/vh_add_07.html.

To find out more about vision therapy, go to visionhelp.com.

To read about the connection between vision and development and learn some activities to try with your child, read *Visual/Spatial Portals to Thinking, Feeling and Movement* by Serena Wieder, PhD, and Harry Wachs, OD.

FOOD FOR THOUGHT

The Verbal Behavior Approach

BY MARY LYNCH BARBERA, PHD, RN, BCBA-D

The verbal behavior (VB) approach is a type of applied behavior analysis (ABA) program used to teach children with autism. More than five hundred articles published since 1985 concerning ABA and autism have elevated ABA to be the treatment of choice for children on the spectrum, especially young, newly diagnosed children (Lovaas Institute, 2013).

The move toward the VB approach (as opposed to more traditional ABA programs) began in 1998 with the publication of *Teaching Language to Children with Autism or Other Developmental Disabilities* (Sundberg & Partington, 1998). Since the late '90s, with more published research studies and VB books including *The Verbal Behavior Approach: How to Teach Children with Autism and Related Disorders* (Barbera & Rasmussen, 2007) and *The Verbal Behavior Milestone Assessment and Placement Program* (Sundberg, 2008), many home and school ABA programs are now using the VB approach.

I am often asked, "Which is better, ABA or VB?" I say that this is like asking, "Which is better, a pet or a cat?" In a nutshell, ABA is the science of changing behavior and VB is a *type* of ABA, just as a cat is a *type* of pet. As a BCBA, I follow the principles of ABA first and foremost, but I also use B. F. Skinner's analysis of verbal behavior (or, in easier terms, the VB approach) as I assess and teach language and learning skills (Barbera, 2009). After working with hundreds of children and some adults on the autism spectrum, I have found that implementing scientifically proven ABA/VB techniques results in improvements in behavior, language, and learning skills no matter what the age or ability level of the child.

It all started in 1957, when B. F. Skinner published his classic book titled *Verbal Behavior*. This book described language as a behavior and defined verbal behavior as any behavior mediated by a listener. One thing to keep in mind is that a child does not need to speak to be "verbal" since verbal behavior includes gestures, sign language, exchanging pictures, and pointing. A child who falls to the floor or hits you is also displaying verbal behavior. As long as a listener is present and a child is displaying some behavior to communicate, that behavior is verbal behavior.

In *Verbal Behavior*, Skinner coined the term "verbal operant" and created names for the four elementary verbal operants: the mand, tact, echoic, and intraverbal. These four verbal operants are the parts of verbal behavior that traditional linguists and speech therapists often call "expressive language." Skinner also described "listener responding," which is equivalent to receptive language.

Using the VB approach, both receptive and expressive parts of language are seen as behaviors that can be taught with each function of the word being taught directly. The various functions of the word "ball," for example, would be taught usually by using verbalization or sign language. The child would be taught to ask for or, in VB terms, mand for the ball when he wanted it. Once the mand is mastered, the child would then be taught to label (tact) a picture of a ball, to say (echo) "ball" when the adult said "ball," to touch the ball when directed to do so, and finally to answer questions (respond with an intraverbal) about a ball.

When starting a VB approach program, it is important to assess what items and activities your child likes and to pair the work area, the people who interact

with your child, and the materials with these items. Once the reinforcers have been identified and paired, the central theme for a VB approach is to teach your child how to request things since the mand should be the centerpiece of VB programming.

Because the teacher and parents focus on pairing and manding, the child should willingly approach them, as opposed to some other programs where the child is brought to the worktable, whether he wants to be there or not. In the VB approach, the child immediately starts receiving the things he likes. Once this relationship has been established and the child is responding to and asking for reinforcers, other work is slipped in very gradually.

Studies show that children with autism, in order to make optimal progress, require up to forty hours per week of school and/or home-based ABA programming with well-trained therapists and oversight by skilled professionals. But, for a variety of reasons, including lack of skilled professionals and financial constraints, many families cannot implement full ABA programs. But, even without implementing forty hours per week of ABA/VB programming, there are several scientifically proven techniques (such as focusing on the mand first) that parents and teachers can immediately begin using to help children with autism and related disorders.

Mary Lynch Barbera, PhD, RN, BCBA-D, offers a unique perspective as a parent of a child with autism, a Board Certified Behavior Analyst, and an author. In 2007, she published The Verbal Behavior Approach: How to Teach Children with Autism and Related Disorders (which is now available in several languages). For more information about Dr. Barbera or the VB approach, visit barberabehaviorconsulting.com.

Irlen Lenses

Irlen lenses were developed by Helen Irlen for individuals with a sensory perceptual problem known as Irlen syndrome. Irlen's theory is that people with reading problems and perceptual difficulties are very sensitive to white-light spectrum wavelengths, which overstimulate certain cells in the retina, resulting in incorrect signals being sent to the brain. She found that by placing different-colored overlays on printed pages, light sensitivity and perceptual distortions were reduced. These colors were then applied as a tint on glasses. There is no strong empirical research to support the use of Irlen lenses as an autism-specific therapy; however, colored overlays on printed matter and tinted glasses have been shown to be helpful for a number of schoolchildren. There is anecdotal evidence that some people with ASD

have light sensitivity, and many have reported a major difference in their sensory processing when wearing tinted glasses.

RESOURCES

irlen.com

Reading by the Colors by Helen Irlen

Intensive Teaching Approaches

Here are two intensive teaching approaches. Applied Behavior Analysis works on specific skills to improve a person's level of functioning. In DIR/Floortime, mastering emotional milestones is considered important before working on skills the person needs to learn. Other educational strategies are also useful and some are listed below or in Chapter 7.

Applied Behavior Analysis (ABA)

ABA has been used for many years to successfully teach individuals of varying abilities, and can be used to teach in all skill areas, including academic, self-help skills, speech and language, and socially appropriate behavior. Specific skills are taught by breaking them into small steps, teaching each step one at a time, building on the previous one. Different methods are used to help the child learn, such as prompting (helping the child by guiding him through the desired response), shaping, and rewarding (for correct responses).

B. F. Skinner is the grandfather of ABA, thanks to his study of “operant conditioning” and his book *The Behavior of Organisms*, published in 1938. ABA is based on the theory that all learned behaviors have an antecedent (what happened before the behavior was exhibited) and a consequence (what happened after the behavior was exhibited) and that all such behavior is shaped by the consequences of our actions, meaning that we are motivated by the consequence to repeat that behavior. For example, most

adults work because they are rewarded by a wage or salary. If they stopped receiving that wage, they would stop working.

FOOD FOR THOUGHT

DIR/Floortime

BY DR. JOSHUA FEDER

Developmental individual differences relationship-based intervention (DIR/Floortime) is, like applied behavioral analysis (ABA), an approach to evidenced-based practice that is used for a variety of purposes and, like ABA, has been used extensively for helping people with autism and related challenges learn to relate, communicate, and learn.

ABA focuses on looking at the antecedents and consequences of behavior, working toward compliance, knowledge, and skills. By contrast, DIR/Floortime supports caregivers (parents, teachers, others) to develop trusting relationships with a person with challenges, through which the person can become more able to communicate, relate, and learn. As part of this process, we look at the person's abilities and challenges to being regulated, such as sensory, motor, and cognitive difficulties, and use that understanding to help the person be more regulated with us, in a widening range of settings, and to interact with us in a flow of interaction. The interaction, as with anyone, is what helps the person learn to be heard, to problem solve, and to learn.

DIR/Floortime works from the person's desires and ideas to build these abilities, and so there is internal initiation and motivation to learn and integrate new skills and information. Although less widely known, research on autism intervention supports the aims of DIR/Floortime as evidenced-based practice. DIR and ABA can be complementary or used separately. Families should have information on a range of interventions so that they can make informed consent decisions about what might be best for them.

Dr. Joshua Feder is director of research at the Graduate School of the Interdisciplinary Council on Developmental and Learning Disorders, voluntary associate professor at UCSD School of Medicine, and medical director at SymPlay, teaching, advocating, and developing technology to support relationship-based interventions (joshuafedermd.com).

Some of the terms used in ABA include:

- *Task analysis.* This consists of analyzing a skill or task that needs to be taught, by identifying each step of the skill, and which steps the person needs to learn. For example, if teaching someone at home how to set the table, you would analyze the whole sequence: walking to the cupboard, opening the cupboard with the right hand, picking up a plate with the left hand, closing the cupboard with the right hand, walking to the table, and so on.
- *Discrete trial teaching (DTT).* This is a method of teaching that is very systematic and consists of the teacher's presentation or request, the child's response, and the consequence to that response (i.e., a reward if correct); a short pause, and then the next trial. Each trial is "discrete"—that is to say, separate—so it is clear what is being requested of the child, and what is being rewarded.
- *The Lovaas method.* This is an intensive ABA program, aimed at preschool children, developed by Dr. O. Ivar Lovaas at the UCLA Young Autism Project. In 1987 Lovaas published a study that showed dramatic results on nineteen children with autism who had received intensive ABA therapy: The average gain in IQ was twenty points, and 47 percent of the children (nine of them) completed first grade in a mainstream class. In 1993, eight of the nine were still enrolled in mainstream classes and had lost none of their skills.
- *Verbal behavior therapy.* This is ABA therapy as it pertains to language behavior and is based on Skinner's behavioral analysis of language.
- *Errorless learning (no-mistake learning).* When a new behavior is taught it is important for the student to be successful from the beginning. Thus, teachers *prompt* a successful behavior, physically motoring the student through if necessary. The prompts are gradually removed so that the behavior will eventually occur simply in response to a request or some other cue.

Care should be taken when choosing ABA providers. Check with your local autism support group about the ones in your areas. For more

information on board-certified providers, go to the Behavior Analyst Certification Board's website (bacb.com).

RESOURCES

Teaching Developmentally Disabled Children: The ME Book by O. Ivar Lovaas

A Work in Progress: Behavior Management Strategies and a Curriculum for Intensive Behavioral Treatment of Autism by Ron Leaf, John McEachin, and Jaisom D. Harsh

Crafting Connections: Contemporary Applied Behavior Analysis for Enriching the Social Lives of Persons with Autism Spectrum Disorder by Mitchell Taubman, Ron Leaf, and John McEachin

The Verbal Behavior Approach: How to Teach Children with Autism and Related Disorders by Mary Barbera

DIR/Floortime

DIR/Floortime was developed by Dr. Stanley I. Greenspan as part of his developmental approach to therapy. Parents and Floortime therapists help children master the emotional milestones needed to develop a foundation for learning. The approach is based on Greenspan's belief that emotions give meaning to our experiences, as well as a direction to our actions. Floortime seeks to have the child develop a sense of pleasure in interacting and relating to others, and is done through play, based on the child's interests, and through creating an increasingly larger circle of interaction between the child and an adult. Parents and therapists work on four goals: encouraging attention and intimacy, two-way communication, encouraging the expression and use of ideas and feelings, and logical thought. This method is often used as the play component for children who are in ABA programs.

RESOURCES

The Interdisciplinary Council on Developmental and Learning
Disorders: icdl.com

Profectum: profectum.org

stanleygreenspan.com

*Engaging Autism: Using the Floortime Approach to Help Children
Relate, Communicate, and Think* by Stanley I. Greenspan and
Serena Wieder

Visual/Spatial Portals to Thinking, Feeling, and Movement by Serena
Wieder, PhD, and Harry Wachs, OD

Speech and Communication

Communication is one of the most basic skills that we have and need. We hope that all children will learn to speak. However, not all children with autism develop speech early on.

Speech therapy can be very helpful and is necessary if you have a child who is behind in his language development. If your child has delays or is not speaking, it is important to get an assessment and begin therapy with a qualified and experienced speech and language pathologist. Check with other parents in your area, or use this listing to find a professional near you: speech-therapy-information-and-resources.com.

FOOD FOR THOUGHT

Facilitated Communication and Supported Typing

BY DARLENE HANSON, MA, CCC

Some children have a hard time developing speech. It's important to offer alternative ways of communicating, which research shows actually can help speech develop. One method is facilitated communication training (FCT), which is a strategy that provides physical, communicative, and emotional support to the individual as he or she communicates. The strategy is described

through what we know about praxis or motor planning, memory, language development, social communication, augmentative communication (use of alternate modes of communication), and natural supports.

Many individuals who require the support described in FCT are able to demonstrate literacy skills such as understanding print, word formation, and written language. Some who use FCT use it to communicate more reliably, and consistently access the use of icon-based communication, such as with line drawings or photos. Others may use FCT or supported typing to communicate using a keyboard. The identification of the need for support does not mean the person is literate. It does mean the person can communicate more efficiently with support.

Those using the strategy of FCT according to the “Standards of Best Practice” do so using the least to most hierarchy of support, for example from the wrist to light touch on elbow to shoulder to no support. Therefore, the least amount of support should be provided for the most communication. It is also recommended that those who use FCT develop and use more independent communication to meet as many of their communicative needs as possible. This can be in the form of limited speech, communication books with line drawings, sign language, or other systems. The individuals are also encouraged to develop a reliable means of communication without the need of support. These are goals, and independence is a process.

The efficacy of the FCT strategy is found in both qualitative and quantitative research (see soe.syr.edu/centers_institutes/institute_communication_inclusion/Research/default.aspx). Many bodies of research attempt to prove the efficacy through “blind tests” and “double-blind” tests. Other researchers have chosen to look at the use of the strategy in more natural and purposeful moments. The strategy itself dates back to the 1970s when Rosemary Crossley began documenting the use of support for individuals with severe communication needs in Australia. In 2000, the Facilitated Communication Institute at Syracuse University published “Standards of Best Practice for Facilitated Communication.”

Providing a person who does not have efficient use of their speech with a way to communicate is important. When using augmentative communication, some people need support to do so. The provision of support using best practices and augmentative communication can open doors to those without efficient communication.

Darlene Hanson, MA, CCC, director of communication services, WAPADH, is a speech and language specialist with an expertise in working with individuals with severe communication impairments, and has been working in this field for almost thirty years. Her work focuses on bringing alternative modes of communication to those who do not use speech to communicate effectively. She is recognized as a Master Trainer in Facilitated Communication, has participated in the writing of the “Standards of Best Practice for Facilitated Communication” from Syracuse University, and has coauthored research on

Some children develop speech later with the help of speech therapy. However, there are still many children who have difficulty using speech. It's important to realize that if your child does not have an appropriate way to communicate, he will communicate with his behaviors—many of them inappropriate. It can be very frustrating for a child or teen who has no way of communicating. Even if the goal for your child is to use his voice to communicate, research shows that using alternative and augmentative forms of communication (AAC) helps speech develop.

Some alternative and augmentative forms of communication include sign language and using devices specifically designed for communication purposes. There are many apps that have been developed for tablets and smartphones, such as the iPad and iPhone. AAC devices are much more costly than the iPad, but they may be covered by insurance.

For information on AAC devices, go to asha.org/public/speech/disorders/AAC.

New communication apps are being created all the time, and a speech and language pathologist who is experienced in working with students with severe communication challenges should be able to advise you. For example, there is Proloquo2Go, which enables a child to create sentences with picture icons or words (much like PECS, see page 121) or to type with voice output. There are other apps for those who type that provide voice output such as Assistive Chat. Check with other parents and educators on what is currently available.

Some other alternative methods of alternative communication are listed below.

Supported Typing/Facilitated Communication (FC)

FC is a form of AAC in which people with disabilities and communication impairments express themselves by pointing (e.g., at pictures, letters, or objects) or, more commonly, by typing (e.g., with a keyboard). A

communication partner may provide needed supports, including emotional encouragement, communication supports, and a variety of physical supports (e.g., monitoring to make sure the person looks at the keyboard and checks for typographical errors) to slow and stabilize the person's movement, to inhibit impulsive pointing, or to spur the person to initiate pointing; the facilitator should never move or lead the person.

It often is referred to as facilitated communication training (FCT) because the goal is independent typing, nearly independent typing (e.g., a hand on the shoulder or intermittent touch), or a combination of speaking with typing—some individuals have developed the ability to read text aloud and/or to speak before and as they are typing. Typing to communicate promotes access to social interaction, academics, and participation in inclusive schools and communities. To read the research on FCT, go to soe.syr.edu/centers_institutes/institute_communication_inclusion/Research/default.aspx.

Rapid Prompting Method (RPM)

RPM is a method used for teaching academics by eliciting responses through intensive verbal, auditory, visual, and/or tactile prompts. RPM aims to increase students' interest, confidence, and self-esteem. Prompting is intended to keep students focused while allowing students to be successful. This is a very low-tech method requiring only paper and pencil to begin with. A lesson might begin with a teacher's simple statement, followed by a question about what was just said. Next, the teacher writes possible answers and spells the choices aloud. Students learn to select answers by picking up choices and eventually pointing to letters on an alphabet chart or keyboard to spell answers. RPM was developed by Soma Mukhopadhyay (see page 131). For more information, visit Helping Autism Through Learning and Outreach (HALO) at halo-soma.org.

Picture Exchange Communication System (PECS)

PECS is a practical communication system that allows a person to express his needs and desires without being prompted by another person, by using pictures or a series of pictures to form a sentence. The child first learns to communicate by handing someone a picture of the object he wants, then sentence strips, and so on. Not only does this facilitate communication, it motivates the child to interact with others. PECS is easy to incorporate into any existing program, and does not require expensive materials.

Behaviorally based instructional techniques are used to implement the program (such as prompting, shaping, fading, and so on). Basic concepts such as numbers, colors, and reading can be taught using PECS, and the picture icons can be used for visual schedules to help the child.

Codeveloped by Andy Bondy and Lori Frost, this method helps relieve the frustration of those unable to speak and does not inhibit a child's ability to acquire and use speech. Many children who began with PECS have gone on to develop verbal language.

For more information, visit Pyramid Educational Consultants at pecs.com.

Social Relationships

Social relationships are important for all people, yet are difficult for many on the autism spectrum to develop naturally. Developing relationships entails having social skills, knowing about expected yet often unstated rules of behavior, and social boundaries. Below are a different ways of teaching what children with ASD need to learn about relationships.

Social Skills Training

Social skills are a difficult area and need to be taught for those with ASD. There are different methods of teaching social skills. Here are some of them:

Social stories. This method promotes desired social behavior by describing (through the written word) social situations and appropriate social responses. Developed by Carol Gray, social stories may be applied to

a wide variety of social situations and are created with the learner, who takes an active role in developing the story.

Social stories usually have descriptive sentences about the setting, characters, and their feelings and thoughts, and give direction in regard to the appropriate responses and behaviors. Comic strip conversations are illustrations of conversations that show what people say and do, as well as emphasize what people may be thinking. Social stories and comic strip conversations can be adapted to many functioning levels and situations, and anyone can learn to create them. They are particularly useful for learning how to deal with unstructured time, such as recess and lunchtime.

RESOURCES

Comic Strip Conversations: Colorful Illustrated Interactions with Students with Autism and Related Disorders by Carol Gray

The New Social Story Book by Carol Gray

The Original Social Story Book by Carol Gray

Social skills groups. These teach specific social skills by breaking them down and providing practice in a “safe” environment. Depending on the age or grade level, different social skills are emphasized, including making conversation; taking turns; joining a group; dealing with bullying; friendship; and understanding facial expressions. Social skills training usually takes place in groups of four to six children and is usually beneficial for the more able person with ASD. Social skills development is one of the biggest challenges children with ASD face, and a well-structured social skills group can be beneficial. For more information, see udel.edu/bkirby/asperger/social.html.

Social thinking. “Social thinking” is a term that was coined more than fifteen years ago by Michelle Garcia Winner, a speech pathologist who developed the related approach for her students with high-functioning autism and related challenges in San Jose, California. This approach is different from teaching social skills because it teaches the specific needed thinking strategies that occur before social interaction and communication take place. Social thinking refers to the thinking we do about people, which

affects how we behave, and then how people respond to us, which then affects our own emotions.

RESOURCES

Thinking About YOU Thinking About ME by Michelle Garcia Winner
socialthinking.com

Hidden Curriculum

The hidden curriculum refers to the unstated and unofficial behaviors, values, and rules that are “assumed knowledge” that people generally learn by osmosis. These can include expectations about how to act in public (e.g., standing in line, not picking your nose), messages about social hierarchies, and so on. Individuals with autism don’t usually learn these naturally and need to be taught these expected yet assumed rules of behavior.

RESOURCES

The Hidden Curriculum: Practical Solutions for Understanding Unstated Rules in Social Situations by Brenda Smith Myles, Melissa L. Trautman, and Ronda L. Schelvan

OTHER BOOKS ABOUT SOCIAL SKILLS TRAINING

Teaching Children with Autism to Mindread: A Practical Guide for Teachers and Parents by Patricia Howlin and Simon Baron-Cohen

Autism: A Social Skills Approach for Children and Adolescents by Maureen Aarons and Tessa Gittens

Incorporating Social Goals in the Classroom: A Guide for Teachers and Parents of Children with High-Functioning Autism and Asperger Syndrome by Rebecca A. Moyes and Susan J. Moreno

The Autism Social Skills Picture Book by Jed E. Baker

Social Skills Training for Children and Adolescents with Asperger Syndrome and Social-Communications Problems by Jed E. Baker

Do-Watch-Listen-Say: Social and Communication Intervention for Children with Autism by Kathleen Ann Quill

FOOD FOR THOUGHT

Tips from Temple Grandin

Temple Grandin is a woman with autism who has a successful international career designing livestock equipment. Temple has a PhD in animal science from the University of Illinois and is now an associate professor of animal science at Colorado State University. She credits early intervention, starting at age two and a half, for her recovery from autism.

Temple has written several books, including *Thinking in Pictures* and *The Autistic Brain*, as well as many informative articles, which can be found on the website of the Center for the Study of Autism (CSA) at autism.org.

Over two phone conversations, Temple shared with me the following important information about what can help people with ASD learn:

THERAPIES, TREATMENTS, AND INTERVENTIONS

As every person has different areas of strengths and challenges, what works for one person may not work for the next. For each person, finding the right balance of strategies is important. Donna Williams, who has many sensory challenges, uses a combination of strategies to offset the difficulties she encounters. She wears Irlen lenses, is on a gluten- and casein-free diet, and is now taking a tiny daily dose of Risperdol (a quarter of a milligram a day), an antipsychotic. Temple takes Norpramin, an antidepressant, and still uses the “squeeze machine” she invented years ago. Temple designed and built this machine as a teenager after observing the calming effect a squeeze chute had on animals at a relative’s farm. This was in response to her need for deep pressure, under her control, that she craved and that helped her cope with anxiety.

EDUCATIONAL STRATEGIES

Temple has accumulated much information and experience over the years about what is effective in helping others learn (see page 236). The most important point she makes is that intensive and early intervention with the right kind of teacher is crucial, more important than the type of program.

MEDICATION

Temple reports that medications have helped her tremendously over the years. In her book *Thinking in Pictures*, she includes a chapter on the different kinds of medications and how they can be helpful. She has recently reviewed this chapter and found the information still to be valid, although more recent developments, such as the newer atypical antipsychotic medications, are not listed. When treating with medications it is important to look at the benefits of the medication versus the risks—especially with children, whose bodies are still not fully developed—and to start with tiny doses. Temple says that a good rule of thumb in deciding whether or not to continue using the medication is to look at the “wow” factor. If a child is put on a medication and there is an obvious dramatic, positive change in him (e.g., a nonverbal child can now speak), then the benefit may outweigh the risks.

For example, Temple told me that she once attended a conference with Donna Williams and was amazed at how Donna was able to tolerate sitting and having dinner with her and other people in a noisy environment. If Donna lapses from her gluten- and casein-free diet now, the effects are not so severe. This way she can travel and eat in restaurants. She attributed her improvement to the tiny amount of Risperdol she takes daily.

However, it is important to find a doctor who is knowledgeable about autism and medications, and to try medications only under the guidance of such a person. Ask your local autism chapter for names of doctors who are familiar with medications, doses, and the effects on people with ASD, as again, this treatment needs to be individualized for each person.

Other Therapies

Listed here are some adjunct therapies, usually used to target a particular skill area or as part of a wider program, and potentially extremely useful depending on the individual’s needs. Again, it is important that the therapist be knowledgeable and experienced with ASD.

Occupational Therapy

Depending on the age, ability, and need of the individual, occupational therapists provide different services. Their aim is to help the person meet goals in areas of everyday life that are important to them, such as self-care, work, and leisure. Assessments are carried out initially to discover the needs of the individual and provide support to learn skills in those areas. Some

therapists are specifically trained in sensory integration. For more information, visit the American Occupational Therapy Association at aota.org.

Music Therapy

Most people respond favorably to music, including people with ASD. Music is motivating and enjoyable. In music therapy, goals are tailored to the needs of each individual and may include increasing nonverbal interaction, such as turn-taking and eye contact; exploring and expressing feelings; and being creative and spontaneous. Some parents have reported that their children began to learn to speak as a result of being taught nursery rhymes and other songs. Research shows that there are some favorable benefits to music therapy. For more information, visit the American Music Therapy Association at musictherapy.org.

Neurologic Music Therapy (NMT)

NMT is a type of music therapy that focuses specifically on music and rhythm's physical effect on the brain and brain connections (neuropathways). Specific research-based techniques and NMT interventions are applied in a consistent manner based on the therapeutic goal of the client. Neurologic music therapists complete additional training beyond standard music therapy certification in order to maintain their NMT designation. For more information on NMT, go to colostate.edu/dept/cbrm/academymissionstatement.html.

FOOD FOR THOUGHT

Beam Me Up!

It's a Wednesday morning and I am volunteering at the jog-a-thon at my daughter's school. As we await the start of this event, other mothers are standing around talking. I approach a few I know and hear a bit of their

conversation: “I hear Pasqual got voted off.” “Oh, no, he was my favorite!” “Mine, too.” I move in and ask, “What are you talking about?” They look at me as if I have just landed from another galaxy, and say, “*Survivor!*” I say, “Oh, you have time to watch that?” and as they look at me, one replies, “We make time, the whole family!”

They continue to talk about *Survivor* and I drift away. I am left with the usual feeling of being an alien on another planet. Is it because I have a son who is severely handicapped by his autism, leaving me with a lack of time for trivial time-fillers, that I don’t fit in?

It’s hard to feel as if you fit in when you don’t have the same points of reference. The parents huddled around, waiting to pick their children up after school, talk about their daughter’s latest piano recital, her high scores on her SATs, or how their son is representing the school at the county science fair. Somehow, the highlights of my fifteen-year-old son’s week (he sat in his mainstream class and participated appropriately for a one-hour stretch, and hasn’t wet the bed once) don’t seem like the kind of information that I can just slip into the conversation and share as an accomplishment.

What are my time-fillers? Filling out paperwork to explain why I still need respite and other services; preparing for my son’s annual review at school and documenting why he needs occupational therapy and ABA; explaining to the medical insurance company why my son needs a certain treatment; attempting to keep him from “redecorating” the family room; making picture icons; trying to reach the neurologist about seizure medication; reading up on the latest research; making my son clean up the mess he made when he did redecorate; sending letters to politicians; attending voluntary board meetings; taking my son for a swim or a run because he is too hyper; cleaning spots off the rug, the couch, and the walls you really don’t want to know about; and oh yeah—trying to earn a living.

I don’t share the same cultural points of reference as most of the other inhabitants of this suburb. My reference points are those of autism: Talk to me about ABA, OT, MMR, IEP, NAS, GFCF, DTT, ASD; I’m sorry, I don’t know how to talk reality TV.

Assistive Technology

Broadly, assistive technology means any item, piece of equipment, or product system that is used to increase, maintain, or improve the functional capabilities of a person. It can be a high-technology item such as a Lightwriter to help someone type what they cannot say verbally, or an iPad with voice output apps. Or it can be low technology such as picture icons used to communicate something a person wants, or larger letters on keyboard keys. Check with knowledgeable speech therapists and your

school's assistive technology expert to see what items they have found useful, as well as with the latest research and computer specialists to see what is new.

Some children with autism can easily use computer programs or apps and learn by using them. Others struggle with the sensory issues of too much to look at and too much to listen to. Some programs have been designed for students with autism in mind. This area is in constant evolution as advances in technology continue. Although not ASD-specific, here are good places to get information:

RESOURCES

The Alliance for Technology Access (ATA), a network of community-based centers, vendors, and professionals: ataccess.org

TCI teachers, speech therapists, and staff at the Children's Institute provide feedback and reviews of assistive technology and iPod, iPad, and iPhone apps that are used to support their students: tcischool.org/techtips

A book about apps for the iPhone and iPad: *Apps for Autism: An Essential Guide to Over 200 Effective Apps for Improving Communication, Behavior, Social Skills, and More!* by Lois Jean Brady

NEVER UNDERESTIMATE THE POWER OF A PARENT

Tito and Soma

Tito Rajarshi Mukhopadhyay is a young adult from India who is severely autistic and writes eloquently. His mother, Soma, raised him and educated him with little help from anyone else. When he was two and a half, he was diagnosed as autistic and she was told to keep him busy. Soma did just that. She read to him from textbooks on subjects ranging from science to literature when she wasn't engaged in teaching him other skills. Any physical activity, such as riding a bicycle, she had to teach him by physically motoring his body through the motions. She taught him to write by attaching a pencil to his fingers with a rubber band as he was unable to hold it on his own. She taught him to

point to numbers and letters, also by physically prompting him through the tasks. By age six, he was able to write independently.

In December 1999, Soma took Tito to England, to Elliot House (the Centre for Social and Communication Disorders run by the National Autistic Society), where he was observed and assessed by Drs. Lorna Wing, Beate Hermelin, and Judith Gould, among others. Tito at the time was eleven, yet reached the level of a nineteen-year-old on the British Picture Vocabulary Scale administered by Dr. Gould. His story, from India to the UK and back home again, is the subject of a BBC program, *Inside Story: Tito's Story*. The National Autistic Society subsequently published a book written by Tito titled *Beyond the Silence: My Life, the World, and Autism*. The revised U.S. edition of Tito's book, *The Mind Tree*, provides valuable insight into the life and mind of persons with little to no expressive language.

In autumn 2001, the Cure Autism Now Foundation (CAN) invited Soma and Tito to move to Los Angeles so that Soma could try her teaching techniques on U.S. students with autism. In addition, Tito graciously consented to undergo extensive testing by experts, such as Dr. Michael Merzenich, a neuroscientist at the University of California at San Francisco Medical School. Merzenich's tests helped validate and clarify Tito's written experiences, while shedding light on the brain function of people with severe autism. For example, in perception testing where lights are flashed on a computer screen at the same time as the sound of beeps is issued, most people can sense the beep and the light at the same time. However, Tito cannot see the light on a computer screen unless it appears a full three seconds after the beeps. He explains that he can use only one sense at a time, and has chosen to use his ears. This is in marked contrast to the experience of Temple Grandin, a professor at Colorado State University who holds a doctorate in animal science and has autism. Dr. Grandin explains that she thinks totally in pictures, that thinking in language and words is incomprehensible to her, and that she has difficulty with her ultrasensitive hearing because she cannot tune out unwanted noise the way most of us can.

Soma worked for two years with a class of severely autistic children using the method she developed with Tito, which she calls the Rapid Prompting Method (RPM). Soma teaches academics by simultaneously stimulating auditory, visual, and kinesthetic channels. She elicits responses from children at a rapid pace, which keeps students focused on the lesson at hand.

Soma is now educational director of the nonprofit organization Helping Autism Through Learning and Outreach (HALO), based in Austin, Texas. HALO provides individual instruction for students and training for parents and professionals interested in RPM. Soma has adapted her method to different learning styles.

Neuroscientists such as Dr. Merzenich are hopeful that this teaching method will help many.

6

Family Life

Family life can be a test of love and resilience, so taking good notes and understanding each other's needs and wants are vital to the success and survival of any marriage. After children arrive, there is a balancing act between caring for their needs and putting time and effort into the maintenance and growth of the marriage. This rite of passage in the development of family life is challenged still further by disability or chronic illness.

—ROBERT A. NASEEF, *Special Children, Challenged Parents*

I was raised in a French Catholic family, one of six children. As my parents had emigrated to the United States from France, we had no extended family, but we were very close. We did everything together: ate dinner as a family every night, rode our bikes, played tennis, watched TV (the few hours a week we were allowed), went to church, and socialized with other families. We had very little time on our own and were not encouraged to join clubs that would take us away from our family activities.

So I had always expected that when I had a family, though it would be much smaller, it would be the same kind of close-knit family life with shared activities. This was important to me. However, having two children who are basically living on separate planets (one is severely autistic, with poor motor skills; the other is very social and athletically gifted) makes it tough to have the kind of family life I grew up with. I had to learn to let go of my expectations, change my perception of what family life meant, and figure out what we could still do together as a family and what we would

have to do separately. We have had to create our own version of family life. But we are still a family; we just do things differently.

Autism Spectrum Disorder and the Family

Having a child with ASD has a major impact on the family. Besides the stress associated with bringing up a child who needs more attention and care, children with autism are not as social as other children and do not reach out to parents in the same way that other children do. This lack of spontaneous signs of affection from one's own child is very difficult for a parent.

Often families tend to isolate themselves either because of concern over their child's socially inappropriate behaviors or from fear of being embarrassed by some of the child's behaviors or because of the extreme fatigue most parents of children with ASD suffer from. Families stop doing what they did before the ASD was very apparent. Single-parent families find themselves alone with their hands full and no free time to keep up any kind of social life, increasing their isolation. Being a single parent, adoptive parent, stepparent, foster parent, or grandparent raising a child with ASD adds even more difficulties to an already precarious situation.

A marriage or relationship with a significant other can deteriorate due to added stress, fatigue, and differences of opinion on how to handle certain situations. Often one or both parents are having difficulties coming to terms with having this child and are on different parts of the grief cycle. Add to that the searching for support and trying to get an appropriate education for the child, and it is easy to see how many couples come to call it quits.

Siblings can suffer from being raised in a family with a child who has ASD. Not only do they have a sibling who is hard to understand, has limited interests, and is not social; they also have to deal with some pretty wild behaviors. And they also feel the stress their parents are under, as well as the fact that inevitably more of the parents' attention is taken up by the sibling with ASD. However, research indicates that there are also positive aspects of having a sibling on the spectrum.

Extended family members such as grandparents also have a difficult time in dealing with ASD. Some refuse to face the facts, others don't know what to say or what to do. Again, as the parents, it is up to you to decide when and what information you want to share. Much depends on the type of relationship you have with your relatives and how close you are to them.

It is difficult bringing up a child with ASD. But first and foremost you are raising a child, not a disability. No matter how bad the behavior or situation, there is always a solution. And mainly it is the parents' attitude that will make the biggest difference. In this section, practical suggestions on family life are offered.

Family Life with Children with ASD

The sooner you realize that your family life will not resemble the Waltons', the better off you will be. Take heart from knowing that your family life would probably never have resembled that perfect ideal, and if it had, you would have been bored out of your skull. Think of the Addams family and how much more fun they seemed to be having regardless of the daily household disasters.

FOOD FOR THOUGHT

Managing Your Energy

BY MARSHA MARKLE

As parents of special needs children, we require plenty of energy to meet the series of unique challenges we may face. Self-care becomes an essential part of our healthy functioning. Without appropriate self-care we risk becoming physically exhausted, emotionally isolated, mentally scattered, and spiritually depleted.

In order to manage our lives and have a reserve of resourcefulness to use in service of our mission, we must learn to give ourselves intermittent renewal. Research reveals that when you expend a lot of energy you must institute habits that replenish that energy. You need to put yourself on the front burner for at least fifteen minutes a day and increase that time or frequency as you develop these new habits. Don't wait for that once-a-year vacation. If you feel

overwhelmed at the thought of fitting self-care into your day, then that is a sure sign that you need to do just that.

If you want to live your life by design, not default, plan ahead to give yourself renewal in all the energy resource domains: physical, mental, emotional, and spiritual. Start by identifying your core values. Check your daily activities to see how much time and energy you are spending within those values and how much is squandered on nonessentials. Imagine what you can say “no” to so that you can begin to make the time and energy for self-care. What is zapping your energy that you might be able to eliminate?

What gives you healthy energy that you can add to your lifestyle? Get the help of your partner, family, and friends to get these needs met. If necessary, find a personal coach to assist you in this endeavor.

You'll have more energy, power, patience, and sustainability when you can take care of your needs as well as those of your loved ones. Without self-care and managed energy you will be at risk for burnout, irritability, and feeling the effect of things outside your control. Exercise your self-care muscles to create a healthy balance for yourself.

Marsha Markle, MA Communications, MA Psychology, EdS School Psychology, is a special education advocate with Pacific Coast Advocates in San Diego County and is an adjunct faculty member at National University in the special education department. Marsha was a school psychologist for twenty-two years and is the parent of an adult son on the spectrum.

Life for your family will never be boring from this point on. It may get monotonous, but it will not be boring. Start buying rubber gloves, cleaning liquids, disinfectants, and carpet stain removers in wholesale quantity, as you will be using them often. I wonder if the sales figures for cleaning materials rise at the same rate as ASD diagnoses. But I digress.

It is not easy striking a balance between family life and all that is inherent to having a child with ASD. It is true that you probably will not have the family life you envisioned. But many people who do not have a child with ASD do not either. People get divorced, lose a partner or a child. They grieve, but then they move on and rebuild another kind of family life. And families with a child with ASD need to do that as well. Grieve about the loss of your expectation for the family life you envisioned, and then start building the one you will have. You owe it to the rest of the family. It will be hard work, but you can do it.

You may find some of the books listed in the Resources section helpful to you. To start with, here are some basic guidelines to keep in mind:

Do not isolate yourself and your child. Primarily, parents must take care that the family does not become isolated. This is vitally important for all members of your family. Now, more than ever, you need to be surrounded by relatives and friends, and so does everyone in your family. Isolation occurs because you are too tired to go out, you cannot handle your child in public, or you are embarrassed by your child's behaviors. People soon stop inviting you over, either because you have previously turned down invitations from them or because of your child's behavior or because you are obsessed about ASD and that is all you can talk about. You stop inviting people over because you are too exhausted to play hostess and you are embarrassed by your child's behaviors. Do not be one of those people who says, "I remember when I used to have a social life. Look, I even have pictures to prove it."

Get over caring what other people think. Do not be intimidated by looks and remarks when you go out in public, and do not feel you have to justify your actions to family members and friends. If you are too embarrassed to take your child out in public, then you need to analyze why you feel that way. If it is because of your child's behaviors, and they are very disruptive or unsafe, then you need to work on those behaviors. If it is because you feel uncomfortable that your child appears "odd," then I suggest you get over it. Your child is here to stay, and he needs your support. And the general public needs to be reminded that none of us is perfect.

Get your child's worst behaviors under control. This is never easy and can sometimes be extremely difficult. However, this child is your responsibility now. You need to help him. First you need to try to understand what is causing the behavior. If you can eliminate the cause, that's great. If not, you need to try to get disruptive behaviors under control. It is not fair to the rest of the family, nor will it make you friends out in the community. There are positive behavior techniques that can be used to decrease and eventually eliminate the worst behaviors, and with practice a parent can learn how to use them. Your pediatrician or local autism support groups should be able to provide you with a professional who can help you. If not, there are various books you can consult that will explain in simple

terms what to do. They are listed in the Resources section at the end of this book.

Keep your sense of humor and take time to laugh. Surround yourself with uplifting media. No matter how bad things are, you can and will make it through today. Play good upbeat music, not the tunes that make you feel even more depressed. If you have ten minutes to read or watch TV, make sure it is something amusing. Don't waste it on reading or watching the news. Usually the news is depressing, and you can't do anything about it. Keep entertaining videos around the house, as well as light reading. Humor helps, even if it is gallows humor. You may not be able to control the situation you are in or solve your problems, but keeping your mood uplifted will help you have a more positive frame of mind.

Do what you can to stay healthy. Take care of your physical health. Try to eat properly, catch up on sleep when you can, and exercise regularly. Even just a twenty-minute walk three times a week will keep your body healthier and will make you feel better. Your physical health affects your mental health, which in turns affects the whole family.

Remember that you are only human. You may try to act like a superhuman and do the impossible. That is okay, if you are feeling up to it. However, watch out for burnout. Revert to acting human and do not feel guilty for only doing what you can. Think of all you have accomplished, not what you wish you had done.

How to Continue Doing the Family Activities You Enjoy

Most parents think that family activities should be done as a unit. Parents of a child with ASD may try to include the child in all family outings, hesitating to leave him at home while everyone else is out enjoying themselves. Others may rarely take their child out in public. What is needed is a balance. Pick activities to share as a family unit that will be enjoyable to all, and schedule other activities or family outings that can be done separately with individual members of the family.

FOOD FOR THOUGHT

Learning to Share

Having to *share* my parents with two older brothers was the main thing. I see too many families where the needs of the autistic person run the day. There has to be a balance, between that very needy person and needs of parents and siblings. I don't care how needy he is, he has to learn that he is not the sun with the rest of the world as planets revolving around his every tantrum. I was very lucky to have two older brothers and two parents whose egos weren't totally tied up in what I thought of them or how I succeeded.

—Jerry and Mary Newport, *Autism-Asperger's and Sexuality*

Parents need to look at the activities they enjoyed doing before and what they would like to continue doing now. See how you can adapt them for the home life you have now. Analyze whether it is easier to change the activity or to change your child's behaviors or to drop the activity. You will probably have to do a bit of all.

The following basic suggestions will be helpful to some of you, especially parents of younger children and children severely impaired by ASD. These strategies are included here for those who have no supervised behavior program and need to teach their child some basic skills. If your child has a behavior program, he is probably already learning these skills.

Teaching Your Child Basic Communication

The first skill your child should learn is how to communicate. Some children with ASD are verbal and are able to communicate effectively; others may have enough speech to at least get their basic needs met. Many have no speech whatsoever, or had speech and then lost it.

Not being able to communicate is very frustrating and can lead to major tantrums and disruptive behaviors. Teaching some basic communication

skills can alleviate a lot of this frustration. PECS is a wonderful system for helping children to communicate (see pages 121–124). At the basic level it teaches the child that by giving you a picture of an item that he wants, he will get that item. Without professional help, you can teach your child to give you or point to pictures that represent what he wants or needs. This will not inhibit him from learning to speak and is a good practical starting point to help you at home.

For example, start by cutting out the labels of food or drink items your child enjoys. When you first introduce this concept, have another person help you. The first step is to pick a moment when you know he wants a particular item. Make sure you have a picture of that item. Hold up the item, and have the other person physically help the child to hand you the picture. In exchange you can immediately give him the desired item. This will only work if he really wants that item, and if he can't reach it without your help. You can add more pictures, perhaps laminate them, and put them somewhere easy for the child to find—perhaps stuck to the refrigerator or on the kitchen table. You can keep adding pictures so that he can request to go outside, have a ride in the car, watch TV, listen to music.

For use on the iPad and iPhone, Proloquo2go is picture-based software that can be used to communicate. It also has word processing and typing capabilities.

Teaching Your Child to Wait

Another skill your child will need to master to make home life easier is waiting. At home, he needs to wait for someone to help him, he needs to wait for dinner, he needs to wait to go out. In the community, he needs to learn to wait at the doctor's, wait at the supermarket checkout, line up to get on a bus or a plane. Learning the concept of waiting (you will get what you want eventually) will help to lessen the number of tantrums.

Autismcollege.com has a free video showing how to teach this necessary skill. It's titled "Teaching the Skill of Waiting: Autism Parenting Tip from Autism College." You can find it on YouTube.

Here is how to teach the skill. Make or find a picture that will represent "waiting" to your child. We have used a simple line drawing of a person

sitting in a chair, with the face of a clock next to it. Write “waiting” clearly on the card. Laminate the picture and place a piece of Velcro somewhere on it. Next, make sure you have pictures of whatever items your child usually requests or wants immediately (favorite food, toy, ride in the car), backed with Velcro, and a seconds timer. The next time he requests an item put the relevant picture on the Velcro on the waiting card, then turn the timer on for a few seconds. Say, “We are waiting” or “Waiting” and point to the card. When the timer goes off, immediately fulfill his request.

Some children need to start with a wait of only three seconds, and work up from there. Some can start at ten seconds or more. Once your child has learned to wait for those few seconds, add more. You know your child, so you will have to gauge where to start. Eventually, he will understand that he will get what he wants, it is only a matter of time.

Creating Schedules

Another helpful tried and trusted method is schedules. Posting pictures or words about the day’s activities in the kitchen or by the front door can be helpful for a child having difficulty making sense of the world around him. Knowing what will happen and in what order is comforting. You must be sure to explain verbally what the words and pictures mean, otherwise children who are auditory learners may not make sense of the schedule. There are many apps that can help for schedules on the go.

Scheduling also helps those who have sensory problems in some areas to get ready for a not-so-pleasant onslaught of sensory input. For example, I have noticed that if my son is forewarned that he will be visiting the dentist or the hairdresser, he appears to have an easier time of it, as if he has prepared himself mentally. If I have forgotten to put it on the schedule earlier in the day, and then show him the picture just before leaving the house, he appears to be anxious and unhappy, often refusing to get in the car, which he usually loves.

If your child is very young and home all day, you may find it helpful to establish a routine of activities that will fill part of his day and use a schedule to show what that routine is (eating, getting dressed, free play inside, napping, TV).

Being Consistent

For any behavior changes that you are trying to make with your child, it is important that you follow through and be consistent, and that the other family members do so as well. If you introduce a way to communicate and then do not respond to his attempts to approach you, you will be doing your child a disservice. If you teach him to wait, but do not give him the item he is waiting for, he will not learn the concept, and will be even more confused.

Handling Family and Social Gatherings

Although it is true that it is harder to participate in family and social gatherings, it can be done. Gatherings can be overwhelming, and attending with your child requires a certain amount of preparation on both ends, depending on the type and size of the gathering. This is a balancing act between making your child comfortable, making the other guests and the host comfortable, and ensuring you will be invited back.

Your relatives and good friends might not understand why your child acts the way he does, why he won't sit still, or why he is on a special diet. I wrote a book called *What Is Autism?: Understanding Life with Autism or Asperger's* as a simple and short read that answers the most-asked questions about autism to help educate those around a family with autism.

Here are some guidelines for handling family and social gatherings:

- Prepare your relatives and friends for how your child might act and what it means. For example, if your child runs immediately out of the room when there are more than a few people, explain that it is not personal, but that your child cannot tolerate noise because his hearing is oversensitive.
- Make sure they understand that your child is not “misbehaving” but that you will be keeping an eye on him and you are teaching him to control his behaviors, but it takes time.

- If there are breakable items sitting around, you may want to ask if you can move them out of reach.
- Ask which rooms or areas are “off-limits” and make sure you enforce that.
- Just like a designated driver, you need a designated child watcher. If you are going with another adult, decide who will be keeping an eye on your child, and when.
- If your child is on a particular diet, you will need to bring plenty of food that she is fond of. Depending on how well you know the others and how they may react, you might ask about not leaving certain foods out to munch on, and bring something to share that all can enjoy.
- Look at the traveling tips on page 147, and follow some of the ideas to familiarize your child with what is going to happen and who he is going to see, such as showing pictures and talking about who is going to be there and the schedule of activities for the day. If you anticipate noise, make sure you tell your child a few times in the days ahead. If you know certain holiday music will be played, you can put some on at home every day for a short while so the child can get accustomed to it.
- Bring some familiar toys and favorite items to make the child feel comfortable and more at home.

Faith, Organized Religions, and Spirituality

Many of us seasoned parents joke that over the years we have become more religious: We pray our child will not have a toileting accident in public, we pray they will behave themselves while we are visiting relatives or doing the family shopping, we pray that we will have the strength to politely ignore the judgments passed upon us and our “misbehaving” children.

All joking aside, faith has been helpful to parents and many on the spectrum. Many parents find solace in religion, and often families find that their faith is what keeps them going. Often, the place of worship becomes

another support group. Some provide religious instruction to children on the spectrum and opportunities for inclusion and for their children to make friends.

Many parents find their place of worship embraces their child with special needs, though this is not always the case. One would expect that, by the nature of a religion's spirituality and beliefs in love for fellow man, that families with autism would find acceptance of their children. However, we all know that ignorance knows no boundaries. Some families have had difficulty continuing to attend services or, if they do, their child's behaviors can be a challenge for the other worshippers.

There are news reports from recent years of youths with autism being banned from worship services due to unruly behavior, at least one even involving a court case. On a personal note, my son, Jeremy, and I stopped attending church services a few years ago because Jeremy no longer felt welcomed there. At the time, no one reached out to ask why we were no longer attending or why Jeremy was no longer participating in the young adult group.

Some families report that their children with autism seem particularly spiritual and connected to God, and some adults do as well. There are a few books on this topic, and they are listed in the Resources section of this book.

Some places of worship provide religious instruction to those with autism; some do not. Luckily, there are now more resources to help. For information on how to include children with autism in Christian and Jewish services, visit autism-society.org/living-with-autism/family-issues/religion-and-autism.html. Some of these tips may apply to other religions as well. An online search yields blog posts on autism and various faiths posted by parents, which might also be helpful.

Traveling and Going on Vacation as a Family

Traveling can be trying even at the best of times when you have small children. Traveling with a child with ASD can be even more of a challenge. Airports and train stations are areas that involve lots of waiting. Leaving the

security of home for a new place can be off-putting for a child with autism. How you prepare your child depends on his age and how the ASD affects him. Some suggestions are given here that you can adapt for your own child's needs and level of ability. Remember that the first time you use this he may not understand, but over time, he will.

- Teach your child the “waiting” skill if he does not have it.
- Put up a monthly calendar and check off each day until it is time to go. Bring the calendar with you and mark off the number of days in the new place, always having the departure date indicated.
- Put together a “travel book” of pictures (and/or words) of the means of transport you are going to be using to travel (airplane, boat, train), who you are going to see (relatives, friends), where you will sleep (hotel, Grandma's house), and what you will do or see at your destination (swimming, playing outside, visiting monuments). Go over this with him as often as you like in preparation for the trip. If your child prefers an actual book, a three-ring binder works best, because you can add extra pages or insert the calendar mentioned above for use on the trip. For those who have access to an iPad or tablet, there are apps that can help you create schedules and books on your tablet.
- Put together a picture or word schedule of the actual journey to take with you on your trip. Add extra pages to the travel book. If you are using a binder, use Velcro to attach pictures or words in sequence. Add an empty envelope to put the “done” pictures in when you have finished that step of the journey. For example, if you are flying to Paris, start with a picture of the taxi or car that will take you to the airport. When you are at the airport, have him remove the taxi picture and put it in the envelope. Then have a picture of the airport, followed by the “waiting” picture, and then the airplane, and so on.
- Think of your child's daily routine and the items he likes or needs for it, and bring them along to make him feel more at home. Bring whatever foods and drinks will keep him happy on the trip.

- Buy some small inexpensive toys that he can play with. If he only plays with one favorite item, try to find a duplicate and see if you can “break it in” before the trip. Do not wash any toys before you go, as your child may find comfort in the “home” smell of his cherished item.
- When staying in a hotel, it is a good idea to call ahead and ask for a quiet room. You may wish to explain about your child’s behavior if there is a good likelihood of him exhibiting it in the public part of the hotel. The same with a friend or relative’s home. It can be a bit disconcerting for everyone concerned if your older child takes his clothes off and races through a friend’s house stark naked.
- Make sure your child has an ID tag attached to him somewhere, with current phone number and “autism” written on it. You can order medical bracelets, necklaces, and tags to attach to shoelaces. If you can persuade your child to keep it in his pocket, also make an ID card with a current photo and date, plus home and mobile phone numbers and the number of where you are staying. Indicate that your child has autism. Be sure to add any other important details: allergies, medications, and any specific information—for instance, whether the child is nonverbal.

TIPS FOR TRAVELING BY PLANE

- Waiting lines at the airport have “special assistance coordinators.” You may wish to explain about your child’s disability and some of the behaviors that may inconvenience other travelers (for example, rocking in the seat).
- If you will need help because you have other children and some carry-on luggage, and your child is a handful, request that assistance be provided to get to the gate after you check in, and ask that assistance meet you at the airplane upon arrival. Remember that the person may not understand about your needs. They may ask you questions and say that assistance is only for the physically handicapped, so you may need to explain in concrete terms why you need help (e.g., your child cannot

move from one place to another without physical assistance). Always be polite but insistent.

- On the day of departure, talk to the airline agent at the check-in counter as well as the security agents about avoiding the long lines. If they are unable to help you, ask to speak to a supervisor. Sometimes, it is helpful to stress the inconvenience that the other passengers will experience (e.g., “When waiting more than fifteen minutes in a crowded area he will scream at the top of his lungs and will not stop for twenty minutes, which can be annoying to other passengers.”).
- If there are two responsible persons traveling, you may wish to purchase walkie-talkies to communicate in the airport (in the event cell phones are off limits) so that one person may wait in line while the other is keeping the children happy elsewhere.
- Let the airlines know ahead of time if your child has food allergies or sensitivities. They may be able to accommodate his special diet. Always bring food items that your child can eat in case there is a flight delay or there has been a mix-up.
- Make sure your child is wearing clothes that are loose, comfortable, and easy to pull off and on if needed. Bring any medications or pull-ups, baby wipes, assistive communication tool, diapers, preferred food and drink items, and books and toys the child likes.
- Allow yourself plenty of time to get to the airport. Everyone will be calmer if there is a feeling of calmness rather than a hurried pace.

FOOD FOR THOUGHT

Those Who Help

As time went on, the world of professionals, friends, acquaintances, and strangers became divided into two camps: those who rendered things more difficult, and those who helped. The first camp was far more heavily populated than the second. But notwithstanding the sometimes painful lack of sympathy

Marc and I and Anne-Marie encountered, we were fortunate—indeed, blessed—in the people we did find who helped, each in his or her own way.

—Catherine Maurice, *Let Me Hear Your Voice*

Addressing Other Issues Central to Home Life

There is not enough room in this book to discuss all the important areas that parents may need to work on to make life easier at home.

As you may have realized, it is not always easy to know how to interact with your young child with autism to help you establish a connection. A good resource is *An Early Start for Your Child with Autism: Using Everyday Activities to Help Kids Connect, Communicate, and Learn* by Sally J. Rogers, PhD; Geraldine Dawson, PhD; and Laurie A. Vismara, PhD.

There are areas in which your child will need specific instruction. Those listed here are important, but there are many others. Luckily there are resources out there. Some families have access to ABA home programs, and they should be able to help you in these areas. There are many books and articles on the Internet that can help.

Although these books are older, *Steps to Independence* by Bruce Baker and Alan Brightman and *One on One* by Marilyn Chassman are great places to start for learning how to teach your child at home. They are simple and have great practical ideas. *Steps to Independence* explains how to teach functional living skills to children at home, and *One on One* is the best book I have seen for teaching skills to the less able child with autism.

Here are some suggestions:

Toilet training. This can be difficult for some, easy for others. Some children who have sensory processing issues and poor muscle control may not “feel” when they have the need to urinate, or they may not have the necessary motor control. It can take a long time to toilet-train some people. There are books specifically about toilet training that are good, and *Steps to*

Independence by Bruce Baker and Alan Brightman and *One on One* by Marilyn Chassman have sections on toilet. On the Internet, Autism Speaks, TACA, and autismcollege.com have good articles about toilet training.

Chores. Teaching a child to do chores not only gives him independence, but also makes the statement to siblings that everyone contributes to the household. Both books mentioned above have ideas for you to try.

Desensitizing. Some children with sensory processing issues have a terrible time getting their hair cut, their teeth checked by the dentist, wearing a hat, and so on. Teaching a child to get used to an item or sound, little by little, is helpful. Anyone who has a practical knowledge of ABA can devise a system. *One on One* by Marilyn Chassman has a good section about how to teach your child to tolerate stimuli that are difficult for him.

Behavior plans. These are an important part of making life easier at home and teaching a child responsibility for his actions. Again, these are ABA techniques and *Steps to Independence* by Baker and Brightman has a section on them.

Social skills training. Children with ASD need to be taught social skills in order to participate in activities with other children. In Chapter 5, different ways of teaching these skills and helpful resources are discussed. If your child is passionate about a particular topic or type of object, this could be a way to get them to interact with others.

Safety training and other safety challenges. Many children with ASD do not have any notion of safety and this needs to be taught to keep your child safe. You may need to make some changes in your home to keep him safe. There are some good tips at “Safety in the Home” on the Autism Society’s website.

Wandering and drowning are particular safety issues associated with children with autism. There are great resources on how to prevent these tragedies from happening on the National Autism Association’s Autism Safety website, autismsafety.org.

Another safety issue is that individuals with developmental disabilities are at a higher risk of abuse—mental, physical, and sexual—than their neurotypical peers. Two great resources available at disabilityandabuse.org are “The Risk Reduction Workbook for Parents and Service Providers” and

“The Risk Reduction Workbook for People with Intellectual or Developmental Disabilities,” both by Nora J. Baladerian, PhD.

Adolescent Issues in ASD

Some adolescent issues will be discussed in Chapter 7 on education, and the reader may wish to consult that chapter as well. Jerry Newport, Michael John Carley, Jesse Saperstein, and other authors with ASD have written about their teenage years and how their ASD affected them in contrast to their neurotypical peers. Parents should read some of these accounts. They will give you information you can share with your child’s teacher. See the Resources section.

For a more in-depth look at adolescence and resources, read my book *Adolescents on the Autism Spectrum: A Parent’s Guide to the Cognitive, Social, Physical, and Transition Needs of Teenagers with Autism Spectrum Disorders*. Online training with regard to adolescence and autism is also available on autismcollege.com.

Puberty and Hygiene

Puberty is usually an awkward time, even for neurotypical people. Bodies are changing, hormones are raging, moods are swinging. All children nearing adolescence need to have an understanding of what is going on in their bodies. Children with ASD need even more information and input from parents at this time. Most children with autism have difficulty with change, thus the importance of explaining the changes that will happen to their bodies. Things to keep in mind:

- Boys usually start puberty around age eleven and it may last until age seventeen. They start producing testosterone, which leads to an Adam’s apple. Boys need to be told about how their bodies are changing, about erections and “wet dreams” that can happen while they are sleeping, and that ejaculation can happen when their penis is

rubbed, or they may be perplexed and wonder what is wrong with them.

- Girls generally start puberty before boys, beginning sometimes as young as nine years old. In girls, overall body shape starts to change as breasts and hips begin to develop, the menstrual cycle commences at some point, and hair begins to grow on the legs and pubic area and underarms. It is important that girls are told about the menstrual cycle before their first period, so they are not confused and upset and think there is something physically wrong. They will also need to be told who are the appropriate people to discuss this with (parents, a teacher, a girlfriend) and that it is not necessarily a lunchtime conversation topic in a mixed group.
- Seizures may appear during puberty for one in four individuals with ASD, possibly due to the increase of hormonal changes in the body. Sometimes the seizures are associated with convulsions and are noticeable, but for some they are very minor and may not be detected by simple observation. You may wish to keep an eye out for the signs that indicate sub-clinical seizure activity. These signs are little or no academic gain in contrast to doing well during the childhood years; losing some gains academically or behaviorally; and showing behavior problems such as severe tantrums, self-injury, or aggression. You may wish to discuss any such changes with a knowledgeable professional.
- Hygiene is an area that needs to be addressed at this time. Puberty brings the onset of sweat, and some teenagers will develop acne as a result of intensified amounts of oil in their glands. Good habits need to be developed. Daily face-washing and the application of deodorant and grooming of facial hair for boys. Girls will need to learn how to use feminine hygiene products.
- Teaching about puberty depends on the functional ability your child demonstrates. However, remember that nonverbal does not mean non-understanding. The use of social stories with pictures tailored for that youth is helpful. Some youths will need to go over the material more often than others. Others may need help learning each step of a self-

help skill mentioned above. If your child learns very slowly, an early start will be helpful in the long run.

Helpful books for teaching tweens and adolescents about these issues are:

Taking Care of Myself: A Hygiene, Puberty, and Personal Curriculum for Young People with Autism by Mary Wrobel. The information provided can be adapted for different ability levels.

The Boys' Guide to Growing Up: Choices and Changes During Puberty by Terri Couwenhoven, MS

The Girls' Guide to Growing Up: Choices and Changes in the Tween Years by Terri Couwenhoven, MS

Sexuality

Sexuality is a topic that many of us would rather skip talking about, even with our neurotypical children. However, sexual feelings are natural and everyone has them, regardless of their level of ability. Children become adolescents and then young adults. Some individuals with ASD want intimacy and to get married; some do not. Many want friends and to date; some may not. But as adults, it is up to them to choose, and it is up to us as parents to help them develop the social skills they will need and teach them about self-esteem and self-respect and about relationships and sex.

Even if your young adult is not interested in relationships or intimacy or sex, this subject needs to be addressed. Sadly, people who have intellectual disabilities are at a high risk of sexual abuse and of contracting HIV/AIDS. Even if your child does not have intellectual disabilities, the very nature of ASD makes it difficult for someone with the condition to read the social cues and understand appropriate versus inappropriate behavior. These cues need to be taught. There are different ways to teach them, and he needs to learn these things from you. This is the time, while he is still living at home, to be teaching your child about appropriate behavior. Even if as an adult he

chooses not to have a sexual relationship, he needs to know what is appropriate and inappropriate behavior toward him, about giving or withholding consent, how to say no to others, and how to let others know if he needs help or support. He needs to learn to be able to tell a responsible person about any inappropriate behavior that someone might be doing to him. It is imperative for your child's safety that he be able to identify appropriate places on his body where people can touch him. Not only does your adolescent need to understand about behaviors, he needs to understand what is behind them.

Autism-Asperger's and Sexuality: Puberty and Beyond by Jerry and Mary Newport is a wonderful resource for the more able teenager and young adult, although parental guidance is recommended. The publishers suggest photocopying certain sections of the book to give to your child to read. In this way you can give him the information he is ready to handle. Jerry and Mary Newport are a married couple who both have Asperger's and share their experience and advice about puberty and sexuality.

Intimate Relationships and Sexual Health: A Curriculum for Teaching Adolescents/Adults with High-Functioning Autism Spectrum Disorders and Other Social Challenges by Catherine Davies and Melissa Dubie is a frank resource on sexuality tailored to the unique characteristics of high-functioning adolescents and adults on the spectrum. The authors present "all you ever wanted to know but were afraid to ask/teach," taking into the consideration the learning styles inherent in autism. The curriculum comes complete with lessons, activities, handouts, resources, and more and has a CD with all the handouts for easy duplication and individualization.

Concepts That Every Adolescent Needs to Learn

Modesty—private versus public. If your child has not mastered the concept of modesty, now is the time to teach him. He needs to learn the appropriate place for private acts (such as dressing or being naked). If he does not understand through an explanation of the concept, then perhaps visual icons will help. Pick an icon or color to represent public and one to represent private (do not confuse him by using smiley and sad faces). Put the private icon on his underwear drawer and his bedroom and bathroom doors, and the public icon on the doors to the rest of the rooms and going

outside. If he gets dressed in a place other than the bathroom or his bedroom, or if he runs around the house with no clothes on or in his underwear, now is a good time to teach him what is appropriate to wear in public and in private. Perhaps you don't really mind at home, but think of when he will be living with others and how inappropriate it will be then. He needs to learn now, or he won't understand what the fuss is about years down the line. If he comes out with no clothes on, you can remind him by showing him to his room or bathroom with the appropriate icon, and pairing it with the icon on his clothes drawer. Also, your child needs to learn about using the toilet on his own with the door closed.

For some children, social stories will be effective in teaching about what behaviors are to be done in private and which ones are okay in public. This concept of private versus public is crucial to the child's learning about the body parts that are okay for others to touch, and the parts that are private and should only be touched with his permission.

Masturbation. This is one of those activities that needs to be explained as okay to do, but in private. Your adolescent needs to understand that it is a normal behavior, but only in private. Many individuals with ASD practice self-stimulatory behavior, and masturbation is the ultimate such behavior, so a parent needs to accept the inevitable and make sure it is done in an appropriate place. If your son starts touching himself in public, he needs to be told that that is a private area, not to be touched in public. If your child is masturbating at school, then a plan should be put into place.

Communication on this issue should occur between home and school. One way to handle this is to tell the student it is inappropriate at school and that he can have private time at home. Then the student should be allowed that private time once he is home.

Teaching to say or communicate "no." Some children with ASD are compliant and have learned through years of special education to follow instructions and rules of behavior. However, for safety reasons, now that your child is becoming a young adult, he needs to learn to say "no" even to you and people of authority. One way to do this is to offer him a choice between two things (e.g., a bar of chocolate or a carrot). When he states his preference, give him the wrong one—and teach him to say, "No, I want the . . ." This needs to be generalized to all kinds of subjects. Then you can make a list of situations to say "no" in, some serious and some funny to

make it fun (e.g., a stranger asks you to get in the car; your dad wants you to eat worms). You can also teach him to say “go away” by invading your child’s space when you know he doesn’t want you there (e.g., when he has closed the door to his room and is watching TV). Stand very close to where he is sitting, and when he does avoidance behavior (pushing you away, moving to another spot), prompt him to push you and say “Go away.” When you are teaching the concepts of “no” and “go away” you must respect his right to choose, but do not confuse him by asking instead of telling in a situation where he really has no choice (e.g., “Do you want to get ready to go out now?” instead of “Time to get ready to go out.”). You can, however, create choices (e.g., “Time to get ready to go out. Do you want to wear your blue jacket or your red sweater?”) that he really has.

Relationship boundaries. This can be a difficult concept to teach. First your child needs to learn about the various relationships (husband, wife, sibling, aunt, colleague, close friend, neighbor, shopkeeper, and so on). Next comes the concept of appropriate types of conversations and behaviors. One way to teach this is through a “circle of friends.” Draw a dot in the middle of a big piece of paper, with ever-increasing circles surrounding it. Each circle defines the acceptable behavior and acceptable conversation of people in that circle. The circle closest to the dot represents behaviors of people you are extremely close to, and when first introducing the concept write “close hug” in this circle, then in the next circle “big hug,” and so on with “handshake,” “wave,” and so on. “Stranger” will be the largest circle farthest out. Hang this up in your child’s room and add the people (by name or picture) he knows to the different circles, discussing the concepts at his level. Then, when he meets new people, you can add them to the circle.

Grooming and Dressing

In the teenage years, how you are dressed and how you present yourself are extremely important. Luke Jackson and Jerry and Mary Newport in their respective books talk about the importance of looking right. Jerry and Mary say that right from the first day at school it is important to not look like a misfit. ASD teenagers need help in this area. Reading parts of Jackson’s

Freaks, Geeks, and Asperger Syndrome and the Newports' *Autism-Asperger's and Sexuality* and *Your Life Is Not a Label* can be very helpful to the teenager. The different aspects that need to be taught to your child are what matches and what doesn't; what's "in" and what's "out"; and the importance of basic hygiene and cleanliness.

Parents, your teenager needs your support here. First impressions are crucial. Jerry Newport talks about the importance of looking right to avoid bullying, in addition to making friends. If you have no other teenager in the house, get a friend's teenager to tell you and your child what is hot and what is not. Often the brand name is important. If you have a very small clothing budget, it is better to buy the right thing from a secondhand store than the wrong thing new. Find out what the current hairstyles are and teach your teenager how to have that look. See if your teenage fashion adviser can go shopping with you and your child to help with getting the right look.

Some children grow into teens who are still attached to their favorite item and want to wear it everywhere—perhaps a Cinderella or Sponge Bob T-shirt. One way around this is to have rules about wearing the shirt—that is, in the house only. Taking a picture of the item and having it available in their pocket or on their cell phone or tablet can be a good solution. If it is the softness of the old clothes they like, purchasing gently used clothes that are already broken in may help.

Teenage Emotions

With raging hormones come feelings that your child may not be familiar with. Authors on the spectrum discuss this in their books as well. Reading about their experiences will help you understand about the thinking processes of many people with ASD, and give you ideas on how to help your child get through this crossroad in his life.

Teenagers with ASD may physically be maturing at the same rate as their teenage peers, but emotionally they tend to mature much later. Early adolescence is when most young people seek more independence from their parents, strive even more for approval from their peers, and try to fit in with the crowd. Teenagers start showing an interest in romance, dating, and perhaps getting physical with members of the opposite sex. Thus, while

their peers are interested in romance and start testing the system, the teenager with ASD may continue to stick to the rules and value high grades.

The young person with ASD who as a child had difficulty with meltdowns and aggression may calm down at puberty. However, adolescence is often a time when tantrums appear or reappear. Usually these are due to frustration, which is a normal feeling to have when you have ASD and don't understand the social cues and changes in your non-ASD peers. Another change is that usually in primary schools the children are in the same classroom with the same teacher for most of the day. In secondary school the teenager has to deal not only with different teachers, but also with moving around to different classes. These issues are discussed in Chapter 7.

There is a risk of depression during these years as it becomes apparent to the teenager with ASD how different he is from his peers. As he becomes more interested in socializing, he may be teased and scorned by others due to his lack of required skills. Your child may be experiencing feelings of anxiety, depression, or the "blues" that will go unrecognized if he is not encouraged to talk about his thoughts with you. Your child needs to know that these feelings are normal and how to recognize and identify the different feelings he is having. For those less able, picture icons or simple drawings of happy and sad faces can initially help the nonverbal person to communicate how they feel.

Research has shown that there is a higher incidence of depression or manic depression in families with a child with ASD, perhaps due to a biological predisposition. It is important that a person with ASD who is depressed be treated by a professional knowledgeable about the condition.

Reports from adults on the spectrum indicate that many of them suffer from anxiety and that this was heightened during the teen years. It is important that if your child has this anxiety it is acknowledged by the family and school and not just accepted as a fact of life. According to research by Dr. Scott Bellini, individuals with autism tend to suffer from anxiety at a greater level than the general population. As well, the study showed that poor social skills were associated with social anxiety in teens.

Cognitive behavior therapy may be helpful as well as teaching social relationship skills. *Exploring Feelings: Anxiety: Cognitive Behaviour Therapy to Manage Anxiety* by Tony Attwood is a useful book.

Bullying

Bullying is a significant problem in secondary school, and for this reason I have written about it in Chapter 7, which the reader may wish to consult. However, a few suggestions are in order here for parents.

Bullying is very upsetting for the victim and should not be treated as a fact of life that everyone deals with, because in reality it is only people who are different who are bullied. Teenagers need to learn what is responsible behavior and how to be tolerant of others. If they don't learn this in school, where will they learn it?

There are a number of steps to take when handling bullying. First, there is reporting it so that it will stop. Second, there needs to be sensitivity and empathy training for the typically developing students. Importantly, the student on the spectrum needs to be taught social and conversational skills.

If your child is bullied, make sure you report it to the principal in writing. If he or she does not respond, then go up the chain of command in the school district. When a student with a disability is bullied, it is considered harassment and therefore becomes a civil rights issue, requiring the school to report it and the school must take action. The school is responsible for ensuring it does not continue, and this requires long-term monitoring. If you are not getting the proper response from your school, you may contact the Office of Civil Rights (OCR) at hhs.gov/ocr/off. For more information on bullying, visit stopbullying.gov.

FOOD FOR THOUGHT

Practice Helps

One way to help our young men is to help them learn a few stock social scenarios. Support groups should have practice sessions in introductions. Family members can go on “dates” with their daughter or son with autism. The practice of any social activity is a good training ground.

—Jerry and Mary Newport, *Autism-Asperger's and Sexuality*

As a parent, you can request that the school teach the social skills, behaviors, and conversations that other teenagers expect from your child. Make sure that goals and objectives for these are listed in the child's IEP (see Chapter 5). You can also try to teach the social skills to your child that will make him understand more about neurotypical teenagers and the behaviors and conversation that they expect from your child. Consult the Resources section of this book.

Some on the spectrum find that learning martial arts increases their confidence. Luke Jackson also mentions that learning tae kwon do helped him in many ways, including impressing his would-be tormentors. It not only helped him with his motor skills, it boosted his confidence and made him feel better about himself.

FOOD FOR THOUGHT

My Brother Jeremy

BY REBECCA SICILE-KIRA, TWELVE YEARS OLD

Jeremy is my older brother. He is fifteen years old and has autism. He likes to watch TV, spin tops, twirl toys, and play computer games. He also likes to go for car rides and go swimming at the pool and the beach. His favorite foods are french fries, cheese, pasta, rice, salad, strawberries, cookies, and chocolate. He is in ninth grade. He has some friends that he hangs out with at school. He also goes to school dances with one of his aides.

I like playing games with my brother a lot. I'm usually busy, but when I am free I try to play with him. We play games on the computer as well as board games. Some of the games we play are babyish, so they can get really boring after a while. One of my good friends, Rozlin, plays with my brother, too. She plays with him when she comes over, and at the Boys and Girls Club.

Sometimes I get mad at my brother. If I don't lock the door to my room while I'm not in, he will mess up my whole room! He is constantly playing with my toys. If he sees one of my toys lying around, he will pick it up and twirl it, until he finds something else to twirl. After a while that gets very annoying. I also can't leave my toys out because he might break them. It's not often that he breaks my toys, but when he does I get really mad.

Now that Jeremy is learning how to type, he is able to communicate more with us. I like this because now we can ask him a question and get an answer. Unlike when he couldn't type and we couldn't ask him anything. Sometimes he types something about me or to me. I like this because when he says something about me, it is usually something nice. I do not mind that he is autistic too much. He has gotten better at many different things. He does not hit as much as he used to. He is also a lot more patient. Even though he is autistic, I like having him as my brother.

Social Skills and Dating Skills

Even if your teenager prefers to spend a lot of time alone, he will need some social skills to get by in life. In Chapter 5, strategies for teaching social skills are described. In Chapter 8, ideas for actual situations or places for socializing are discussed. Again, social skills should also be taught at school and addressed in the student's IEP, but dating may be a subject you want to discuss at home.

For the able teens and young adults who are interested in dating, Jerry and Mary Newport offer many words of wisdom in their book *Autism-Asperger's and Sexuality*. Have your teenager read certain sections (this can be done by photocopying the section in question, which is authorized by the book's publisher for this specific purpose), then you can discuss them with him and provide any support he needs. Luke Jackson's book is a good resource for the early teen years.

Girls on the Autism Spectrum

Although boys are five times more likely than girls to have autism, there are still many girls with autism. Girls and women have areas of strength that can mask their deficits. Often they display characteristics that make diagnosing autism difficult.

Dr. Tony Attwood has identified some characteristics of women and girls on the more able end of the spectrum, such as:

- May be so successful at “faking it” that they only come to the attention of a clinician when a secondary mood disorder emerges.
- Usually have a single friend who provides them with guidance and security. They also tend to offer peer support to others.
- May use doll play to replay and understand social situations. Often have imaginary friends and extremely detailed imaginary worlds.
- Before making a first step, they try to understand a situation. As well, they may mimic or even try to take on all the characteristics of someone they are trying to emulate.
- May read fiction or watch soap operas to help them learn about other people’s inner thoughts, feelings, and motivations.
- Often want to appease others and apologize frequently.
- They tend to have what is classified as a “male brain,” and they may be specially gifted in engineering and math.
- May be categorized as “tomboys,” and usually show no interest in appearances.
- Tend to have a faster rate of learning social skills than boys, but they may still need to be directly taught certain social skills.
- Often have a special interest that is more likely to be unusual in terms of intensity.

RESOURCES

Asperger’s and Girls by Tony Attwood, Temple Grandin, et al.

Girls Under the Umbrella of Autism Spectrum Disorders: Practical Solutions for Addressing Everyday Challenges by Lori Ernsperger and Danielle Wendel

Safety Skills for Asperger Women: How to Save a Perfectly Good Female Life by Liane Holliday Willey

Aspergirls: Empowering Females with Asperger Syndrome by Rudy Simone

Girls Growing Up on the Autism Spectrum: What Parents and Professionals Should Know About the Pre-teen and Teenage Years by Shana Nichols

Parenting Girls on the Autism Spectrum: Overcoming the Challenges and Celebrating the Gifts by Eileen Riley-Hall

Siblings

It's not always easy to be a sibling, but having a brother or sister with ASD has added challenges. These challenges can have both positive and negative effects on a sibling. Parents need to be aware of the sibling's feelings in order to develop strategies of support to help him adjust. Some helpful resources for siblings are listed in the Resources section.

On the positive side, many siblings develop a maturity and sense of responsibility greater than that of their peers, take pride in the accomplishments of their brother or sister, and develop a strong sense of loyalty. Siblings of ASD children are usually more tolerant of the differences in people, and show compassion for others with special needs.

On the down side, many siblings feel resentment at the extra attention the child with autism receives, and some feel guilt over their own good health. They may also feel saddled with what they perceive as parental expectations for them to be high achievers. Many siblings feel anxiety about how to interact with their brother or sister. Often there is a feeling of resentment at having to take on extra household chores, coupled with restrictions in social activities.

Living with a Brother or Sister with ASD

Because of the behavioral characteristics inherent to autism, living with a brother or sister with ASD is not easy. It is hard to foster a relationship with

a sibling who does not show any interest in being your playmate. After a while the sibling stops making attempts to interact with the brother or sister. It is hard to harbor tender feelings toward someone who invades your personal space and tears your favorite art project off the wall, or twirls the tail right off one of your favorite stuffed animals. And how can a sibling feel comfortable inviting friends over, knowing her older brother with ASD may come running down the stairs with no clothes on at any moment? Some of the behaviors exhibited by children with ASD would be typical of a younger child's behavior, but it is hard for a sibling as time goes on and the behaviors continue (or are replaced with other, more interesting ones) to feel anything but resentment.

Concerns of the Siblings

Some of the concerns siblings feel are about the ASD itself. They wonder what autism is, if they can catch it, and if their brother or sister will get better or not. Many feel that the parents spend more time with their brother or sister, and thus feel that the child with ASD is loved more. They can be resentful of the special treatment the other child receives and of the extra burden and responsibility they feel they have. As they get older, siblings are more and more concerned about the reactions of their friends.

How Parents Can Help a Sibling Adjust

Several different factors affect how a sibling adjusts, including the family size, the severity of the brother or sister's impairment, the age of the sibling at the time of the diagnosis, as well as the gender and age of the sibling, and their place in the birth order. An older sister may well feel responsible for a younger sibling with ASD and try to "mother" or take care of him. On the other hand, a younger sibling may find herself caring at times for an older brother, in contrast to the traditional roles that she may be observing in other families. This can lead to feelings of resentment. All in all, the parents' attitudes and expectations have a strong bearing on how a sibling adjusts.

There is much a parent can do to help a sibling adjust and experience more positive than negative effects. Here are some tips:

- Keep the lines of communication open. Knowing that they can ask questions and talk about their feelings is the most important thing for siblings. Let them know their feelings are normal.
- Remind siblings that just because you give more of your time and attention to the child with ASD, it does not mean that you also give him more of your love. Let them know you love them just as much and that they are just as important. They need to hear it.
- Make sure that siblings have a private, autism-free zone to call their own. Install locks to make sure they have a secure place to keep their precious objects. Siblings need to feel they are safe and have privacy.
- Set out consequences for the child with ASD if he wrecks or ruins siblings' belongings.
- Teach siblings how to play or interact with their brother who has ASD. When they learn the skills of getting his attention and getting a response from him, they will be able to interact with him on his level and that will make them feel good about him.
- Make time on a regular basis to spend with each of your children alone. It doesn't have to be a long period of time—a fifteen-minute breakfast alone can be beneficial for parent and child. Schedule a special outing every once in a while.
- Do what you can to try to get the behaviors of the child with ASD under control.
- Make sure siblings have some time when they can have friends over and spend time with them without having to always include their brother or sister with ASD.
- It may be helpful for siblings to meet or talk to children in the same situation. Check with your local organizations to see if a support group

for siblings exists in your area. If not, see if there is any interest, and start your own with other families. The Sibshop information online at siblingsupport.org/sibshops and the book *Sibshops: Workshops for Siblings for Children with Special Needs* by Donald J. Meyer and Patricia F. Vadasy will help you do this.

Grandparents

Unlike the parents, who are focused on the autistic child's needs, grandparents are concerned about the effects of autism on their adult children (the parents), other grandchildren, and future generations. They also suffer stress similar to that of the parents and siblings. Grandparents may provide the autistic child's parents (who may be depressed, single, or divorced) with necessary support in the way of childcare, financial support, and advocacy. But, in certain situations, they may also contribute to stress because of conflict regarding behavioral symptoms and treatment. Sometimes grandparents get involved in the blame-game about the possible causes of the child's autism.

Grandparents may want to help by babysitting, but most do not have the training in behavior management or may not have the physical strength required to handle behavioral episodes. They may just want to play with the child and spoil him or her, and end up feeling rejected by the lack of "typical" exchange.

Providing available and willing grandparents with information and a little training that can enable them to step in and give the parents a few hours of respite can be beneficial to all involved. Explaining to them why their grandchild acts the way he does (i.e., sensitivity to sound and light, not being able to make sense of the world, lack of communication skills) is helpful. Suggesting they offer to do a specific task, such as teaching the child to catch and return a ball or play a simple game, or teaching a simple learning skill that needs much repetition and positive reinforcement, can be helpful. In this way they can understand both the effort needed and the excitement to be had in teaching their grandchild an interactive skill. Grandparents will feel empowered knowing they are making a positive

difference in the family's life, and the parents will feel supported and more relaxed.

A useful book is *Grandparent's Guide to Autism Spectrum Disorders: Making the Most of the Time at Nana's House* by Nancy Mucklow.

FOOD FOR THOUGHT

On Marriage

Anything you read about autism almost always says that the parents' marriage suffers more than anything. A lot of people separate. Men especially seem to have trouble. I think men suddenly feel they are not the head of the family anymore. . . . If I was going to believe in what I was doing, and allow my wife to take hold of her growth and help my son, then I was going to have to step out of traditional roles and complement her.

—Bill Davis, *Breaking Autism's Barriers*

Marriage with an Asperger Partner

Asperger's syndrome (AS) was officially recognized for the first time in 1994, and many adults who fit that label were misdiagnosed before then and treated for mental illness. (Since May 2013, the label "Asperger's syndrome" does not technically exist under DSM-V, but the individual characteristics still exist under the broader category of ASD.) Although traditionally three out of four children diagnosed with ASD are male, there is growing consensus that there may actually be more females who fit the label of Asperger's syndrome but have been misdiagnosed with mental illness. Keep in mind that the information below is based on heterosexual partnerships, although same-gender relationships occur just as they do in the population at large.

Sometimes the diagnosis of an adult follows that of their child, sometimes it follows marriage therapy, and sometimes it is problems at work that finally lead to a diagnosis. A spouse may seek out a therapist with complaints of a cold, uncaring, and unemotional husband, although she may have chosen her mate because he appeared calm and reliable. An AS adult may appear depressed because of the flat affect, monotone voice, and lack of direct eye contact. Others may appear controlling and rigid, insisting everyone in the household stick to the same schedule and participate in the same activities, due to a need for sameness and inability to empathize. It is this lack of empathy that has the biggest impact on the partner's ability to understand their spouse, as well as any children, and to recognize that their needs, perceptions, and thoughts are different from their own. Poor empathy in the AS parent may contribute to behavioral and psychological problems in the children. However, a parent with AS may be better able to understand and cope with a child who has the same diagnosis.

Anxiety and stress can run high in adults with Asperger's due to the difficulties in communication and social interaction. Most lack what we think of as common sense. Body language and subtexts of intonations are lost on them, so that they may hear the words that were spoken, but not understand the real message or context. Persons on the spectrum can be honest to a fault and may make inappropriate comments in public, thus appearing rude and uninterested in social situations.

These same communication problems can affect a person's ability to keep a job or move up the corporate ladder. Temple Grandin, PhD, often speaks about how she almost got fired from her first important job because she kept writing letters to the CEO telling him how he could improve the company. She had no clue that the hierarchy at work dictated how, what, and to whom you communicate.

Physical demonstrations of affection can be difficult for those adults who suffer from sensory processing disorder and are overly sensitive to touch. Often the AS spouse is surprised that his partner and children are feeling unloved and unsupported, not realizing that his behavior does not show the support and love he says he has for them. Some couples report that the partner on the spectrum insists on routine even in sexual activity.

Finding out that a partner has ASD can provoke different feelings. One of them is anger at missing out on aspects of a marriage that the partner was

looking forward to. Another feeling is relief that there is finally an explanation for the problems they are facing. The positive aspects of having a spouse with Asperger's can include the realization that they are in most cases loyal, honest, and dependable. Those who are diagnosed as adults who knew they were different feel empowered and relieved once they receive the diagnosis, as now they have a starting point for finding strategies that are helpful.

For a marriage between a partner with Asperger's and a non-autistic partner to work, each spouse needs to recognize the differences they have and why. Understanding the deficits, reinforcing the strengths, and acknowledging the needs of each partner is helpful. Teaching the willing AS partner behaviors that are important to his spouse (such as greeting her when he walks in the house, asking about the partner's day at work, giving her a kiss) can be effective. Research for my book *Autism Life Skills* indicated that those willing to learn can be taught expected behaviors and strategies. Some of these include teaching them the "hidden curriculum" (i.e., what non-autistics automatically learn and take for granted) and making lists for visual learners; see page 126. Information for partners and families can be found on these websites: Asperger Syndrome Partners and Individuals, Resources, Encouragement, and Support (aspires-relationships.com) and Families of Adults Affected by Asperger's Syndrome (faaas.org). A couple of good books by Rudy Simone are *22 Things a Woman with Asperger's Syndrome Wants Her Partner to Know* and *22 Things a Woman Must Know: If She Loves a Man with Asperger's Syndrome*.

How to Keep Your Marriage or Significant Relationship Intact

All relationships need tending, no matter who your partner or spouse is. Many couples look forward to having children, and all parents know the effects those little bundles of joy can have on your relationship with each other. It is put on the back burner as the new addition to the family takes center stage. When children enter the picture, the couple may realize that they don't see eye to eye on everything, and there are squabbles about child-rearing: how the children will be disciplined, what the appropriate

bedtime is, how much TV the children can watch, what constitutes an acceptable diet, and the importance of table manners. Add to the mix the household division of labor (who does what), plus the monotonous day-to-day routine of running a household, and often the relationship starts to resemble two partners of a company gone bad rather than the romantic liaison it once was.

The same is true when a couple has a child with ASD. However, more ingredients are added to the pot: the emotional turmoil of the grief cycle when a diagnosis is pronounced; the lack of support from the community; the waiting for information from professionals; the incredible demands brought on by the behaviors characteristic of ASD and the struggle to find and obtain an appropriate education, as well as other essential services. For many, as the child gets older, the demands of caring for him do not lessen as they do with neurotypical children, and the difficulty of finding someone to care for those older children with challenging behaviors so you can have some time alone sometimes becomes a challenge in itself.

This is a lot for any couple to survive, no matter how strong. The good news is that according to a 2010 study, the actual divorce rate for parents of children with autism hovers at the same rate as those with neurotypical children—64 percent—according to researcher Brian Freedman, PhD, clinical director of the Center for Autism and Related Disorders at the Kennedy Krieger Institute in Baltimore.

In the end, no matter the situation, it is up to you, the couple, to do what you can to keep your relationship or marriage afloat. Here are a few basic suggestions:

Arrange for scheduled time alone on a regular basis. The first step in being a parent, whether ASD is a factor or not, is to find someone to watch your children on a regular basis, even if only for an hour or so to have time together. Even when the children are not all-consuming, it is easy enough to fall into the trap of never having free time alone. Use this time to do something that you always enjoyed doing together before you had children. Granted, it is not always easy to find someone to care for your child. Your concern should be for your child and the carer's safety. You will need to tell any person helping you about the behaviors your child has and what they should do about them. Here are some tips:

- You know your extended family. Can you ask them to watch your child?
- Do you belong to a church or community group? You may find some volunteers who may wish to help you.
- How well do you know your neighbors? Are they likely to know someone?
- You may be eligible for respite services from a federal, state, or local agency (see Chapter 4).
- Call the local university and ask them to put a notice up that you would like to hire a college student.
- If you need to pay for the respite and do not have deep pockets, apply for and use any available benefits. If all else fails, barter a service in return. Perhaps you can exchange hours with another couple needing a few hours off.

For more tips on finding and hiring respite workers, see “Tutors, Babysitters, and Respite Providers,” page 259.

Discuss and decide what the division of responsibility and work will be. There is a lot more to be done when you have a child with ASD. It is rare to find a partnership that naturally absorbs the extra work and stress without one of the partners feeling as if the burden has been placed on them. Usually, one person jumps right in and takes over (usually the mother). This will lead to burnout, and even more disengagement on the part of the other partner. Sometimes, when one parent is working to support the family and the other is the homemaker, the extra burden falls on the homemaker, while the breadwinner tends to be around less and less, as the workplace starts to seem more fun than the home environment at the moment.

Find someone to talk to. Sometimes, talking to other couples in the same situation can be helpful. Just being with another couple who know what the two of you are living every day can make you feel better. Perhaps you can help each other out by sharing information or tips, or just meet up

to relax among understanding grown-ups. You can meet other couples through your local support groups.

Go to couples' counseling. If you are having a difficult time and feel that your relationship is severely suffering and heading the wrong way, couples' counseling can be helpful. Don't wait till things are so bad you are talking divorce. And if your partner refuses to go, then go alone. Contact your physician for a referral. Try and find a counselor who has experience with ASD. Ask your local support group for the names of any professionals they may know.

How to Provide for Your Child for When You Are Gone

Thinking about what will happen to our children when we are gone is not always pleasant and is something we'd rather not have to think about. But the reality is, no one lives forever, and provision needs to be made. No matter the ability or needs of the child, there are always challenges you know they will face. Whether your child is still a toddler or approaching middle age, a plan needs to be created.

Many people procrastinate when it comes to this all-important area in regard to our children. Parents are so busy just trying to deal with the present. And having to take the first step toward making these plans is acknowledging that one day you won't be around, and that is a painful thought. However, making plans is empowering because you are planting the seeds for your child's future, and you can rest assured that no matter what happens, you will have helped him as much as possible, even when you are gone. Would you want the future of your child to be decided by strangers because you hadn't made plans?

Ten Steps for Future Care Planning

In order to prepare a plan in a simple step-by-step procedure without feeling overwhelmed by the process, Bart Stevens, author of *The ABCs of Special Needs Planning Made Easy*, recommends that families commit to knowing the following ten life planning steps. If these steps are followed with the

assistance of a qualified special needs planner, the family will create a comprehensive plan that addresses the lifestyle, legal, government benefits, financial, and care needs of the person.

Regardless of the age or severity of the disability, creating a plan is critically important now.

1. *Prepare a life plan.* Decide what you want regarding residential needs, employment, education, social activities, medical and dental care, religion, and final arrangements.
2. *Write informational and instructional directives.* Put your hopes and desires in a written document. Include information regarding care providers and assistants, attending physicians, dentists, medicine, functioning abilities, types of activities enjoyed, daily living skills, and rights and values. Make a videotape during daily activities such as bathing, dressing, eating, and recreation. A commentary accompanying the video is also useful.
3. *Decide on a type of supervision.* Guardianship and conservatorship are legal appointments requiring court-ordered mandates. Individuals or institutions manage the estate of people judged incapable (not necessarily incompetent) of caring for their own affairs. Guardians and conservators are also responsible for the care and decisions made on behalf of people who are unable to care for themselves. In some states, guardians assist people and conservators manage the estate of individuals. Many parents who have children with disabilities do not realize that when their children reach eighteen, parents no longer have legal authority. They must petition the courts for appointment as a legal guardian. Choose conservators/guardians for today and tomorrow. Select capable individuals in the event you become unable to make decisions in the future.
4. *Determine the cost.* Make a list of current and anticipated monthly expenses. When you have established this amount, decide on a reasonable return on your investments, and calculate how much will

be needed to provide enough funds to support your child's lifestyle. Don't forget to include disability income, Social Security, and so on.

5. *Find resources.* Possible resources to fund your plan include government benefits, family assistance, inheritances, savings, life insurance, and investments.
6. *Prepare legal documents.* Choose a qualified attorney, paralegal, or certified legal document preparer to assist in preparing wills, trusts, powers of attorney, guardianships, living wills, and other necessary documents.
7. *Consider a "special needs trust."* A special needs trust holds assets for the benefit of people with disabilities and uses the income to provide for their supplemental needs. If drafted properly, assets are not considered income, so people do not jeopardize their Supplemental Security Income or Medicaid. Also, they don't have to repay Medicaid for services received. Appoint a trustee and successor trustees (individuals or corporate entities, such as banks). There are various types of special needs trusts. Make sure the person preparing your documents understands the differences and provides you with the right one.
8. *Use a life-plan binder.* Place all documents in a single binder and notify family/caregivers where they can find it.
9. *Hold a meeting.* Give copies of relevant documents and instructions to family/caregivers. Review everyone's responsibilities.
10. *Review your plan.* At least once a year, review and update the plan. Modify legal documents as necessary.

Once you have decided to prepare a plan, find someone to help you or hire a professional planner. Referral sources are available through governmental agencies, organizations, or local support groups. Solutions are available. The next step is up to you.

RESOURCES

wrightslaw.com/info/future.plan.index.htm

specialneedsalliance.org/home.

The Special Needs Planning Guide: How to Prepare for Every Stage in Your Child's Life by John Nadworny, CFP, and Cynthia Haddad, CFP

A short, easy-to-read book written by a certified financial planner and a parent of a young adult on the spectrum is *F.A.M.I.L.Y. Autism Guide: Your Financial Blueprint for Autism* by Greg Zibricky, CFP, ChFC, CLU, CASL.

7

Education

It would be nice to think that things had changed since my school days, but, in discussions, teenagers still at school today described the same problems and issues as people in their thirties and forties (many of these school problems, incidentally, were described in Hans Asperger's original paper in 1944). In the '80s and '90s, awareness and research into Asperger's syndrome increased dramatically, but it is still taking considerable time for this new knowledge to reach teachers and others "on the ground."

—CLARE SAINSBURY, *Martian in the Playground*

My story is like Helen Keller's, the amazing woman who started out deaf, mute, and blind. Helen Keller had a teacher, Anne Sullivan, who taught her and took her out of isolation . . . My mom saved me from a life of despair, much like Anne Sullivan did for Helen Keller, and then many good teachers followed in Mom's footsteps.

—JEREMY SICILE-KIRA, *A Full Life with Autism*

I really hated to do it, but I had to file for due process when Jeremy was in elementary school. I did not want to go through the cost in time, energy, stress, and money we didn't have. But there comes a time when you have to take a stand. My son was regressing, and there was abuse and neglect occurring in the classroom, which had been documented.

The severely handicapped class he was in was being taught by an untrained substitute teacher, and there were different untrained school aides in there every other week. They were barely providing babysitting services,

let alone a safe environment or an appropriate education. Meetings with the school district's director of special education just supplied us and other parents with unkept promises. The advocate we had hired said she had done all she could.

We removed my son from school, started a home program, hired a lawyer, and filed for due process. We were spending all our savings, and I was doing nothing else but teaching our son, overseeing the other tutors, making educational materials, and taking data. But I knew I was ethically and legally right, and that I could prove it. At home, Jeremy gained back his lost skills and learned new ones.

We wanted to avoid going to fair hearing, so we attempted mediation. The school district came to the bargaining table with no alternative or compromise for us to consider, and was chastised by the mediator for wasting everyone's time. We were obliged to proceed to fair hearing. On the first day of the hearing, the new director of special education (the old one had gone) agreed that the school district would refund us the money we had spent educating our son at home, and agreed to provide an appropriate program for him, including training for staff, stating that none of this should ever have happened.

A Few Facts About the Special Education System

If you are an older parent or a professional who has been in the trenches for a while, this chapter will ring a few bells. If you are a parent of a newly diagnosed child, a member of the general public, or a new teacher straight out of college, you may be surprised by what you are about to read. If you are in a position of power or hold the purse strings at the state or federal level, I hope that you will read carefully, and reflect long and hard about the state of education for children with ASD in the United States today and the working conditions the educators are faced with.

The United States has arguably the best laws in terms of education and protecting the rights of people with disabilities. As the years go by, advances are being made, and in terms of education, students in need of

special education services are so much better off today than their counterparts of thirty years ago.

Challenges, Expectations, and Demands

However, there is a crisis going on in early intervention programs and schools across the country. Nationwide, the number of children being diagnosed with ASD is rising at an unbelievable rate. The settings may be different, but the challenge is the same: Parents and professionals everywhere are grappling with the issue of how to educate an increasing number of children in the best possible manner. And more and more, as the struggle intensifies between the expectations of the parents and the budgetary policies of administrative officials, it is the frontline teaching staff who get caught in the crossfire, and the children who are the casualties.

Over the last fifteen years, the expectations of the parents have increased drastically. This is due to an increase in the number of teaching methods and strategies known to be effective for children with ASD, and the access to knowledge that parents now have thanks to the Internet. Regardless of ability, parents expect their child to be treated with dignity and respect, and to be given the opportunity to learn, using the methods that are known to be effective. Parents believe that every child has the right to reach his or her potential, no matter his capability. And rightly so.

FOOD FOR THOUGHT

It's a Team Approach

BY PATRICIA H. SNIDER

Effective programming for children diagnosed with ASD requires a team approach. Whatever the amount of programming (twenty hours, twenty-five hours, and so on), a good one is based on ABA and includes social skills and play skills. We believe that a highly structured classroom with at least three-to-one staffing is necessary to be able to provide both one-to-one and small group instruction. In addition, effective programming includes parent support activities

such as clinics and periodic inservice. In order for the program to be effective, everyone in the child's environment must understand and provide "therapy." Hence, parents, school, and independent providers, such as regional centers, must act as a team.

But it's expensive! Yes, an effective program is very expensive. Two extremely important team members are the state and federal governments. It is crucial that the federal government fund its share of our mandated special education programs as it promised. Then it is equally important that the state government fund an additional fair share. This way, local school districts will not be put in the position of paying for special education—mandated costs from the general education budget dollars, as is currently the case. If everyone is in the boat rowing in the same direction, the boat goes forward. Otherwise the boat goes in circles. We need a team!

Patricia H. Snider, MEd, EdS, was the director of pupil services, Del Mar Union School District in California. She has been involved in education for more than forty-five years, teaching both general and special education, and served as an administrator in the field of special education for many years.

As the parents' knowledge base and expectations for their children have changed, so have the demands on the teaching staff, school administrators, and education budgets. As demands intensify, educators are requesting more support in terms of assistance and training in order to provide for these students, which, of course, translates into the need for more funding.

The large numbers of court cases attest to the tensions that exist between the school districts and parents. When communication breaks down between the two, large amounts of time and money are spent on litigation instead of programs and training.

When it comes to a challenge as all-encompassing as the education of our children, there are no easy solutions to suggest. Parents and educators alike know and live this crisis every day. But parents and educators should not be the only ones concerned. Today's children with ASD will become adults. If they do not receive a proper and intensive early intervention, if the educational system does not provide adequate resources for the educators teaching them, as well as proper resources for preparing adolescents to transition into real adult life, society as a whole will suffer. Not only will the costs to support these individuals all their lives be greater than those of

a proper education, but society will lose out on the valuable contributions they could have made.

Special Education and the Law

Basically, students in need of special education services (i.e., special class services, one-to-one school aides, assistive technology) are protected under the Individuals with Disabilities Education Act (IDEA). IDEA was originally created in 1975 and has been reauthorized several times, most recently in December of 2004, with final regulations published in August 2006 (Part B, for school-aged children) and in September 2011 (Part C, for babies and toddlers). IDEA ensures that all individuals have access to a “free and appropriate education” (FAPE), thus requiring public schools to make education available to all children with disabilities. Until 1975, disabled children were often excluded from school. Since 1975, IDEA has protected and continues to protect the rights of hundreds of thousands of children with disabilities, including ASD.

FOOD FOR THOUGHT

Taking Responsibility

Everyone needs to take responsibility in an emotionally intelligent way. Parents need to take responsibility for not accepting less than an appropriate education for their child, while supporting the educational staff whenever possible and having good communication with all concerned.

Teaching staff need to accept responsibility by stating their needs to their superiors and refusing to provide services without the proper training and specialist support, as well as asking parents for information that can help them understand the child’s learning style.

And finally, special education administrators and the principal need to take responsibility for leading the way by listening to what the frontline teaching staff are telling them, understanding the educational needs of the child, and making some effective changes. With the increasing numbers of children being diagnosed with ASD today, this challenge is not going away any day soon.

As parents, educators, and administrators, we are responsible for the future of all individuals with ASD. It is our responsibility to work together to ensure the best preparation for the future of these children. They are counting

on us and we must not let them down. As neurotypicals, we should be able to handle the pressure, communicate effectively, empathize with, and understand each other well enough to work together. Aren't we the flexible, socially cognizant ones?

IDEA is a federal act, and each state may provide more special education rights than provided by IDEA, but a state may not take away rights that are provided under this act. Much costly litigation takes place between parents and school districts over the interpretation of what is considered an “appropriate” education under the student’s right to a “free and appropriate education.”

In January 2002, the No Child Left Behind Act of 2001 (also called the NCLB Act) was enacted. It expired in 2007 and since then has been stalled in negotiations in Congress. Federal education law has been due for congressional reauthorization since 2007. This law specifically forbade schools and states from excluding students with disabilities from accountability systems, and all students must participate in tests that accurately gauge their progress. This is important because tests give parents and educators valuable information to target the areas in which the child needs help. Parents have a right to know, even for the most cognitively challenged, what their child is learning and if the teaching strategies being used are effective or not with their child.

To stay up to date on changes to the law, parents and educators can stay informed on special education and funding facts and concerns by checking the U.S. Department of Education website (ed.gov) and your state department of education.

Funding Facts and Concerns

When IDEA was created thirty-eight years ago, 40 percent of the funding for educating special education students was supposed to be provided by the federal government. Before 2004, the annual appropriations from Congress for IDEA had only been around 14 percent. For 2009, the most recent year with data available, IDEA federal funding covered 16.9 percent of the

estimated excess cost of educating children with disabilities, less than in 2008 when federal funding covered 17.6 percent of the cost, and the same as in 2007. Therein lies the crux of the matter: Local school districts are mandated to provide a “free and appropriate education,” yet they are not receiving funds that were promised when the federal law was originally created. This creates much tension at the local level as special education encroaches on the general education budget.

The most recent cost figures, released in 2003 by the Center for the Special Education Finance, show that students with autism have the highest per pupil expenditure for special education services (\$11,543). Also interesting to note was the disparity between the states (the thirty-nine that participated) in the amount spent per special education student. The figures ranged from a low of \$2,889 (in Oklahoma) per special education student to a high of \$12,899 (in New York) for the 1998–99 school year.

Obviously, funding is a major issue when it comes to providing for special education students.

Personnel Facts and Concerns

The most important aspect of any educational program is the frontline educational staff teaching the children. Studies and presentations released by the Center on Personnel Studies in Special Education (COPSSE) show that:

- There is a high turnover rate in special education teachers. Thirteen percent of special education teachers depart each year, which is ten times the rate of general education teachers. The available data suggests that there is a critical shortage of special education teachers willing to work at the salaries offered, under the working conditions that exist in the classrooms. The shortage of special education teachers is chronic and long-term, and 10 percent of all teachers are uncertified (“Teacher Education: What Difference Does It Make?” April 2003).
- Work environment factors such as low salaries, poor atmosphere, lack of administrative support, and role-definition problems lead to stress

and low levels of job satisfaction and commitment. These, in turn, can lead to withdrawal and eventually attrition. Teachers who were younger and inexperienced, and those who were uncertified, had higher rates of attrition, as did those with higher test scores (“Special Education Teacher Retention and Attrition: A Critical Analysis of the Literature,” Bonnie S. Billingsley).

- In the 1990s and 2000–2002, the role of paraprofessionals (i.e., school or instructional aides) evolved into one with a high level of responsibility including decision making regarding adaptations, providing behavioral supports, and interacting with team members including parents. The teachers’ roles changed, too, becoming more like managers and instructional team leaders (“Paraprofessionals,” Teri Wallace).
- Federal provisions require that all paraprofessionals be adequately prepared for their roles and responsibilities. The 1997 Amendments to IDEA require training and supervision for paraprofessionals who assist in the provision of special education services. Despite these laws, many local and state agencies do not provide significant preservice or in-service training (“Paraprofessionals,” Teri Wallace).
- Special education administrators face the increasingly difficult task of recruiting, retaining, and developing the professional skills of special education personnel. Skilled administrators are sorely needed to steer special education in the right direction. However, in the past ten years, the preparation and licensure of special education administrators has not received much attention. Also, states vary on how they endorse and certify special education administrators (or avoid doing so) (“Special Education Administration at a Crossroads: Availability, Licensure, and Preparation of Special Education Administrators,” Carl Lashley and Mary Lynn Boscardin).

Most special education administrators are (or should be) familiar with an important 2001 study by the National Research Council’s Committee on Educational Interventions for Children with Autism; the book describing the study, *Educating Children with Autism* by Catherine Lord and James P.

McGee, is available online from the National Academies Press (nap.edu/catalog/10017.html) and the usual online bookstores. Parents and frontline teaching staff would benefit from it as well.

FOOD FOR THOUGHT

Know the System

As you prepare to explore the special education maze, you will need to know how the process of special education works. Your knowledge of the school system's procedures and your skills in communicating information about your child are essential to becoming an effective educational advocate. . . . As parents going into school meetings, you are moving into a situation where the people you meet use a language and a body of knowledge you may not understand completely.

—Winifred Anderson, *Stephen Chitwood, and Deidre Hayden,*
Negotiating the Special Education Maze

The study created a framework for evaluating the scientific evidence concerning the effects and features of early intervention and school programs designed for children up to age eight. The authors conclude that one of the weakest elements of effective programming for children with ASD and their families is personnel preparation (among other things). They also state that teachers are faced with a huge task and outline recommendations for educating children with ASD properly and for giving personnel the training and tools to do so. This report has been cited by due process hearing officers and the courts in terms of appropriate services.

Conclusion

Obviously, each individual state would be better off in terms of funding special education if the federal government would follow through on its

promise to provide 40 percent of the funding of IDEA. However, for this to really help, the states, when receiving these monies, would need to put them into the special education budget, and not (as has happened at least in one state . . .) put it in another purse.

Money helps, but it is not the cure for all ills. Suggestions for retaining qualified personnel have been made by many and include keeping class sizes and caseloads smaller, providing higher salaries for special education teachers, providing some secretarial help to manage the paperwork, offering graduate-level courses paid for by the school district, clearly defining job descriptions, and providing opportunities for shared decision making.

Ensuring that instructional aides or paraprofessionals are adequately trained and making sure their roles are clearly defined has also been suggested, as has providing information to regular education as well as special education personnel.

As school administrators are the leaders and decision makers when it comes to funding and training, the preparation and licensing of these professionals needs to be carefully examined to ensure that quality candidates are supported in their quest to move upward in the system.

As one of the wealthiest (and supposedly more civilized) countries in the world, we owe it to our future generations to leave the educational system all the better for having been a part of the process—whether educator, administrator, parent, or simply just the taxpayer.

How to Get the Educational Provision Your Child Needs

Although this section is intended primarily for parents, educators may find it interesting reading.

In Chapter 5, various types of therapies and teaching methods were discussed. To determine which of these methods—and exactly what program—best meet the educational needs of a given child, information-gathering must take place. Different professionals will do assessments, but as parents spend the most time with their child, they can learn a lot about his abilities and learning styles just by observing him. Regardless of

whether your child is a baby or school aged, you will need to form your own opinion based on your observations of your child in his daily life.

FOOD FOR THOUGHT

The Meek Shall Inherit the Earth, but Only the Bold Will Get a Decent Education for Their Child with Autism

This chapter may be difficult reading for those who are used to abiding by authority and professional opinion. I mean no disrespect, but after living in three different countries with my son, I can tell you that one must be polite, but not be meek, when it comes to getting the education your child needs. If you do not fight for your child, who will?

The status quo will not change unless parents become proactive, learn about their rights and responsibilities, and convince the special education administrators that they know what the effective teaching strategies are for their child with ASD, and that they won't go away until they get them, regardless of the school or ability level of the child.

Be careful of the words of assurance from people in positions of power. Get promises in writing. If people don't call when they are supposed to, keep calling until you get them on the phone. Document everything. Be polite, but be insistent. And most of all, be brave.

The observations you note about your child's abilities, challenges, and learning styles will clarify which educational strategies and therapies could be useful for your child. Significantly, they can also help you in your quest for the right educational program. Once you know about your child, you can look at what is on offer (and what is not!) and decide if they will meet his needs. And if you believe that what is available is not appropriate for him, your documented observations will help you get others (teachers, school district administrators) to agree with you that another educational program or therapy is needed for your child.

Determining What Your Child's Educational Needs Are

Here are some good books for helping you determine your child's educational needs and how to get them addressed by the school district through the IEP process:

Negotiating the Special Education Maze: A Guide for Parents and Teachers by Winifred Anderson, Stephen Chitwood, and Deidre Hayden is an excellent user-friendly book that has good advice on becoming an educational advocate for your child. The authors explain how to make observations and collect information, and suggest what questions to ask when visiting prospective schools and classrooms. They also supply useful charts and questionnaires to use as guidelines to gather information. Teachers may find the book helpful as well.

Wrightslaw: From Emotions to Advocacy: The Special Education Survival Guide by Peter W. D. Wright and Pamela Darr Wright gives good, simple advice on how to become an advocate for your child and obtain the education he needs. The Wrights have a website with current updates on special education and the law and more of their advice: wrightslaw.com.

The IEP from A to Z: How to Create Meaningful and Measurable Goals and Objectives by Diane Twachtman-Cullen and Jennifer Twachtman-Bassett. This book provides sample goal and objective templates for different content areas, which are useful for writing goals and objectives that are measureable.

Another good book is *How Your Child Is Smart: A Life-Changing Approach to Learning* by Dawna Markova and Anne Powell. This book is helpful in determining your child's learning style—auditory, visual, or kinesthetic.

The Everyday Advocate: Standing Up for Your Child with Autism or Other Special Needs by Areva Martin, Esq. This book, written by an attorney who is also a parent, teaches parents the skills to become better advocates for their children.

Observing and Recording Your Child's Abilities

This kind of information is invaluable when thinking about your child's needs, and what kind of educational program would serve him best. Yet planning an appropriate program for a child requires documented and specific facts about the child, not just impressions and concerns. Parents need to learn to observe their child, to organize the information they glean, and to make sense of it.

Anderson, Chitwood, and Hayden give suggestions for recording observations on how the child acts in different environments, and how he relates to objects and people. These observations need only take five to ten minutes at a time. A good way to do this is to step back from your role in the family and watch your child, and see how he does without your help. For example, can your one-year-old sit himself up without your help? Does he know and respond to his own name? If your child is five, does he understand the rules of games and does he follow them?

Different developmental areas. Once you have written down your observations (e.g., "Sam can eat with a fork"; "Debra can do long division unaided and correctly"), you can organize them into the different developmental areas they pertain to. These areas are senses and perception, movement, self-concept and independence, communication, thinking skills, and social relationships. Your child will have different abilities in the different developmental areas. Knowing about these different areas will be helpful for you in identifying problems in your child.

In regard to young children from birth to five, check with your child's pediatrician. A good resource is "The ABCs of Child Development" on the PBS website (pbs.org/wholechild/abc), or for a baby's monthly milestones, see the Baby Builders website (babybuilders.com/developmental-stages).

If you do a search on "developmental milestones" on the National Institutes of Health website (nih.gov), you will have access to information about speech and language milestones. For school-age children, your child's teacher should be a good source of information as to what is considered normal development.

Your child's learning style. Children are different from each other, and so is their learning style. Think about yourself. Do you learn better by hearing information or by seeing it? Do you work best in a neat

environment or a messy one? Do you work long and hard, or do you take frequent breaks?

Now think about your child and what you have learned from observing him. Observe him some more if you are not sure, thinking about how he learned to do the things he does. Does he like watching videos and has he learned some phrases from the programs he watches? Does he copy an action he sees someone else do? Does your child do homework better alone or in the company of friends? Does he do his homework in a quiet environment or a noisy one? Sharing this kind of information with those who will be or are teaching your child will enable them to create the best possible setting for him.

Take extra care when considering how your child learns. Your child may be looking intently at objects, but may not be processing what he sees. Or he may not respond to his name because he is hearing all sounds too painfully well and may not be able to differentiate your voice from the background noise. The usual hearing and visual tests will not show what is really occurring in terms of visual and auditory processing. For more information on visual processing, go to visionhelp.com; for auditory processing, go to nidcd.nih.gov/health/voice/Pages/auditory.aspx.

Getting Early Intervention and Special Education for Your Child

Perhaps you are the parents of a preschool child, or you have an older child who is experiencing difficulties. It may be that you are a teacher who has concerns about a child in your class. A child may have been identified as having special educational needs as a baby or toddler before entering the school system, when he starts school, or when he starts encountering difficulties as he gets older. Sometimes the teacher has concerns; sometimes the parents; or perhaps a young person is having anxieties about their own ability to progress or difficulties in certain areas.

It is not my intention to give legal advice, or an in-depth explanation of how the system works, as each person's situation is different, and every state is different as well. Parents should be aware of their rights and responsibilities. Teachers as well should know their rights, and need to inform themselves about how IDEA is implemented in their state. There are

wonderful resources available, for both parents and schools, which are listed in this chapter and at the end of this book. Every state has a federally mandated “protection and advocacy” agency that can provide information and protection on the rights of persons with developmental disabilities through legally based advocacy. To find the one in your area, check acl.gov/Programs/AIDD/Programs/PA/Contacts.aspx.

Basically, every child under the age of three and at risk of developing a substantial disability if early interventions are not provided is eligible for early intervention. Your physician should be able to point you toward the resources in your area and any assessments your child may need. However, if your physician says, “Wait, your child will catch up,” and yet you feel that something is amiss, do not hesitate to go see another doctor for a second opinion.

The names of the different programs vary by state, but you can check with your state’s Department of Health, Department of Developmental Disability, or Department of Education about early intervention in your area.

If your child is eligible for early intervention, an individualized family service plan will be drawn up including the infant’s present levels of development and a statement of outcomes to be expected, among other things.

Once a child is eligible for preschool services, the educational system takes over. An individualized education program (IEP) is developed that sets out ways of helping the child with his areas of difficulties, and goals and objectives are developed. IEP team meetings take place annually to review the child’s progress and placement, but may take place more often. The IEP team is made up of the child’s teacher; a general education teacher (if that is not his regular teacher); the parents; any professionals providing services such as speech and language, occupational therapy, or adapted physical education; and a special education administrator. Tips on preparing for the IEP meeting are discussed later in this chapter.

If a parent has concerns about a child’s progress, she should first discuss matters with the teacher. If the concerns have already been discussed with the teacher, and nothing has been resolved, you could approach the special education administrator or ask for an IEP team meeting.

Advocating for Your Child Throughout the Special Education Process

It may be that you are one of those lucky individuals living in a school district that is truly knowledgeable about ASD and what works best for these students, and that provides good training to its staff. Perhaps you have a wonderful early intensive program with trained staff and appropriate supervision. Or perhaps your older child with ASD is fully included at your neighborhood school with specialist support, teachers who are knowledgeable and have the support they need to help your child, and not a bully in sight.

However, you are probably one of the many who are obliged to persuade their school district administrator about what is best for their child. If you have other children, you may already have experience with the educational system. However, when you have a child with special educational needs, you are entering unfamiliar territory and you need to learn a new set of navigating skills.

For a few years I wrote and gave workshops with Merryn Affleck in the San Diego area. Merryn was president of the North County Chapter of the Autism Society of America in San Diego, and is now CEO of Autism Northern Territory Inc. Our workshops were about developing the skills to become an advocate for your child, and creating a good working relationship with your child's school. Whatever your situation might be, as a parent you will need to follow these suggestions derived from our workshops to ensure that your child is getting the program and educational services he needs.

Get to know how your child learns. For a preschool-age child, observe how he interacts with people and objects. Does your child imitate others? Does he try to do new things with different toys? Does he appear curious about his environment? For older children, look at what your child's track record says about his learning style. For example, does he learn new concepts only with one-on-one instruction? Is he able to focus with twenty-nine other students in the classroom? Does he need a communication device? Does he learn by imitating others? For how long can he successfully be integrated into a mainstream school with support? What has worked in the past for your child and what hasn't? What has worked for other children like yours?

Learn about the educational strategies that work for ASD. Join local autism groups, look at resources on the Internet, read books, talk to other parents and professionals. Read Chapter 5 for a general overview on treatments and therapies, and read the section for teachers later in this chapter (beginning on page 217), as well as Chapter 6 on family life. You will find plenty of information about educational strategies and what research has to say about the various techniques, plus resources to find out more. ASD is a spectrum; all children are different. Find out about which particular teaching methods and strategies have been proven to be most effective with children like your child.

Learn about IDEA and “No Child Left Behind” and what these acts say about the school’s duties and parents’ duties with regard to the education of children. Live by the motto “Always be prepared.” You and your child are consumers of the education system and have certain rights as well as responsibilities. As a consumer you need to be informed as to what those are. You need to be as astute on the law as your school district is. As mentioned earlier, there are resources to help you. Every parent should contact their state’s protection and advocacy agency (visit acl.gov/Programs/AIDD/Programs/PA/Contacts.aspx to find your state’s agency).

Learn about your local school district. School districts vary on what kinds of programs or specialist support they have given in the past and are geared toward providing. There are regional differences, and some are better about hearing the needs of the child versus the budgetary constraints. Again, it is up to you to think outside the box. Don’t depend on the district giving your child what he needs; more often than not you will have to ask for it. Remember, your child’s IEP should be about meeting his educational needs, not what the school district is used to providing. Find out from other parents what your school district’s track record is for children with ASD.

FOOD FOR THOUGHT

Parents and Educators as Partners

BY ELLEN LEGARE

Remember when kids went to school to get an education and parents reinforced learning by helping (but not too much) with homework? Like it or not, times have changed; and so must we. We must recognize that children may go to “toddler school” or preschool and although parents are a child’s first teacher, they may share the educational experience with a variety of professionals.

Educators educate and parents parent; but somewhere along the line these two groups come together to form a “team” to provide an appropriate program for kids with special needs. Both are educated, experienced, and want the best for kids.

Team meetings get personal. Discussions may range from where and how the child sleeps and eats at home to the level of training a teacher may have. How can meetings between educators and parents be successful?

TRY A FEW OF THESE IDEAS:

- Stick to the facts and don’t try to interpret
- Don’t be quick to judge
- Listen to each other
- Be honest
- Be respectful
- Stay organized
- Discuss the present—not the past
- Recognize barriers
- Collaborate
- Communicate in a nonthreatening manner
- Question each other
- Explore all the possibilities

It takes time and energy to build a relationship, to trust in another person, and when concerns and issues become barriers it is even more difficult to reach an agreement. Don’t limit the team meetings to discussing the goals and objectives without recognizing that each team member brings individual expertise as well as their own perspective. Do remember that each perspective is just that—their own view. Listen respectfully and move on to address the issues and concerns that brought the team together.

Meetings between parents and educators should be considered “works in progress” and dynamic. Listen and learn; you may be glad that you took the time to do so.

Ellen LeGare is a special education advisor (and a parent) with over thirty years' experience building relationships with educational teams. An active member of parent associations such as PTA, CAC, and EFRC (Exceptional Family Resource Center), Ellen has been trained in alternative dispute resolution and mediation methods.

Familiarize yourself with the different types of school options. Your child has the right to a free and appropriate education in the least restrictive environment. Depending on where you live, your child, and his needs, there are different options, including full inclusion in his neighborhood school, resource units, learning centers, special education classes in neighborhood schools, regional classes, classes for severely handicapped children, learning-disabled classes, residential placement, homeschooling, and private schools.

Visit different schools and different types of classrooms. Before making a decision regarding your child's educational program, and what you think would be best for your child, visit the different options that are in your area. Keep in mind, however, that the class you are seeing now may not look the same the following year, and the teacher whose class you are visiting may not be there when your child is going to be a student there. There are many factors to consider when making a decision about your preference, regardless of the type of classroom. At any school, the appropriate questions to ask would include:

- How many children are in a class?
- What is the ratio of staff to children?
- Do the staff have appropriate skills and access to training to help your child?
- Are there any specialist resources (such as a behavioral consultant)?

- What kind of experience do the school and the teacher have with children with ASD?
- What teaching methods and strategies specific to ASD are the staff trained in?
- Is the school prepared to fit their systems around the child rather than being concerned about how a child will fit into the school system? For example, if your child is fully included, is there a “safe” place for her to go if she is feeling overwhelmed and stressed? Can school rules about eating in the dining hall be bent so that vulnerable children and their friends can eat together and have a lunch club in an empty classroom?

It is critical to ask specific questions about the teacher’s experience with and knowledge of ASD. Flexibility is also important. A teacher may not have much knowledge about ASD, but may be flexible about the needs of your child and willing to learn what is necessary to make this a positive experience for your child.

Do not be comforted by a good ratio of staff to children in a special education class unless you know that the teaching aides or support staff can demonstrate a functional knowledge of teaching methods proven to be effective with children with autism. Even the best teacher cannot be effective if she has untrained staff.

As autism is a spectrum, the staff may have had experience with a different ability level from that of your child or a different severity of autism. You want to make sure the staff have a working knowledge of your child’s type of difficulties or ensure that specialist support will be provided by someone with that level of knowledge. Some children with autism require a one-on-one aide, and you will need to consider whether or not you feel it is necessary. Again, this person will require training.

Develop good relationships. Develop and maintain good relationships with everyone you meet. If your child is already in school, make sure you have open lines of communication with the school staff. There should be a good flow of information going in each direction to make sure that you are all on the same page when it comes to behavior plans, toilet training, and

homework. Often the frontline staff have their hands tied. By working together you may be able to get resources for your child or the classroom.

Learn about intensive behavioral therapy. (See page 112.) This has been shown to be the most effective treatment for young children. Some districts are providing this for students with ASD. If you think this is what is best for your child and want to find out more, contact local autism support groups in your area and ask to be put in contact with parents who have experience with this in your area. Contacting other parents can be very informative.

Keep good records. Make sure you have copies of any assessments, reports, individualized education plans, and statements. Keep all assessments and reports in chronological order; they will be easier to find. Make sure you get copies of any assessments the school district has requested on your child's behalf.

Keep good notes of any phone calls, meetings, and conversations about your child. Keeping a notebook for this purpose is a good idea. Sometimes it is easy to forget suggestions professionals may make that are helpful, or when someone at school has told you something they are doing for your child, so writing notes (including names, professional positions, and dates) is very helpful. This is also a good way to jog people's memories about timelines and follow through on actions that need to be taken. It is also an ideal place to note attempts that you make to contact individuals who are having a hard time getting back to you. It's helpful to keep each contact on a separate page. This makes it easier to refer to in any meetings or letters, as well as to organize as evidence in any potential due process.

Do not be afraid to ask questions. If you don't understand certain expressions or jargon, or what someone said, ask for an explanation. If you are unclear about who is supposed to be doing what when, ask specific questions. This is especially true in something as important as a statement. Make sure the wording is specific. For example, what does "help on a regular basis" mean? Does that mean once a year, once a month, or once a week? How small is a "small group"? If you are told that a particular professional will monitor a program, the question begs to be asked, who is devising the program, carrying it out, and how often? Sometimes the wording is vague in order to allow flexibility. However, it should be

specific enough so you know who is responsible for what, and how often it should happen.

Do not feel intimidated by the professionals. Remember, you are the expert on your child. Never feel intimidated or that your input is less valuable than that of the teaching staff, other professionals, or the school district. If you feel intimidated, learn more about your child, his disability and abilities. Knowledge is power. Remember that you can consent in whole or only in part to team decisions made. You can delineate in writing that which you do not agree to.

Keep focused on your goal: a free and appropriate education in the least restrictive environment for your child. Although you do want to develop good relationships, remember that this is not about whether people are “nice” or trying to do what they can. Either your child is getting an appropriate program (meaning staff are knowledgeable and trained or given the specialist support they need if necessary) and is showing progress, or he is not, and that is the crux of the matter.

Monitor your child’s progress and educational program. Education is a continual process, including review and assessment: You review what is supposed to be happening, and you assess its effectiveness. Parents of neurotypical children monitor their children’s progress all the time. Parents of children receiving special educational services may need to be more vigilant. There are a variety of ways to achieve this. Base your monitoring method on your relationships with your child’s teachers, therapists, and school administrators.

Develop good relationships in the community. Being on the local school board or advisory committee of the school or district your child is in is an excellent way to meet other parents and to network with the professionals. I encourage those of you out there with extra energy and time on your hands to get elected. This is where decisions are made regarding local school issues. Our children need to be represented. You can have a positive impact on your community.

The Individualized Education Program (IEP)

If your child is receiving special education services, an individualized education program must be developed at a meeting with at least the parent or parents, the child's teacher, and a school district administrator. At time of writing, this meeting must take place at least once a year.

The IEP document is very important, as it establishes what services your child will receive and the goals and objectives for the coming year. For more information read *The IEP from A to Z: How to Create Meaningful and Measurable Goals and Objectives* by Diane Twachtman-Cullen and Jennifer Twachtman-Bassett; it's a great resource for helping to prepare an IEP. *Better IEPs* by Barbara D. Bateman and Mary Anne Linden is another great book.

It may be that you and the other members of the IEP team meeting are in agreement about your child and his educational needs. Sometimes, however, this is not the case. Remember that team meetings are not meant to be battlegrounds. If you are not in agreement after listening to the other members of the team, then state your position. If you cannot agree with the team, then you must agree to disagree. Once you start "losing it" in front of staff and make insulting and degrading comments in front of others, you have most likely already lost the battle. If you have concerns that a team may have differing opinions, it's a good idea to ask permission to tape-record the meeting (you will need to check your state's required notice time and the district may tape-record the meeting as well). This saves a lot of "he said, she said" if ever there were to be mediation or due process.

Eighteen Tips for Getting Quality Special Education Services for Your Child

The following tips were written by Ellen S. Goldblatt and Dale Mentink, senior attorneys at what was then called Protection and Advocacy Inc. (PAI, now Disability Rights California), a private nonprofit organization that advocates for the rights of Californians with disabilities. Each state is mandated by federal law to have an advocacy agency to protect the rights of people with disabilities, including those with developmental disabilities. Go to acl.gov/Programs/AIDD/Programs/PA/Contacts.aspx to find the one in your state.

BEFORE THE IEP MEETING

1. *Request needed assessments in writing or get independent assessments.* Your child can be assessed in any area of suspected disability and for any services needed for him to benefit from school. For example, assessments may be done of reading or math levels, on the modifications needed to fully include your child, for therapy services (OT, PT, speech, mental health), and to identify assistive technology like a communication device. If you disagree with the school district's assessment, you can obtain an independent assessment at public expense. Always request assessments in writing. An assessment plan must come within fifteen days. Once you sign the plan, the assessment must be completed and the IEP meeting held within fifty days (with some exceptions).
2. *Ask to obtain assessment reports one week before an IEP meeting.* Whether you or the school district requested the assessments, ask the school *early on* to provide you with copies of the written assessment reports *a week before* the IEP meeting. This is very important so that you can read the reports, discuss them, and plan for the meeting.
3. *Plan for the meeting with a friend or advocate.* In planning for your child's IEP, you may want to contact a local advocacy organization or parent advocacy group. (All states have a protection and advocacy agency and, depending on where you live, there may be other advocacy resources or attorneys who specialize in special education law.) Or buddy up with another family and assist each other to plan for IEPs.
4. *Review any assessment reports with this person.* Identify your aims for the meeting, and think about what your child accomplished last year and what you hope he will learn next year. Identify the special difficulties or strengths of your child that you want to bring to the school's attention. If you are seeking full inclusion or increased integration, identify how your child interacts with nondisabled children outside of school and what makes it successful.

5. *Consider full inclusion or increased integration.* The law says that to the maximum extent appropriate, as decided by the IEP team, children with disabilities shall be educated in their neighborhood schools and attend regular classes (with supplemental aids and services). These placements are called “full inclusion.” Today many researchers and parents believe all children with disabilities can and should be fully included. You should definitely consider before the IEP meeting whether you want your child fully included or simply want to increase her integration opportunities in classroom and/or extracurricular activities (clubs, field trips, etc.) at her school.
6. *Make a list of the points you want to raise at the IEP meeting.* However well you plan, you may get nervous or distracted at a meeting with several professionals. Thus, it is good to make a list of points and questions in advance so you won’t forget. You can check off points as they are discussed and jot down the answers to your questions.

AT THE IEP MEETING

7. *Bring a friend, advocate, and/or a person who knows your child.* You can invite anyone you want to your child’s IEP. It is always a good idea to have someone with you. If there is a day-care operator, grandparent, tutor, behavior specialist, or other person who knows your child and her learning style, it can be helpful to bring them to the meeting.
8. *Don’t be afraid to ask questions, and make sure you understand any “jargon.”* Schools are required to explain all findings and recommendations in easily understandable language. District staff use the same terms every day and may forget that the world doesn’t know what they mean. Some parents don’t ask questions because they feel it makes them appear unintelligent or unsophisticated. The fact is that the most intelligent and sophisticated parents often ask the most questions.

9. *Discuss the present level of your child's performance.* Discuss reports, assessments, and your own and the teacher's observations of your child's performance; record his abilities and issues.
10. *Develop annual goals and short-term objectives.* Review progress on prior goals, then formulate new goals and objectives. If you want your child to have greater integration or full inclusion, then you should request objectives that include interaction with nondisabled students (e.g., "Molly will learn to take turns by playing a game with nondisabled peers").
11. *Identify full inclusion or integration opportunities and the supports needed for success.* The district must provide supplementary aids and services to accommodate the special education needs of students with disabilities in integrated settings, including, for example, a trained aide, use of a tape recorder, an inclusion specialist to help the regular education teacher modify curriculum, or a behavioral plan to address disruptive behaviors.
12. *Describe the placement for your child and identify specifically the supports and related services needed.* All related services, such as speech therapy, should be identified, including frequency and duration; for example, twice a week for one hour. The parameters of the placement should be stated clearly (e.g., "Karen will be fully included in second grade with a full-time aide and five hours a week of a full-inclusion specialist" or "John will attend a special day class for communicatively handicapped students with mainstreaming for science, chorus, and all regular school activities"). You do not have the right to require the district to provide its services from a particular teacher in a particular classroom. Specific placement options should, however, be discussed at the IEP.
13. *Sign the IEP only if you are satisfied.* You do not need to sign the IEP at the meeting—you can take it home to discuss it with others and think about it. You can consent to only part of the IEP so those services you agree with can begin. If you sign the IEP and later change your mind, you may withdraw your consent by writing to the

special education administrator. If you and the district disagree on services, the last agreed-upon IEP remains in effect while a due process hearing is held. This is called “stay-put.”

AFTER THE IEP MEETING

14. *Meet your child’s teacher(s) at the beginning of the year—be a classroom volunteer if possible and/or participate in school activities.* Parents have different amounts of time and money. Analyze your situation and then contact the teacher or school to determine how you could be of assistance. If you work during the day you may be able to help prepare materials in the evening in your home. Not only will you become more familiar with the school and its staff, but your child will feel special.
15. *Support your child in developing friendships with her classmates.* Assist your child in calling friends outside of school and to make playdates. Having friendships with nondisabled and disabled children will help your child be part of the community.
16. *Monitor your child’s progress.* You may want to arrange for a regular communication system with your child’s teacher, such as a notebook that goes back and forth to school. Note projected target dates for your child to master particular skills and ask the teacher to let you know of his progress. Monitor to ensure that supplementary aids and services are actually provided.

IF THINGS DON’T WORK OUT

17. *You can file a compliance complaint if the school district does not follow the law or fails to provide services required in a signed IEP.* You can, as a recourse, filing a compliance complaint when you believe the district has violated a part of special education law or procedure. The complaint is investigated by the district or the state Department of Education, which then issues a written determination of whether the district was or is “out of compliance.” Check with your local advocacy agency for more information.

18. *You can file for a due process hearing if you and the school district cannot agree on the special education services appropriate for your child.* When you and the district disagree about your child's eligibility, placement, program needs, integration, or related services, either of you may request a due process hearing. At the hearing both parties present evidence to an independent hearing officer (hired by the state). The hearing officer will decide on the facts and the law and issue a written decision. Check with your local advocacy agency for more information.

FOOD FOR THOUGHT

Living with Inclusion: How It Works Best for This Autistic

BY JUDY ENDOW

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As an autistic, I sometimes feel boxed in by the best practice strategy of inclusion. Please don't get me wrong—inclusive education is a very good thing! Historically, people with disabilities were not given access to public education. Then, over time, laws changed. Today we have special ed classrooms in our schools and the progressive schools practice inclusion.

TODAY'S INCLUSIVE EDUCATION

Inclusion means that all the students get to learn in the regular environment. Instruction is differentiated while physical, sensory, emotional, and every other need of each student is taken into consideration so that all students learn together, each one doing and being his very best self. Inclusion allows each student to belong to the community of his peers.

MY PERSONAL TAKE ON INCLUSION

I love the idea of inclusion. It is right and good. It is very important. *And* sometimes this setup doesn't work well for me. I am not able to access my thoughts and words in real time. Even a quiet environment, when several people are in the same room, it does not necessarily allow me access to those people or even to my own thoughts. Sometimes this sort of situation can propel me to shut down or melt down.

In fact, now that I have access to the typical world and experience an inclusive adult life in my community, I am discovering that I don't always want to participate in the typical world. If inclusion is good and right, then why is this?

A BREADTH OF INCLUSIVE EXPERIENCE

As I ponder this question for myself as an autistic, I realize that the world is run according to the majority. This means a neurotypical (NT) brain is what is behind the conventional constructs of our society. Inclusion works the way inclusion works for the NT majority. Inclusive opportunities, and indeed all of inclusive education and life, happens via NT style. It is what we have. It works for NTs and it even works for me some of the time. It allows a *breadth* to inclusive experiences.

A DEPTH OF INCLUSIVE EXPERIENCE

But at other times I need to honor my autistic neurology. While I love being part of the everyday fabric of life in my community, I also need to spend time living my life with other autistics. This is where I find the *depth* of inclusion my heart and soul searched for my whole life. It feels like home to me. It is the place where I do not need to inhibit my natural noises, flaps, and extraneous movements and moans. I do not need to be mindful of the hundreds of social rules of NT society. I am free to be my true self. My autistic friends do not judge my intelligence, potential contribution, or human worth by my unconventional mannerisms. I belong, just as I am in my natural state, accepted and loved for my whole self—not just for my NT lookalike self.

THE BREADTH, THE DEPTH, AND THE IMPORTANCE OF CHOICE

And still, for me it is quite important to know how to get along in the world at large. I love the freedom of being able to walk in and out of any place in my community and fit in so as to appear to belong. I love being able to take my place in the world at large. I am grateful to have this choice because it hasn't always been this way in our world.

Additionally, a different and just as valid inclusion comes from the community of my autistic friends where all of me—including autistic traits and mannerisms—is understood and cherished. This is the place where I have the most fluid access to the best of my being, likely because I do not have to inhibit my natural autistic self. To me this is special.

FROM A HISTORY OF MARGINALIZATION

At the end of the day, I ponder the situation through history. Being “othered” most of my life in “special” settings never felt like inclusion to me. It felt like being shoved to out-of-the-way places of “less than.” Then later, given only the opportunity for inclusion NT-style, I was left wanting and longing for something I did not understand. It wasn't until I was part of the larger NT-style inclusive

community that I was then, in turn, able to find my home in the autism community, a place my heart longed for over many years.

TO A FUTURE OF COMPREHENSIVE INCLUSION

I believe we may come to discover in the future that to thrive and to be all that we can be, we autistics will need both the *breadth* of NT inclusion and the *depth* of autistic inclusion—two distinct and equally important styles of inclusion. As autistics, we also need to be *empowered to choose* how this mix best works for us in our given autistic bodies. My needs wax and wane over time, but it remains constant that to love and to be loved I need access to both inclusive environments and to be able to choose the mix that serves me best. This allows me to belong and to participate fully in the human race.

THINGS TO BE MINDFUL OF AS AUTISTIC CHILDREN GROW UP

1. Make sure your child learns the social skills and the hidden curriculum necessary to be accepted in the NT-inclusive environments at school and in the community.
2. Give your child the real scoop on his differences with the real language to explain these differences. This is the first step to becoming a self-advocate.
3. Make sure your child has access to autistic inclusion so he has the opportunity to know the comfort of being at home in his own skin among others who experience the world in a similar way.

Judy Endow, MSW, is an author, artist, and international speaker on a wide variety of autism-related topics. She is part of the Wisconsin Department of Public Instruction Autism Training Team, a board member of Autism Society of Wisconsin, Autism National Committee, and also works with Autistic Global Initiative. Besides having autism herself, Judy has three now-grown sons, one of whom is on the autism spectrum. For more information, please see judyendow.com.

Other Tips to Keep in Mind During the IEP Process

- Mediation is an option for parents and schools seeking to resolve a dispute arising either prior to or concurrent with a due process request. These are not limited to disputes involving the IEP. Mediations are confidential, and an impartial mediator facilitates to encourage both

sides to work together to reach a mutually acceptable agreement, which is legally binding.

- The IEP is not the “end all”; rather, it is the beginning of ensuring a suitable education for your child. Maintaining the IEP is a continual process, just like education. As a parent, you may need to monitor the plan that is being implemented.
- Risk-taking is an integral part of life. Many people are timid by nature and do not like to risk the ire of those in power by questioning authority or professionals. However, you are the expert on your child. What is it that you want for your child—what do you think he needs to learn and how does he learn best? If you are not in agreement with what others think is best for your child, you need to think about what the risk is of not speaking up. Think about what you would do if you were not afraid, then do it. Do you want to spend the rest of your life thinking, “What if I had said . . . ?”
- Parents who have a child with a disability have more stress than other parents. Dealing with the systems that are in place to “help” your child often creates even more stress than the child himself does. These feelings will overpower you (remember the grief cycle?) from time to time. You will find that you take your frustration out on the wrong targets, usually the systems and people who are actually there to help you. Learn to recognize when you are not in control of your emotions or your stress level is high.

FOOD FOR THOUGHT

A Teacher’s Quest for Integration

BY KARLA ZICK-CURRY

They are able because they think they are able.

—Virgil

Two days before school started, I got copies of nine individualized education programs (IEPs) from the district secretary. I began reading through the IEPs, speech and language reports, and psychological reports. I began to wonder, how am I going to effectively teach nine students with only two paraprofessionals and myself? I knew that two days of contemplating this question would only cause even more questions to arise, so I decided to focus on the empty classroom that awaited and the endless new employee meetings that I was required to attend.

The bell rang two days later at 9 a.m., and I was about to meet the nine students that were assigned to my classroom. One by one each student entered the classroom either independently or with assistance. As I looked around in a daze, I noticed two feet sticking out from underneath the big blue beanbag that sits in the corner of the room. That must be Kyle, I thought. This was the first of Kyle's many responses to situations that mimicked what I ultimately wished I could do, but I am not diagnosed with autism.

This was Kyle's second year in the district program and, like most students with autism, he came with quite a reputation. I tried to focus on the facts: Kyle was a male, twelve years old, and diagnosed with autism. Eventually, Kyle moved from under the beanbag to on top of the beanbag. I took it as a cue that he was ready for some sort of interaction. I got down on his level, introduced myself, and tried to connect in one way or another. He looked at me with these big green eyes, smiled, and proceeded to attentively look around the room.

Two days had passed, and I was coming to terms with the fact that I was working for a system that supported exclusion, isolation, and the segregation of students with disabilities. I did not think any of my students belonged in my special day class, but I just could not figure out why Kyle was placed in my classroom. He did not have a physical or medical condition, which unfortunately seems to be an automatic referral to the district program. I was not seeing any of the behaviors that I had read about in the psychological reports or heard about from other staff. Knowing what I did about autism, I believed that Kyle was dealing with the change in teachers and programs better than my staff were—or even myself, for that matter. He seemed to be content in just going with the flow.

On the third day, I was ready to throw in the towel. I was tired, frustrated, understaffed, and trying to figure out how I was going to develop an effective and integrative program with the bare minimum of support from the district. I had nine students who had never been integrated into regular education classrooms, general education teachers who had never taught students with multiple disabilities, and two paraprofessionals who thought I was crazy for even mentioning such an idea.

Instead of taking a warm bath or drinking a much-needed cold beer, I decided to thumb through previous student assessments, observations, and recommendations. According to the district, the one thing these students had in common was that their overall developmental delays impacted each student's ability to progress in a general education curriculum, and that he or she would benefit from a program that had a functional curriculum. I was once again reminded that placement is often based on disability rather than the child's needs.

After the first week, Kyle was starting to communicate what seemed to be boredom and the need for attention by running out of the classroom or hitting staff. While Kyle was reaching out for attention, I was trying to meet the basic needs of my other eight students. It was taking three hours to just feed and change the students. I was beginning to feel like a highly qualified babysitter. I expressed my concerns to the district. A few phone calls were made by the administration, and I was “graciously” given a temporary paraprofessional for two weeks.

Over the weeks, Kyle started to have good days and bad days. His teeth were starting to come in so a completely new set of behaviors began to surface. Kyle refused to go anywhere but my classroom and the baseball field. Red flags began to pop up in regard to integrating Kyle this school year. I knew that Kyle would be able to learn and progress in a general education classroom, but did I have the right tools, accommodations, and supports needed to successfully integrate Kyle?

The federal law mandates free and appropriate public education for all children with disabilities in a least restrictive environment (a general education classroom) with appropriate supports and services. I was beginning to realize that it was entirely up to me to find the additional supports for my students. The supports provided by the district were just enough to meet the basic needs of the students. I was frustrated with the fact that I was going to have to rely on volunteers and peer tutors to implement the law, but if that’s what I had to do in order for my students to progress in a natural environment, then I would find a way to make it happen.

I was fortunate to have a change in staffing and receive two new paraprofessionals who believed in the students and my overall mission of integration. I also had an amazing support system at home and at the university that really helped put things into perspective and remind me to take one day at a time. I began to focus on what I did have and what resources I could draw upon to help make my goal of integration a reality. After numerous conversations with general education teachers and phone calls to community agencies, things were starting to happen. With the support of two amazing paraprofessionals, a community volunteer, the site principal, a handful of general education teachers, an intern, and peer tutors, I was able to integrate my students into general education classes.

Kyle was the only student that I was waiting to integrate. I wanted to get everyone else settled in their new classes so I could focus on Kyle’s integration program. He was starting to show interest in the school environment. For example, one day he followed me to the copy room, waited for me to make copies, and walked with me back to the classroom. A few days later, he followed a classmate to art class and sat outside the door.

I knew it was time for Kyle to make his way outside of my classroom, but I needed to find a teacher and classroom environment that would support Kyle’s sensory and security needs. Mr. Sullivan, a science teacher and my inside connection to the general education world, once again helped me find another incredible general education teacher. In just a few days, Kyle was set to attend a first period language arts class with the support of a paraprofessional.

I think my paraprofessional and I were more anxious than Kyle was on the walk over to the classroom. Our goal for the first day was to get him to the classroom, have him sit in his seat, and then stay in the room as long as possible. Once again, Kyle surpassed our expectations. He stayed seated the entire class period, picked up a pencil and started to scribble on a piece of paper that a peer gave him, participated in the class activity by choosing a color for the kimono, and did not once try to run out of the classroom. Kyle was happier than I had ever seen him. I am not sure if it was the natural environment of a general education classroom or the three pretty girls that came to sit with him at his table.

To this day, Kyle has played an integral part in the development of his school program. His unique view of the world is something that I admire and most of all respect. We have both learned to take one day at a time and deal with the fact that life is filled with challenges and rewards.

Regardless of the labels assigned to them, my students continue to grow as individuals and are an essential part of the school campus. Since good teaching means different things to different people, I am thankful to the parents, professors, and colleagues who have positive visions for people with disabilities, thus helping to shape my idea of what good teaching truly is—all students learning together in a natural and inclusive environment.

Karla Zick-Curry has been an advocate of inclusive education for students with disabilities since starting the graduate program at California State University at Northridge in 2001. Karla completed her doctoral studies in educational leadership with an emphasis on inclusive educational leadership. She is currently an assistant principal in Wilmington, North Carolina.

Become More Knowledgeable About the Law

You are going to be your child's advocate in the education system for some time. Empower yourself with knowledge about your rights. Here are some books and organizations that have useful information:

- Know your rights regarding protection and advocacy. If you are in need of advice, your local protection and advocacy agency can help you with advice, or recommend an advocate. Every state has some sort of protection and advocacy agency. Find out what publications they have available; these are free and available online. Go to acl.gov/Programs/AIDD/Programs/PA/Contacts.aspx to find the one in your state.

- *Wrightslaw: Special Education Law* by Peter W. D. Wright and Pamela Darr Wright is an informative and helpful book for those who want to read and understand about the laws that pertain to special education. For more information and for updates, go to wrightslaw.com.
- The Council of Parent Attorneys and Advocates (COPAA) is an independent, nonprofit organization of attorneys, advocates, and parents, whose primary mission is to secure educational services for children with disabilities. You can contact them at copaa.net.
- The American Bar Association is where to go to find out more about attorneys. You can contact them at abanet.org.
- U.S. Department of Education (ed.gov/nclb) is a good place to find out about the No Children Left Behind Act.
- “Building the Legacy IDEA 2004” (idea.ed.gov) explains IDEA and keeps current with any updates on the law.

Become More Knowledgeable About Attorneys and Advocates

Hopefully, you will never need an advocate or an attorney. But if you do, there are some things you should know. If you cannot afford to hire an attorney or advocate, there are usually advocates available through your protection and advocacy agency. Also, if you want to hire someone but have little discretionary income, they can give you the names of individuals who work on a sliding scale. Here are some tips you should keep in mind when looking for someone to represent your child.

FOOD FOR THOUGHT

Back-to-School Tips

BY DANA PULDE, MA, BCBA

With the summer approaching its end and the start of the school year creeping in around the corner, parents may feel a sense of relief to send their children

back to school and have the house to themselves again, but they may be sending them back with some trepidation. Thinking about who will be responsible for teaching your child the knowledge and skills needed to function in society is difficult enough, but having to provide them with a meaningful life is an additional concern that parents of children with special needs must think about. This is why it is important to prepare both yourself and your child for their new environment. But, where to begin?

First, don't wait for the first day of school to meet the teacher. This is one of the most stressful days in a teacher's life. Schedule a time to meet prior to this. Typically teachers have a "back-to-school day" a week before school starts. If you have the time, go and bring your child with you. Give your child an opportunity to familiarize himself with the teacher and the classroom. This will also provide you a face-to-face interaction with the teacher, which can be more meaningful than a phone conversation in many ways. Take a look around the classroom.

- Does this teacher consider spatial arrangements (e.g., for students in wheelchairs)?
- Are items labeled around the classroom (for students who are younger or are in an SDC classroom)?

As a parent, what you should be looking for are the accommodations that your child specifically needs. If your child is a visual learner, make sure the teacher has visual reminders around the room and/or a visual schedule on your child's desk. If your child is deaf and hard of hearing or has difficulty with attention/focus, make sure her desk is in the front of the room.

It is important to note that if your child requires the use of large-font textbooks (for the visually impaired) or assistive technology such as specific computer programs and voice output devices that are written into your child's IEP, make sure to discuss this with the teacher at the end of the previous school year as it takes time for orders to arrive.

What I have found to be one of the key elements to a child's success is creating a positive and supportive space for them, both at home and at school. Though it is the teacher's responsibility to create this place for their students at school, the parents actually play a significant role in this. Building rapport with your child's teacher creates a collaborative and cohesive environment that promotes growth and helps foster independence. Having such a relationship will also ensure your involvement in your child's education. When a teacher feels threatened by a parent, her relationship with that parent is harmed, which in turn affects the child. You are the expert on your child, which is why your involvement is essential to your child's success. The relationship with your child's teacher is reciprocal. Just as they need you to provide them with information about your child, you need them to provide you with educational strategies to use in your home. When you have established a positive relationship with your child's teacher, you may find many teachers who are willing to extend themselves in ways that will help you and your family. Many

teachers, for example, will duplicate materials so that you have an extra set at home and may often be willing to travel to your home to provide training on how to implement the use of such materials and strategies. This is a valuable resource that I recommend all parents take advantage of when possible.

Most important, remember to take a deep breath and relax. Your child will be in good hands as long as they have you in their lives.

Dana Pulde, MA, is an education specialist and private consultant who has been working in special education for ten years. She has taught students in verbal behavior-based classrooms and has completed her BCBA supervisory hours. Dana has worked as an instructional aide, a behavioral tutor, and a teacher in a moderate/severe classroom in both non-public and public school settings.

First, know the difference between an attorney and an advocate:

- An attorney has passed a state bar exam and holds an active State Bar card. A practicing attorney must stay current with the law. There is no national standard for advocates and in reality anyone can call himself or herself an advocate. However, there are many excellent advocates.
- Fees paid to an attorney may be reimbursed in the event that you should win a due process. Advocate fees are never reimbursed. Before hiring an attorney or advocate, talk to parents who have used his or her services and ask:
 - Are they happy with the results? Do they feel they obtained what their child needs and should have under the law?
 - What style does the professional have? Look at what your needs are and analyze the type of person you wish to represent you. For example, is he warm and fuzzy or is he a hired gun? You need to feel comfortable with the person. Speaking from experience, at this point in the game you are looking for someone to be effective in getting what your child needs. If you need support, see a therapist.

Find out more about the attorney or advocate by talking to them over the phone, or if they are very busy and in much demand, ask their office staff to get back to you about any questions you may have, such as:

- What percentage of cases handled by the professional are resolved in mediation? This will tell you about their ability to negotiate and how successful they are in avoiding going to fair hearing.
- How many cases have they handled that are similar to yours, or in your school district, and what is their success rate for those cases? This person may have much experience, but it could be more with learning disabled children and/or in another school district.
- What are the hourly rates, what estimate is there for this kind of case, how much is the retainer, and how is billing handled?

If you are leaning toward hiring an advocate, you need to ask these questions:

- Does the advocate have an attorney to refer you to if necessary? This is important, because if you are unable to come to agreement with the school district and decide to file for due process, you will most likely need an attorney, and your advocate will be able to easily hand the case over to one. Also, if the advocate has any legal questions she is unsure of, she has someone to check with who will guide her.
- How much training has she had in special education law, and how much experience with your type of situation and in your school district?
- Is the advocate a member of the Council of Parent Attorneys and Advocates (COPAA) (copaa.net), and does she attend conferences regularly to keep up with the changes in law?

If your state department of education publishes due process cases online, then you can do a search of the history of the attorney or advocate

you are leaning toward hiring to see their history with that agency.

Keep in mind that once an attorney or advocate has done their thing for you, and the IEP has been worked out and signed, you will be the one left to do the monitoring. You will need to do some relationship building with the school staff.

Educators: Teaching the Child or Adolescent with ASD

Whether you teach a special or general education class, or in a resource center, you will have students with ASD in your class. This section is written particularly for those who work in education; however, parents will find this section informative as well. Some resources are mentioned here, many more are listed in the Resources section.

As indicated earlier in this book, the incidence of ASD is rising and they are not going away. Perhaps you already have a lot of practical experience or knowledge of the best teaching strategies for children with autism, and you work for a school district that is supportive of your need and desire for specialist support or access to knowledge in order for you to use strategies proven to be effective with children with ASD. If so, hurrah!

FOOD FOR THOUGHT

Be Precise

For any classroom assistants or teachers reading this, then please, please try to realize that instinctively knowing where to go or who to talk to, and what to do next just isn't possible for a kid on the autism spectrum. If a teacher says "now get out your books and turn to page 10" and doesn't say "and now start answering those questions," then the AS kid is not likely to know, so to tell them off for doing no work that lesson, is unfair.

—Luke Jackson, *Freaks, Geeks, and Asperger Syndrome*

However, not all school districts or schools give the same level of access to autism expertise or specialist support. Young teachers fresh out of college may not be aware of the politics of education, and some administrators will convince them they know enough to run a class and teach the children with little or no behavioral support or autism-specific training. There are also teachers who do not understand that students with ASD are differently wired; who don't understand that they need to learn specific strategies to be effective with students with ASD; or who have difficulty being flexible enough to accommodate the needs of these students. Nonetheless, most educators, by the nature of their chosen field, recognize that you can never stop learning or have too much knowledge.

The Basics Everyone Working at Any School Needs to Know

Presume competence. Remember, every child is different, and every child deserves the same respect, whether they are nonverbal and appear severely handicapped by their autism or very able with idiosyncratic behaviors. Just because someone is unable to talk doesn't mean he doesn't understand what is going on around him. That student's challenge could be in the output, not in understanding what he hears. There are many written reports by students who are nonverbal that demonstrate their capability. On the other hand, just because someone is verbal doesn't mean he understands more than the literal sense of what you are saying. Assumptions about a child's intelligence cannot be made because of his lack of communication or social skills.

ASD is unlike any other disability. Some children with ASD do not have imitation skills. Imitation is how most people learn. Many children with mental retardation or learning disabilities have imitation skills and are social. They may pick up social behaviors and language "naturally" by being put in a class of their peers. This is not true for the most part for children with ASD. Many have a good academic understanding of social skills but are not able to apply them. They need to be taught how to apply, in everyday situations, the social skills that most of us take for granted. The challenges that people with ASD have are due in part to different wiring in the brain. They are not just being "difficult." Obviously, there are different

ability levels in children with ASD, but regardless, all have problems with social skills, communication, and understanding more than the literal meaning of words.

ASD-specific training is necessary. It does not matter how many years you have been teaching developmentally delayed children, or how many children with ASD you have seen in your class, you need to learn more. It is relatively recent that the results of effective teaching methodologies and strategies are being seen and recognized. Currently these strategies are still being developed or refined or built upon. Your special education administrator and school district needs to be convinced of the need for specialist training and support. This is true no matter what type of school you are working in, no matter the level of disability or ability.

Teaching assistants and all staff working with the child need to be trained. A person who does not have the skills to do the job properly will not be an effective person to have around. Giving people the right skills to do their jobs will make them effective, confident, and provide more job satisfaction, which makes for a low employee turnover rate. And that is always a good thing.

Peers need to be informed about disabilities and taught tolerance. Peers need to be given information so that they understand why people are different and why they act the way they do. This is true for all disabilities, not just ASD. However, autism is an “invisible” disability, as you can’t see it and the person may act neurotypical in most ways. Peers need to be told that they will benefit from having students with differences like their classmates. If there is concern about “labeling” on the part of the parent or the student, it is possible to talk about the issues without naming the disability. For example, peers could learn about how “social communication” is a challenge for some. Just as the student with ASD is learning new appropriate ways of behaving, the peers need to learn to be more accepting of the differences in others. If they don’t learn this at school while they are young, how will they learn to be tolerant and responsible members of society? A good resource is the book *My Friend with Autism* by Beverly Bishop.

Use the student’s strengths and special interests to teach him. Many students have a passion for a particular object or topic. Instead of trying to rid him of this “obsession,” use this interest to teach. For example, if a

student is passionate about trains, you can teach color, numbers, distance, time, math, geography, and history all by using trains as examples. This will motivate them to learn. This passion can be used to help them connect with their peers, and may later translate into a job or career. For example, as a young child, Stephen Shore (now a college professor and author) used to take watches apart and put them back together at home. This was translated into a job repairing bicycles while he was a student in high school and college.

FOOD FOR THOUGHT

On Being Bullied

Another reason I think I have been bullied in the past and am prone to being picked on is that I just don't want to "run with the pack." I never have and never will. I don't see any point in pretending that I like things when I don't. I think this is one of the reasons why other people don't want to make friends with me or hang around with me.

—Luke Jackson, *Freaks, Geeks, and Asperger Syndrome*

Peer tutors are a great resource. Often schools include peer tutors to help teach the child. This is a wonderful idea; however, for this to be successful, the peer tutors need to be appropriately trained. Peers may be used to developmentally disabled individuals who are social but not used to the lack of automatic social interaction and apparent lack of emotion shown by some children with autism, and may be discouraged. For peer tutors to be successful, they need to have an understanding about autism and some knowledge in helpful prompting strategies.

Inclusion and mainstreaming done correctly are important. All students need access to typical peers and inclusion in general education classrooms. This is how they will make friends, and how their peers will

learn to be accepting of those with differences. However, inclusion requires support and planning to be successful. Paula Kluth's website and books are a great resource (paulakluth.com).

FOOD FOR THOUGHT

The Educational Environment

There are many things that people with "autism" often seek to avoid: external control, disorder, chaos, noise, bright light, touch, involvement, being affected emotionally, being looked at or made to look. Unfortunately, most educational environments are all about the very things that are the strongest sources of aversion.

—Donna Williams, *Autism: An Inside-Out Approach*

Providing opportunities to learn life skills is necessary. Life skills need to be taught at school as well as academics. Communication, social relationships, advocacy, and self-regulation are some of the important life skills that need to be taught at school before the student enters the adult world. My book *Autism Life Skills: From Communication and Safety to Self-Esteem and More—10 Essential Abilities Every Child Needs and Deserves to Learn* provides a good overview and some resources.

The principal sets the tone. Tolerance and flexibility are key words that should be practiced in every school toward any student who is "different." Principals should show by their own actions and attitude that bullying by other students will not be accepted and that staff are expected to be flexible to meet the needs of these children.

Communicating with parents is very important. Keeping lines of communication open with the parents can help alleviate a lot of stress at both ends. Many parents are willing to follow any suggestions you may have to help their child. Any behavior plan should be explained to parents

so they can enforce them at home as well. Parents, out of necessity, have become more and more knowledgeable about their children's disabilities and can give you information on ASD and their children that can be useful to you.

Must-Reads for Teaching Staff, Principals, and Special Education Administrators

There are many helpful books on autism for teachers, addressing a specific educational or social challenge. Below are a few general books to start with. Although these books were written with those on the more able end of the spectrum in mind, the information can be helpful for understanding autism in general and can help generate ideas for others.

- Although it was published twelve years ago, this book still remains an essential text for anyone working in education: *Freaks, Geeks, and Asperger Syndrome: A User Guide to Adolescence* by Luke Jackson. It describes what it is like to be a child or teenager with ASD, from one person's perspective, attending a school where the staff and other students have no understanding of this "invisible disability." There are specific examples of how someone who is academically very capable can only understand the literal meaning of words unless taught otherwise, and needs to be taught social skills to be able to act normally in a neurotypical world. This book also shows us, sadly, how youngsters with ASD are routinely bullied by their peers as well as misunderstood by unknowledgeable teaching staff. This alone should put the book at the top of all school educators' and principals' reading lists.
- Another gold standard is *Asperger Syndrome and Adolescence: Practical Solutions for School Success* by Brenda Smith Myles and Diane Adreon. This has a detailed discussion of strategies and supports necessary to ensure a successful school experience for students with AS at the middle and high school levels.
- *Asperger Syndrome and the Elementary School Experience: Practical Solutions for Academic and Social Difficulties* by Susan Thompson

Moore, MEd. This has many practical ideas for addressing the social and academic needs of elementary-aged children with Asperger's syndrome.

- A new video series *Understanding Autism: A Guide for Secondary School Teachers* is available on the website of the Organization for Autism Research, researchautism.org/resources/teachersdvd.asp.

Specific Challenges of Students with ASD

Bullying. Bullying is a major problem for students with ASD. It is apparent in elementary school, but becomes a significant problem in secondary school.

Bullying, which can range from verbal taunts to actual physical encounters, is very upsetting to the victims and should not be treated as a fact of life.

A 2012 study done on behalf of the U.S. Department of Education found that 46.3 percent—or nearly half—of teenagers with ASD receiving special education services are victims of bullying, while 14.8 percent engaged in bullying behavior themselves, and another 8.9 percent were both victims and perpetrators.

Rudy Simone, Jerry and Mary Newport, Luke Jackson, and Jesse A. Saperstein (all authors with ASD) discuss bullying in their respective books at some length. Luke Jackson writes about how he was chased and pinched, shoved, and hit many times. He also describes having personal school items such as rulers and pencils taken from him, having his lunch grabbed and stepped on, and doors being slammed in his face. More distressing are his stories about teachers making fun of his difficulties and calling him names such as “thick” or “dopey” in front of the class.

Bullying occurs for a number of reasons. It can happen simply because the teenager with ASD appears different to the neurotypical teens because of his dress and grooming. Often it is because as the other teenagers start to question authority, the ASD teen is still in the mentality of following the rules and thus seems to be “nerdy.” Sometimes bullying is due to the misinterpreted behavior of the ASD teen. Many children with ASD have

monotone voices, and sound rude or as if they are mimicking the person they are speaking to, which makes it appear as if they are poking fun. Many children with autism have mind-blindness; they do not realize that others have different thoughts from theirs, and so they are unable to anticipate what others may say or do, which creates problems in social behavior and communication. As mentioned before, some of the bullying comes from teachers who are uninformed about ASD. It is hard for teachers and other students to comprehend that someone who is verbally astute and gets good grades for his work is unable to pick up all the nonverbal cues most people take for granted.

A teenager with ASD may give the appearance of being “sneaky” or “manipulative” because of some of his body language when stressed (avoiding eye contact, shifting from foot to foot, speaking in a flat voice). The teen with ASD, usually a stickler for rules, may correct another student or tell off a child who is breaking a rule, thus enraging the teacher, who does not realize that the teen has no sense of hierarchy, only a sense of what is right. If a person with ASD has good language skills, others tend to forget that his comprehension of the language is different—that he only has a literal understanding of language, which can lead to trouble.

In any case, the school is responsible for ensuring that bullying or harassment does not continue, and this requires long-term monitoring. There is no federal law that applies to bullying in general, but when bullying is based on race, color, national origin, sex, disability, or religion, it overlaps with harassment—and it becomes a civil rights issue, and thus the schools are legally obligated to address it.

Section 504 of the Rehabilitation Act of 1973 and Title II of the Americans with Disabilities Act require that *all* schools have a prompt reporting system for grievances for individuals with disabilities, according to the Office of Civil Rights (OCR). The protection of Section 504 or Title II applies regardless of whether a complaint has been made by a student; the school must take action. According to U.S. Secretary of Education Arne Duncan, bullying is now recognized as a school safety issue, and it affects the entire school and must be addressed by school personnel. For more information and resources, visit stopbullying.gov.

FOOD FOR THOUGHT

Teaching Tips from Temple Grandin

As mentioned earlier, Temple Grandin is a woman with autism who has a successful international career designing livestock equipment, and she is a world-renowned speaker on the condition. The following is her advice on what can help people with ASD to learn, based on what was effective for her and information she has accumulated over the years about what has worked for others:

- Intensive and early intervention is very important.
- Having the right kind of teacher is more important than what kind of program you are doing. The teacher needs to be structured and clear in what is being requested and what the correct response is.
- Talents and special interests can be used to motivate a child to work and learn, and as he reaches adulthood it can be transitioned into a line of work. For example, if a child likes trains and is studying math, ask him to calculate how long it takes to go from New York to Boston by train.
- Some people cannot process visual and auditory input at the same time. Their sensory processing system cannot process visual and auditory input simultaneously. These individuals should only be given either an auditory or a visual task.
- Having rooms that are quiet and have low distracters is important. Carpeting on the floor is good for noise absorption. Fluorescent lighting is terrible for many people with autism. Having a lamp at each desk with an incandescent lightbulb is better.
- Children who are echolalic and repeat commercials or jingles do so because they are hearing it in the same tone each time and that makes it easier for them to learn. Be thrilled the child is echolalic. You can teach this person by using flashcards with both the picture and the word on the card, and saying the word in the same tone to begin with. When the child has learned the word in one tone, then teach it using a different tone. Teach nouns first. For verbs and other words, illustrate the action by modeling (e.g., jump while saying “jump,” or make a plane take off from the desk to teach “up” and also visually show the word going up) or by having the word look like the action (e.g., write “falling” as if it were falling).
- Some people with auditory processing issues cannot “hear” consonants, and therefore cannot reproduce them verbally. Overemphasizing

consonants when teaching words is necessary for them to hear and reproduce them.

- Some individuals respond better if words or sentences are sung to them. People with sensitive hearing will respond better to being spoken to in a low whisper.
 - Laptops and the new flat-monitor computers are better for people who have visual processing problems, as some individuals are distracted by the flicker of the screen.
 - For people who like to rock, sitting on a therapy ball or a T-stool (made from two pieces of wood nailed together like a T), which the person balances on, can be helpful.
-

A 2012 study found that school-based bullying interventions need to include skill training for both the student on the spectrum and for neurotypical peers. Students with autism needed to improve on conversational ability and social skills as well as any other conditions (e.g., attention-deficit/hyperactivity disorder). Other bullying interventions that are needed include increasing the empathy and social skills of typically developing students toward their peers with ASD, and increasing social integration into protective peer groups.

These books are helpful for teaching a more able student on the spectrum skills to navigate the social landscape:

- *The Hidden Curriculum: Practical Solutions for Understanding Unstated Rules in Social Situations* by Brenda Smith Myles, Melissa L. Trautman, and Ronda L. Schelvan. This book offers practical ideas on how to teach and learn those subtle messages that most neurotypical people pick up almost automatically and take for granted, but that have to be specifically taught to most individuals with ASD. The strategies and detailed lists of curriculum items is very useful.
- *Asperger Dictionary of Everyday Expressions* by Ian Stuart-Hamilton can help those with Asperger's syndrome who "take things literally" to understand the meaning of expressions the rest of us use. The guide

provides explanations of over five thousand idiomatic expressions plus a guide to their politeness level. Parents and teachers will find this a helpful tool to help teach and explain social communication.

Sensory processing challenges. When interviewed for my book, *Autism Life Skills*, most of the adults on different parts of the spectrum stated that their main challenge in school was making sense of what was going on. Most people with ASD suffer from sensory processing issues, which is mainly why they have difficulty with transitions and need schedules so they can anticipate what is going to happen next. They may easily experience sensory overload, which can lead to meltdowns. Sensory processing can affect learning, as some students have challenges in their auditory processing, some in visual, and some in both. This is also important in understanding how the learning material should be presented to the student. For more information, see “Teaching Tips from Temple Grandin” on page 236. If your student appears not to be learning consistently, consider the need of having the student’s vision processing and/or auditory processing checked. This is different from a routine hearing or vision exam. For more information, go to nidcd.nih.gov/health/voice/auditory.html and visionhelp.com.

Social situations. Social situations are usually a challenging area for a child or teen with ASD. If a child or teenager with ASD prefers to spend time alone, parents and teachers need to respect that. However, some social skills are called for, because we all live in society and have to deal with people at one time or another. All children, no matter the age or ability level, need to learn some social skills. School resembles a mini society and it is one of the first places where people learn how to interact with other people. In the next section some strategies and resources will be discussed.

Safety. Most children with ASD have no notion of safety. This is an area often overlooked yet vitally important, and can range from not understanding the dangers of traffic or fire to not understanding the possibility of personal danger from strangers or aggressive individuals. More attention is being paid to teaching emergency responders about autism, which is a positive move; resources addressing this issue are listed on page 276. However, the child needs to learn some safety notions, and educators as well as parents must work with the child on these.

Transitions. Transitions are another challenging area for students with ASD. Whether transitioning from one school to another, one teacher to another, or one classroom to another, it needs to be prepared for. “No surprises” is a rule to live by, as is “Always tell them what is going to happen next.” Usually in elementary schools, the children are in the same classroom with the same teacher for most of the day. In secondary school, the teenager has to deal not only with different teachers, but also with moving around to different classrooms. For some individuals with spatial difficulties, this is an added stress. Picture or word schedules can help in this area.

The section “For Problems with Finding Your Way Around” on pages 313–314 gives suggestions for how to enable students to move around from class to class. Transition from one school to another needs to be carefully prepared. One way of doing this is through social stories (see pages 124–125); another way is through creating a scrapbook with pictures and descriptions of what will happen so the student can go over it (such as in the tips for traveling on pages 147–150). These can also be created on iPads and iPhones using apps. Teachers who are going to have the student in their class need to be prepared. Information can be given to them about the student, and the student could have a picture and a description of the teacher for his scrapbook or phone and tablet.

Flexibility. Flexibility is a real challenge since those on the spectrum usually do not like change. One way of teaching students flexibility, once they are used to a schedule and know the routine, is to add at the bottom of their schedule “Sometimes the schedule changes.” Then when there is a change in schedule (i.e., due to an assembly), give them notice by making a “Change of routine” card with specific details about the change in time and so on. Prepare this as far in advance as possible. At first they will be anxious about it, but eventually they will recognize that they survive these changes and they will need less and less advance notice.

Girls on the autism spectrum. As described in Chapter 6, there are differences between boys and girls on the spectrum. Girls have areas of strength that can mask their deficits. Often they display characteristics that make a diagnosis of autism difficult. Please read the section beginning on page 163 to understand more about girls and to learn about available resources.

Adolescent issues. Adolescence is a difficult time of life for most people. Hormone levels start flaring, the body changes in weird yet wonderful ways, and teenagers are in a state of flux. Puberty, hygiene, sexuality, dating, and social skills are areas that create special challenges for the adolescent with ASD. Adolescent issues are discussed in more detail in the previous chapter (starting on page 152), which should be consulted by teaching staff, as these areas affect school life. For more in-depth information, read my book *Adolescents on the Autism Spectrum: A Parent's Guide to the Cognitive, Social, Physical, and Transition Needs of Teenagers with Autism Spectrum Disorders*. Online training on adolescence and autism is available on autismcollege.com.

In elementary school, the student usually had one main teacher, and that teacher had to be able to recognize the warning signs of a possible meltdown, and how to defuse it. However, in secondary school, there are many different teachers. If the teachers do not all recognize when a student is nearing meltdown, then more tantrums and unfortunate incidents may occur.

Arranging for a quiet place where the student can go to calm down if he feels overloaded, stressed, or confused is very helpful. School staff should seek advice from experts knowledgeable about ASD and put effective strategies in place as a preventative measure, rather than waiting for a major incident or crisis to occur.

Learning More About Educational Strategies

How does a teacher go about learning more? If you are not getting adequate information about ASD-specific training and conferences from your school district, there is still hope; resources are out there. Look on the websites of the national autism nonprofit organizations listed in this book. Join local chapters of these associations and get on their mailing lists. Read their newsletters and find out about workshops and conferences and when they are being held. Contact the organizations or companies that offer information and training on certain techniques you want to know about (such as PECS, ABA, and social relationships).

Presented here is a condensed version of some effective educational strategies. This is by no means an exhaustive list, but rather suggestions based on what is known to be most effective and practical. For more information on certain techniques, look at Chapter 5 as well as the Resources section.

Applied behavior analysis (ABA). Regardless of what kind of school you work at or ASD ability level you teach, all teaching staff should have a working knowledge of ABA. It is the cornerstone of all effective teaching techniques for people with ASD and, for that matter, all students.

Most people think of O. Ivar Lovaas when they think of ABA, but while Lovaas developed a particular intensive teaching program for young children, ABA has been around for many years and is useful in all contexts. In fact, twenty-five years ago, before Lovaas was known to the world at large, the author was trained to use some aspects of ABA, such as task analysis, prompting, shaping, and rewarding, in order to teach developmentally disabled adolescents at a state hospital.

ABA techniques can be used with all types of students, not just those with ASD. For example, plans can be drawn up for unruly students to teach them appropriate behaviors, and students with cognitive disabilities can have academic skills broken down into smaller teachable steps. So ABA is a good general method that all teaching staff should learn that would be useful in all aspects of their work, regardless of the student population they are teaching.

Specifically, ABA techniques such as task analysis and discrete trial teaching can be adapted to teach academic skills, life skills, communication, anger management, and so on. Many of the effective techniques for students with ASD (such as PECS, social skills training, and TEACCH) are based on or use some behavior principles. If you know basic ABA, you will be more effective in applying these other strategies and with practice will be able to adapt techniques and curriculum for all types of children.

Keep in mind that students with autism do not intuitively generalize. Skills that are learned in one environment may need to be retaught in another. This is important to remember when changing schools, teachers, or aides. It is best to change one variable at a time (such as a new classroom teacher, but the same aide) than to change all at once.

A good introductory guide to ABA is *Understanding Applied Behavior Analysis: An Introduction to ABA for Parents, Teachers, and Other Professionals* by Albert J. Kearney. It explains the basic terminology and underlying principles, as well as the commonly used procedures in an accessible manner.

Behavior plans. Behavior plans that are clear, precise, fair, and written down are necessary to address inappropriate behaviors and replace them with appropriate ones. Bad behavior will not just go away. Students with autism need a systematic way of understanding how to behave appropriately. Consistency is necessary for behavior plans to be effective. They can be drawn up to encourage or eliminate specific behaviors, once the behaviors have been analyzed and the antecedents identified. It is important that anyone working with a student knows what the behavior plans are in order for them to be effective.

It's important to do a Functional Behavioral Assessment—a process of figuring out why a student is behaving in a certain manner—before creating a behavior plan. For example, if you have a student who is kicking the back of someone's chair in the classroom every day, you will analyze why he is kicking the chair, and then you will teach him an alternative appropriate behavior. Perhaps he is kicking the chair because he can't stand the sound of the squeak every time the student moves. He needs to learn to appropriately tell someone, and then the squeak will be fixed. However, if it is discovered that chair-kicking is one of many behaviors he is exhibiting because he has anger management issues, you will use ABA techniques and teach him to express his anger in an appropriate manner. The student will have counseling sessions about why he is angry and what can be done about it. But he still needs to learn in a clear, concise, on-the-spot way which behavior has to stop and what can replace it.

Picture exchange communication system (PECS). For nonverbal children, PECS is very useful. It immediately teaches the child a basic system of communication, and it can convey many academic concepts too. This method is wonderful for small children, but even nonverbal adults who have never developed a communication system can learn to use it. Visit pecsusa.com.

The TEACCH approach. Developed at the University of North Carolina, Structured TEACCHing is based on understanding how

individuals with autism learn and the use of visual supports to provide meaning and promote independence. Structured TEACCHing emphasizes a classroom environment that is highly structured and predictable, including the use of schedules. For more information, read *The TEACCH Approach to Autism Spectrum Disorders* by Gary B. Mesibov and visit teacch.com.

Schedules. Schedules and structure are necessary for students with ASD. Clarity and precision are the key words. Schedules can be pictures or words, simple or complex, depending on the student's need. For some ideas on creating schedules, read handsinautism.org/pdf/How_To_Visual_Schedules.pdf. There are many scheduling apps for the iPad and iPhone as well. A good one is the First Then Visual Schedule app.

Social skills training. Because of the impairment of social skills that people with ASD have, it is very important to teach these. People with ASD don't pick up these skills by rubbing elbows with their peers. They need to be taught systematically. For a more able autistic child included in mainstream classes, this is an area where a lot of support will be needed. Teaching the student some social skills can help him avoid some of the bullying he may be prone to as a result of not knowing what neurotypicals expect in terms of behavior. Again, strategies can be geared toward various ability levels. Social stories can be developed with the student. Social skills groups teach social skills by breaking them down and providing practice in a safe environment. Forming a "circle of friends" has been found to be effective. See Chapter 5 for a more complete description of the different methods.

Self-esteem training. Working on self-esteem is a necessary component of education for children and adolescents with ASD. They need to learn about ASD, the challenges as well as the strengths. Reading to them about the positive attributes of those with autism and highlighting well-known individuals who have autism can be helpful. A good workbook is *I Am Special: A Workbook to Help Children, Teens, and Adults with Autism Spectrum Disorders to Understand Their Diagnosis, Gain Confidence, and Thrive*, 2nd edition, by Peter Vermeulen.

Safety training. This is an area that often falls through the cracks and should be addressed. Whether it is knowing to look both ways before crossing the street or who to approach if you are lost at the mall, or

recognizing certain dangerous situations or what to do in a fire, safety needs to be taught.

Some good resources to check out include autismsafety.org and autismspeaks.org/family-services/autism-safety-project.

Preparing for Life After High School: *Transition to College or Work*

Just as for any other student, plans have to be made for the future. During adolescence, the student and parents should begin to think about the future. It is useful to have discussions with the student, family members, and other people who have gotten to know your teenager over the years to get input and ideas. Of course, the most important aspect to consider is what your student's likes and dislikes are. Temple Grandin suggests taking a good look at any interests and obsessions he may have and seeing if they can develop into a skill that can be useful and enjoyable for after school.

Some other areas to be explored besides the student's interests include what he is capable of doing and what level of support he needs for his life as an adult in terms of living arrangements and finances. Does your teenager want to go to college, get vocational training, or go right into employment? Does he have a support system of friends in the community?

My son and I have provided much information about the transition to adult life in *A Full Life with Autism*, and you may wish to read this.

Regardless of the youth's ability level, there are some life skills that must be taught. How they are taught and to what extent may depend on the ability level of the youth, but all can learn to some extent. The earlier the students start to learn these skills, the better, but at least by high school these need to be addressed. Essential life skills include self-regulation, self-advocacy, appropriate behavior in public, social relationships, and organizational skills.

FOOD FOR THOUGHT

A Meaningful Life

There is so much more to the life of an autistic than just being on SSI and safely tucked away at home, sheltered from the world. That is minimal existence, and I know from my conversations with people with autism and Asperger's that many of you want more than that out of life. You would like to make some money, hopefully doing something you enjoy. I'm here to tell you that it's possible to be gainfully employed, but to accomplish this, you need (1) an idea of what you would like to do, (2) some sense of the availability of jobs in that area, and (3) an appropriate education that will prepare you for working in that field.

—Mary Newport, *"Education and Jobworthiness," in Autism Asperger's Digest Magazine, Sept./Oct. 2002*

A word of caution is in order here. It is important for parents and educators to realize the importance of learning life skills while the student is still under the auspices of IDEA. Once the student leaves high school and the transition program, they may be eligible for adult services. However, adult services are not mandated and they may end up on a long waiting list. The student's school years under IDEA may be their last opportunity to receive training. Thus, the importance of preparing them while still in school is critical.

Regardless of the ability level of the individual, the person's own choice should be taken into account. Obviously for the less able and nonverbal it is harder to get an idea of his wishes. Sometimes the opinions or ideas of people that know him in different aspects of his life can help in making choices through person-centered planning. The person at the focus of planning, and those who love the person and know him well, are the primary authorities on the person's life direction. In person-centered planning, questions are asked about who the person is, and what community opportunities will enable this person to pursue his or her interests in a positive way. Some of the techniques used are individual service design, lifestyle planning, personal futures planning, MAPS, PATH, and essential lifestyle planning. For more information, see the resources at Inclusion Press, inclusion.com.

More on the Politics of Education

For six years, I served in a voluntary capacity on a state-mandated community advisory committee made up of parents, educators, and administrators. For two of those years I sat on the executive board. Our mandate was to give input and advice to the special education directors and school superintendents of the fourteen member school districts, who were obliged by law to listen to, but not necessarily to follow, our recommendations.

One of our most important tasks was to draft a list of priorities for special education in the districts for the coming year. The administrators would look at the priorities and address these areas of concern, then report back to the community advisory committee about what they had done to address those concerns.

One year, a major concern drafted into a priority was about the exodus of qualified special education staff. Our suggestion was that each school district develop and implement strategies to attract and retain competent staff. At the end of the year, we sent a questionnaire to the directors of special education to ask them what strategies they had come up with. One special education director actually wrote back to say that he had done nothing, because staff left because of the parents. This reply begged the question, "What are the parents doing that makes staff leave?" Here are some possible answers:

- *The parents were expecting their child to learn.* For some reason, there appears to be an assumption by some school administrators about severely handicapped children: As long as the child is happy and loved, and goes home with his nose clean and his pants dry, the school has done its job. Often, good teachers who want to teach this population recognize when there is a lack of support from above and leave to go to work in a more supportive environment (possibly a neighboring school district).
- *The parents were expecting that staff would demonstrate a knowledge of teaching methods and behavioral strategies that were proven to be effective with that child.* Often teachers' aides are thrown into classrooms with insufficient (if any) training or knowledge. This is detrimental to the child and the teacher who is running the class, and also to the teacher's aide herself. If people do not have the skills to effectively do their job, they will eventually be unhappy and leave.
- *The parents were expecting that the general education teacher would be given some information about their child and his learning methods.* Inclusion will not work if support is not given to help the teacher. Teachers need to be given the tools and training to do their job; they cannot be expected to be knowledgeable in all strategies simply through osmosis.

Many school administrators like to play the game of convincing the staff that the parents are too demanding. People in a position of power will convince staff that yes, they can do the job, they don't need specialist support or to learn new educational strategies. Then the parent is put in the uncomfortable position of explaining why the teacher (or other school professional) is not able to provide for the child's educational needs. The administrators pit the parents and the teachers against each other, when in reality they should be partners. If you are the only proactive parent in that class, then you also get the reputation of wanting "special treatment" for your child. However, the way the process works, you can only address your child's program, not the whole class. In essence, by requesting that a staff member be properly trained, you are helping the whole class, and smart teachers will recognize this.

The reauthorization of IDEA in 2004 strengthened the requirements for transition planning and some activities begin at age fourteen, and others at age sixteen.

A transition plan should form part of the first annual review at the latest after the child's sixteenth birthday, and any subsequent annual review. The purpose of the plan is to gather information from the parents, as well as a variety of individuals at the school and different agencies, in order to plan for the teenager's transition to adult life.

Transition services need to be planned, and these are intended to be a coordinated set of activities for a student to move from school to post-school activities. These transition services need to be developed and written up as an individualized transition plan (ITP), which is a part of the IEP, or it can be a separate (but agreed upon by the team) document. Because the goal is to transition to adult life, interagency collaboration with whatever local services exist is an important part of the transition IEP. Agencies that may be involved include the Social Security Administration (SSA) and the local Department of Rehabilitation.

A good way for a more able teenager to get some ideas is to do volunteer work or have a part-time job during the summer or on weekends. Parents can help by giving chores to their child to teach a sense of responsibility (no matter the ability level). Finding and providing mentors to help the teen develop any interests into marketable skills is helpful.

According to a 2012 study by Paul T. Shattuck, PhD, et al., youth on the autism spectrum have low education and employment outcomes upon

leaving high school, especially in the first two years after leaving school. In the study, Shattuck found that:

- Fewer than 50 percent had no participation in employment or education in the first two years out of high school.
- 55.1 percent had paid employment during the first six years after high school.
- 34.7 percent had attended college.
- Compared to youths with other disabilities, youths with ASD had the lowest rates of participation in employment, and the highest rates of nonparticipation.
- Those with a higher functioning ability and those from higher income families were more likely to participate in school or paid work.

According to the researcher, these results indicate that better transition planning is needed. Here are good places to go for more information on planning for transitions:

Life Journey Through Autism: A Guide for Transition to Adulthood by Danya International Inc. and the Organization for Autism Research (OAR), free at researchautism.org/resources/reading/#Transition

A Full Life with Autism: From Learning to Forming Relationships to Achieving Independence by Chantal and Jeremy Sicile-Kira

Talents: Careers for Individuals with Asperger Syndrome and High-Functioning Autism by Temple Grandin and Kate Duffy

Autism and the Transition to Adulthood: Success Beyond the Classroom by Paul Wehman, Marcia Datlow Smith, and Carol Schall

The Integrated Self-Advocacy ISA Curriculum: A Program for Emerging Self-Advocates with Autism and Other Conditions by Valerie Paradiz, PhD

Adolescents on the Autism Spectrum: A Parent's Guide to the Cognitive, Social, Physical, and Transition Needs of Teenagers with Autism Spectrum Disorders by Chantal Sicile-Kira

Autism Life Skills: From Communication and Safety to Self-Esteem and More—10 Essential Abilities Every Child Needs and Deserves to Learn by Chantal Sicile-Kira

FOOD FOR THOUGHT

It's Getting Easier

More than thirty years ago I worked with adults with severe autism and other developmental disabilities living in a state hospital. Some of these individuals were going to be deinstitutionalized and live in group homes. My task was to help them learn self-help and community living skills, including how to act in public. Along with other staff, I would take them out to restaurants and teach them safety skills such as how to cross the street. Currently, with my own son, I am faced again with trying to figure out how to find programs and activities that my son will enjoy, as well as finding ways to teach him community living skills. It is not an easy task, but definitely not the challenge that it was decades ago.

Successful people who have ASD, such as Temple Grandin, Stephen Shore, and Liane Holliday Willey, have good, useful advice to share about what was helpful for getting them where they are today, and what strategies they use to continue doing well. Even if the student you are planning for is not at the same level of ability, these stories give insight and ideas that may be helpful for those who are less able or cannot express themselves in the same way. In Chapter 9, their advice, as well as some ideas about employment and college options, are discussed. Parents, educators, and others involved would do well to read that chapter when thinking about transition plans and the future.

8

Community Life

I . . . had trouble learning the rules to the games that other children played and I often played the wrong way, causing the other kids to avoid me as well or tease me. . . . My reactions to various situations were not quite what people expected . . . I knew that I did not act right but I was often at a loss to know what I was doing wrong.

—CLARE SAINSBURY, *Martian in the Playground*

Remember that your child's relationships with others may look different. They may just like to sit quietly and share the space with the other person. That is the first step for people like me. Plan what your child would enjoy, not your idea of fun. Many times people plan celebrations for parties, but they are too noisy for most of us with autism. If the party is really for us, have it be small.

—JEREMY SICILE-KIRA, *A Full Life with Autism*

NEVER UNDERESTIMATE THE POWER OF PARENTS

The Creation of Autistry Studios

BY JANET LAWSON AND DAN SWEARINGEN

It was difficult and heartbreaking to learn that our three-year-old son, Ian, had autism. As he grew through childhood, we made use of many services and programs available in our community. But as we looked at what programs were available once he left high school, we were shocked to realize that there are

very few programs, services, or knowledgeable professionals available when an autistic child becomes an adult. When my husband and I looked forward into that void, we turned to each other and made a commitment to build a program that would help our son become as independent an adult as he could manage. In 2008, when Ian was still in middle school, we started the program that was to become Autistry Studios, located in San Rafael, California.

We started with a group of four young adults on the autism spectrum. We met with the group once a week for a four-hour-long workshop in which we helped them discover their unique interests and develop their skills. In the barn/studio behind our house, we created an environment rich with resources: power tools, hand tools, wood, metal, fabric, paints, clay, books, magazines, etc. Each student was encouraged to create a project of his or her own choosing.

We soon started a second group of four students, and then another group, and another . . . until we outgrew the studio. We moved into a ten-thousand-square-foot warehouse and our student body quickly reached nearly fifty individuals, ranging in age from thirteen to forty-five.

As we listened to our students and became more aware of their needs, desires, and challenges, the program that we had envisioned changed. My husband is a software engineer and managed large groups of programmers building cutting-edge software. He has a background in astrophysics and a passion for model-building. My background is film, theater, and creating information systems. We had foreseen a vocational program based on the acquisition of programming skills as we knew that most kids love computer games. What we discovered was that the young adults who joined our groups, though avid gaming consumers, had little interest or aptitude for programming.

We let go of our vision and concentrated on our students' interests. We learned along with them how to make Halo helmets, teardrop trailers, LARP swords, and many, many more fascinating projects. The nature of our program changed from teaching to helping our students learn. We soon realized that the program was not just about creating a project but about creating an identity. We looked at what obstacles got in the way of them creating what they wanted to create and what was preventing them from becoming the person they wanted to become.

The strong relationships between the students and the mentors and between the students themselves have provided a firm foundation of trust that allows us to challenge each other both vocationally and socially. With this challenge has come amazing growth—for our students, our program, and ourselves.

This has not been an easy journey. We work long hours and at least six days a week. We have donated vast amounts of resources to the creation of Autistry Studios. But we have created a community that our son loves, where he has friends, and where he and others may one day work.

Janet Lawson, MFT, executive director of Autistry Studios (autistry.com), has worked with teens and young adults for many years. She previously worked in the film industry and was a producing fellow at the American Film Institute.

Janet is responsible for the organization's consistent achievement of its mission and financial objectives. Dan Swearingen is the COO of Autistry Studios. Dan's job is to maintain technologies for the students to use in their projects and teach the students how to (safely) use them. Dan was diagnosed with Asperger's syndrome in his late thirties when his son was diagnosed with autism. Dan was educated as an astrophysicist but has worked mainly in the software industry.

WHEN he was younger, my son learned shopping skills with college students who helped him with his afternoon activities. The college students started off by teaching him appropriate behavior in stores, then how to use a modified shopping list, finding the items, waiting in line, and paying for them. One day my son and I were shopping and when we reached the checkout counter the relatively new cashier said, "Hi, Jeremy, how are you? Oh, are you his helper for today? Wait, let him empty the shopping cart; he knows how to do that."

It felt good knowing that the cashier knew him, knew what he could do, and was looking out for him. Now, at age twenty-five, Jeremy likes to go for a walk on the beach and stop at a local restaurant for happy hour specials. New support staff are always surprised at the number of people who say "Hi, Jeremy" as they are walking by, and how the staff at a local restaurant brings fries to him right away. He's a regular customer and so like any other "regulars" they know what he likes and they have it ready for him.

These are small things, but these kinds of connections make the place you live in a community.

Creating Ties in the Community

Most people go through life easily developing all sorts of relationships, from the casual relationship with the store cashier or restaurant waitress to relationships with colleagues, classmates, and a life partner. Like a garden, all relationships take a certain amount of tending to grow and maintain. And like gardens, the more intense the relationship, the more tending is involved. No matter the age or ability of a person, having relationships and

ties in the community is vital. Though we all like to think of ourselves as independent, we are in reality *interdependent*: None of us is self-sufficient; we all rely on other people in one way or another.

The same holds true for people with autism. However, because of the very nature of ASD, developing community ties can be mind-boggling. For those of an age and ability where they are on their own, it can be frustrating and seem unnecessary and illogical. For parents of children and the less able, it is another reminder of how their child does not fit in, and how society on the whole is geared toward the competitive neurotypical person. Creating relationships in the community can be hard work, but it is worth it and necessary. Thankfully, it is now easier than years ago, and people are more accepting and understanding of those with autism. As well, in many communities there are organizations that provide social skills learning opportunities, and others help with the integration of children and teens in the community.

Community ties are the threads in the fabric that binds society together. Whether your child is shopping at the grocery store or is an active participant in the Boy Scouts, he is engaging in some form of social relationship. Adults with ASD also have different levels of contacts in the community. By creating these ties, no matter how small, you are laying the foundations for being a part of the community you live in. This is important for many reasons, not the least of them being safety.

For an adult, community ties can provide a support network you can fall back on if you ever need assistance. For a parent, they can help create the foundation of the relationships your child will have as he gets older, and perhaps be there when he is an adult and you are no longer around.

How to Create Community Ties

Community ties can be developed at different times on different levels. Remember that a person has different relationship needs at different times of his life, but all people need friendships and feelings of security and safety. As people with ASD are in the minority, it is still up to individuals with ASD and/or their parents to educate others and create those connections. Here are some tips.

Identify what the needs and desires are. If you are an adult with ASD, you need to think about what your comfort level is, and what you would like to do in the community. If you are a parent, you will need to identify your child's abilities, challenges, and interests, as well as what community skills he needs to learn to prepare him for adult life.

Identify what information or skill the person needs to develop that community relationship. If a person likes to go shopping but doesn't have the patience to wait in line, then he needs to learn the skill of waiting. A person who likes to go to the library to look at books will not be fostering good community relationships by taking all the books off the shelves and dumping them on the floor.

Identify what information people in the community need in order to facilitate building relationships. Perhaps the adult with ASD does not need any special consideration; it all depends on the individual. For a child learning to shop, perhaps the cashier will need to call him by name and ask him for the money. A recreation leader will need to know the best way to communicate with your child, any sensory and behavior challenges, and how to handle them.

Find out what opportunities exist in the community that might be a good fit for your child. There are many more opportunities available than before. Find out from your local autism support groups what exists in your area that has been a good match for others.

Everyday Life in the Community

Regardless of a person's age or ability, we all need to learn how to go about everyday life and be safe in today's society. Creating community ties is necessary for that to happen. Think of all the skills you use just to function every day and the skills you use to keep safe—most of these require interdependency skills. Shopping for food, stopping at the curb, ordering in a restaurant, asking for directions, going to the movies, having a friend over, locking your door—these are the skills everyone should learn. Children and adolescents with ASD, and adults as well, all need to learn basic community skills. Some of them can be taught or addressed at school, but they still need to be generalized.

Safety Issues and Concerns

Safety is an area that everyone needs to learn about. Children with ASD do not have some of the natural survival skills that neurotypicals do—many have no notion of safety—and these skills need to be taught systematically and thoroughly. Safety issues include wandering, drowning, and elopement. Visit the NAA’s safety website, autismsafety.org, for prevention information and resources. In Chapters 6 and 7, other safety challenges and resources were shared. Later in this chapter other resources for making law enforcement officers and others who work in the community more “autism aware” will be discussed.

Community and Recreational Activities for Children and Adolescents

In reality, integration in community programs is not about *finding* the right fit, but about searching for possibilities and creating opportunities for involvement in existing programs or out in the community. It’s really about *making* a good fit. Making a good fit means starting with finding out what interests your son or daughter, figuring out the strengths they have, and finding clubs or activities that are related. For example, if your child is into trains, find out if there are train enthusiast clubs in your area. In San Diego, there is a train museum that offers regularly scheduled activities. This could be a starting point for some.

If there is no activity or club in your area, consider starting one or helping your child start one at school. It may be extra work for you, but the return in connections for your child will be worth it.

A person who is severely autistic, even if he has no aggressive behaviors, will not be able to participate in any community programs without an aide or support person. In the end, the autistic person may have an easier time, in that he will always have someone watching out for him and guiding him through the experience. A more able person may benefit more from the actual experience, but if he is not accompanied by an aide, he may be vulnerable to, at the very least, misunderstanding by the group

leader; and at the very worst, bullying by his peers. This is why it is so important to choose activities carefully.

Every community offers opportunities for integration. Thanks to the Americans with Disabilities Act (ADA) no one can discriminate against a child or adult who wishes to participate in a community program, and in fact should try and accommodate the person as much as possible. That means that some places (such as our local Boys and Girls Club) may have a recreation leader or two specifically trained to help integrate your child. As always, their training may be general, and not ASD-specific, and so you may have to give them more information. Some places to look are your local parks and recreation department, community centers, recreation facilities, Boy and Girl Scouts, swimming pools, places of worship, libraries, and sports clubs.

Activities have many benefits besides integration. For example, taking a martial arts class such as tae kwon do can help improve motor skills, increase self-confidence and self-esteem, and improve personal safety.

FOOD FOR THOUGHT

How We Prepared Our Son for the Library and Bookstore

My son loves looking at books. Going to the library and bookstore were activities he really wanted to participate in when he was younger. However, although he had quickly mastered the concept of pulling books off the shelves at home to find the one he wanted, he had not mastered the concept of putting them back. He seemed to enjoy having thirty or more books all spread out on the floor. This may be appropriate behavior in one's bedroom, but certainly not in public. He also had, on occasion, ripped off the flaps of pop-up books. We decided that he needed to learn that it was not appropriate to rip books and that books should be returned to shelves. These behaviors were addressed and practiced at home before we allowed him to go into the community to look at books in public. Once he was able to put away books at home with minimal help, and had learned that ripping books would not be tolerated, we started taking him to the local library, and finally the bookstore. Any ripping of books or refusal to put away books and my son was immediately taken out of the library or bookstore. As he enjoys these environments, he learned to treat books in a respectful manner in public, and even at home.

There are also activities designed with individuals with disabilities in mind, or certain times designated at recreational facilities. To find out what is on offer in your area, contact your local parks and recreation department, your local community services department, your local autism support groups, other parents, and your child's school.

How to Find the Right Activity or Program

Depending on where you live, you may have few options or many. The most important thing is to make this a positive experience for your child, as well as for the activity leader and the other participants. The first thing to do is to look at your child and where his interests lie. Here are some questions to ask yourself.

What are your child's likes and dislikes? What makes him tick or motivates him? Does he like music? Computer games? Obviously, if the individual is verbal or able to communicate in some form, you will be able to ask him his opinion as to what he likes or doesn't like, what he would like to learn to do or participate in. Never assume that because you know this person you know what he wants to do. Sometimes we make assumptions, and we need to ask the right questions and make observations to know more. Above all, it is important to choose what makes your child happy, not what makes you happy.

What is your child's passion or obsession? Try and find activities based on that. Even if your child is nonverbal and doesn't communicate well, you may have noticed that he is passionate about a particular object or topic.

What are your goals for your child with this activity? Are you looking for an opportunity for your child to socialize with others his own age? Are you looking for him to develop a hobby or learn how to play?

Does your child easily imitate and learn by watching others? Does he need to be "motored through" an activity (physically prompted) many times, or can he learn with minimal prompting and by watching others? Choose activities where his learning can be adapted to the situation.

Does your child have behavior problems that may prevent him from participating in certain activities? To make a community

experience a positive one for all involved, the child should not be a danger to others. Behaviors such as hitting and throwing tantrums do not necessarily mean that he should be excluded; however, a behavior plan should be in effect and working, which can then be transferred to the community program. Identify any problems, and look at how they affect him working in a particular activity. Then work on those behaviors. In addition, skills such as taking turns and waiting are usually a prerequisite for taking part in activities, and can be successfully taught at home.

What kind of sensory integration or processing issues does your child have? Some activities may seem appropriate, but may be taking place in a physical environment that is bothersome to the individual with autism. For example, if your child has a hard time with noise or bright lights, then a location with an “echo” to it or fluorescent lighting may make the activity difficult to participate in. Perhaps he will be able to get acclimatized to it; perhaps not. It all depends on the individual.

Does your child need a one-on-one aide to participate? Are you providing a person to go with your child, or will they have to manage alone? Who is going to provide the supports your child needs, and how will it be done?

How to Analyze the Different Options Available

Once you have short-listed some options depending on your child’s desires, needs, and capabilities, going without your child to observe an activity or program in progress is the next step. Here are questions you should be asking yourself when observing.

What is the activity leader’s style? Does the leader seem authoritative? Does he appear to make allowances for the different types of children? Is he patient? How would the leader’s style mesh with your child’s personality?

How many other participants are there? Is it a small group or a large group? Is that conducive for your child? Make sure you find out if that is the usual group number.

What is the physical environment like? Are the lights very bright? Is it noisy? Is the space large or small? Are there lots of distracting posters and

artwork up on the walls? Do you think your child would be comfortable and able to participate here? Would your child need some desensitization to the environment?

How to Approach the Activity Leader and What to Tell Him

After observing, if you consider this activity to be a possible match with your child, talk to the leader and see how receptive he is to having your child in his program. Although by law your child cannot be excluded from participating, it will be a much more enjoyable experience if the leader is enthusiastic about your child joining in. You will need to gauge how much or how little to tell the activity leader at this point. The more able the child, the less you may want to say. If your child needs to have a shadow aide or helper with him, you will need to tell the leader. You should ask if you can bring your child to the activity on a trial basis, and arrange the most practical time for all of you.

At some point, you may need to give the activity leader more information. It all depends on your child, the activity, and the leader. You may have your own personal philosophy and comfort level about what to divulge. Obviously, if your child is severely affected by his autism, the leader and others in the group will need to have at least some basic information about him. When placing a more able child, the activity leader (and peers) need to be aware of how your child is different. Luke Jackson (author of *Freaks, Geeks, and Asperger Syndrome*) and Clare Sainsbury (author of *Martian in the Playground*) talk at length in their books about the bullying and misunderstanding they were subject to, all because the teacher and their schoolmates had no knowledge of their condition.

Here are ideas for what you may want to talk about with the activity leader.

Talk about the positive attributes of your child. Any special gifts or interests your child may have that could pertain to the activity would be a good thing for the leader to know. Even if they do not pertain to the activity, they will be a point of contact and perhaps conversation.

Talk about the challenges of your child. If your child is a “runner” or bolts out of the door when he hears the fire drill bell because his hearing is

very sensitive, the leader needs to know that. Does your child have any behavior challenges? The leader needs to know what to do in situations that might arise.

Explain about ASD and how it affects your child. It is a personal decision whether a parent wants to identify their child in a group as having ASD. My personal opinion is that as parents of children with ASD, we should also be advocates and educate the public in a positive manner so that our children will be accepted everywhere. However, not all parents feel the same. Some parents who have very able children do not want to use any label. To each his own opinion. However, the important thing is that even if you do not use the word “autism” or “Asperger’s,” you need to explain the communication difficulties that may arise so that your child does not become the victim of misunderstanding on the part of the leader or the other participants. He may get enough of that at school, and this is supposed to be fun!

Make it clear what your goals are for your child. Are you expecting your child to participate 100 percent in every aspect of the activity? Is your child doing the activity to learn a skill or to learn how to be part of a small group?

Explain the shadow aide or helper’s role. If your child will be accompanied by another person to assist his integration and participation, you need to explain. Offer to come in and talk to the other participants. Again, think of your child. It is important that he does not suffer bullying because of lack of knowledge on the part of others. It is always a good idea to talk about ASD so people will become more accepting and knowledgeable. If you explain to the others about your child’s challenges and interests, they will know why he may seem a bit different and will be more accepting. They may even find any special interests he has cool. A good resource for the parent is *My Friend with Autism* by Beverly Bishop. Beverly is a parent who wrote this book to help explain about autism to peers and teachers at the school where her child is mainstreamed. You may find it helpful.

How to Prepare the Child

Depending on his ability, there are different ways of doing this. Again, as discussed in earlier chapters, schedules of what is going to happen, social stories, and rules about expected behavior are good ways of getting your child geared for the activity. Think of what works in helping him adjust in other areas, and use those strategies here.

Tutors, Babysitters, and Respite Providers

When Jeremy was younger, I began my search for any tutors or respite providers that I needed before the start of every school year. At first, I dreaded doing this. After all, hiring and supervising personnel were my least favorite responsibilities when I was a TV producer. And now, I am hiring people who will be responsible for supporting my son as he learns, works, and goes about his day, people who will be in our house and part of our home life.

I have been doing this for more than twenty years now, yet it is still hard when people have to quit as they move on to another city to go to graduate school, or they become teachers and aren't available. But these people never really leave us; they come back to visit on weekends and during the holidays, tell us their news, and hang out with Jeremy and his sister, Rebecca, if she is in town. They have become part of our extended family, and most of them will always be a part of our family's life. Inadvertently, we have created a support system in every city we have lived in, meaning that even now we have people familiar with Jeremy and his needs in the different places we return to for visits. I have hired individuals with no prior training in autism or ABA, and after their experience with Jeremy many of them have changed focus and gone on to become professionals in special education or ABA. This is another way in which Jeremy contributes to society.

Having Someone Working in Your Home

Some families with two working parents are used to having a babysitter or a nanny in their home on a regular basis during the children's growing years.

However, few families are used to having a constant rotation of people in their home over a period of many years. If you have a child severely disabled by ASD, two or more children with autism who are living at home, or you are running a home program, you will need more than the usual help and understanding provided by the occasional sitter, and perhaps for many more years. Hiring, supervising, and having other people in your home is not always as easy as it seems. You may sometimes feel, for example, as if your privacy is being invaded. However, if you choose the right people, and keep a positive attitude and a happy demeanor, you will grow to enjoy it.

Seeking Work with a Family

For those readers contemplating working as a behavioral tutor or a respite provider in a family with a child who has ASD, this section will give you clues as to what kind of questions you should ask the parents, how to know more about what you are taking on, and what possible challenges you should be aware of. Working for a family with a child with ASD is not like a typical nanny, babysitter, or tutor position. It is hard for families to get used to having people work in their home, and it takes a long time for a child with ASD to get used to you, and for you to understand them. If you are unsure after an initial interview, and the parents are interested in hiring you, ask them if you can come back one more time and spend time with them and the child before deciding. If you explain that you do not take your commitments lightly and want to make sure this is a good match for both of you, they will be happy to have you come back.

The most important thing to remember is that the person you hire is there to help your child, not be a counselor to you. Sometimes parents may start talking to their tutor or sitter about problems at school, how depressed they are, or how anxious they feel, and this is not appropriate. If you need to talk to someone about your feelings, you should visit a friend, another parent, or a counselor. Be sure to make your home a positive work environment for the people who are there to help your child.

How to Hire a Tutor or Respite Worker

If you are looking for a tutor, you will want someone who has experience in or is a good candidate for training in the therapy method you are putting into place, be it ABA, verbal behavior, or Floortime. However, in terms of your expectations and the issue of having another person in your home, many of the considerations will be the same as when you are looking for a babysitter or respite worker. These guidelines are here to give you a starting point and get you thinking about the many aspects inherent in hiring and keeping good people. The responses given to questions on pages 263–265 will help you in evaluating the strengths and weaknesses of potential candidates and how that person fits in with your needs.

Where to place an advertisement. Many people hire nannies and babysitters and respite workers through agencies. These individuals are usually specifically hired to take care of the children, not to be a housekeeper, too.

To hire people directly yourself, if there is a university or teacher training college in your area, those are good places to start. Find out from other parents what places work best to put up advertisements. Put ads in the newsletter of the local chapter of your autism support group, if there is one. If you are planning to have a supervisor oversee your home program, ask if they have any advice or guidelines for hiring tutors, and if they know of tutors who might be willing to work with your child.

What to put in the ad. Take the time to write an ad that gives adequate information as to what type of person you are looking for. Some examples: “Looking for tutors to work with my son. Parent looking for three people who love children and are dependable and flexible, to teach my son, who has autism, using applied behavior analysis techniques. No experience necessary, training provided. Must be available 15 hours per week in 3-hour increments. Hourly rate to be discussed. Please email résumé or call this number.” Or, “Looking for trained behavioral tutors to work with my daughter with autism. Some weekend hours. Behavioral supervision provided. Pay depends on experience.” Or, “Looking for a babysitter. Parent looking for dependable person who loves children and is flexible to provide after-school care for son with autism. Must be available from 3 to 6:30 p.m. Training provided. Pay depends on experience.”

After stating the initial information of what you are looking for, take a few lines to describe your child and his personality, what he likes and

enjoys. You want the person who responds to the ad to think of your child as a child, not a label.

Read “Tips for Hiring In-Home Service Providers” on page 266 and follow Dr. Nora Baladerian’s suggestions in regard to hiring, as it is very important to do as much as possible to ensure your child’s safety. Along with Dr. Baladerian’s suggestions, here are some additional questions to ask about work experience and personality:

Looking over a résumé. You can learn a lot about the applicant simply by carefully reading his or her résumé:

- Does he have work experience?
- Has she had job responsibilities before?
- Has he had a regular work schedule?
- Has she worked with children of the same age group as your child before?
- What has he been studying at college and what kind of work has he done?

Questions to ask on the phone. On the telephone, you may need to ask specific questions to draw the applicant out:

- Has she worked with children before? What age group?
- Has he ever babysat before or spent a lot of time around children?
- How many siblings does she have, and what is her position in her family?
- Why is he interested in working with your child?
- How long can she commit to working with your child?
- Can he provide any work references? If he has no work references, how about personal references?

- Is she willing to submit to fingerprinting (an administrative procedure)?

Questions to ask a person named as a work reference. Refer to Dr. Baladerian's questions, and add these practical ones as well. You want to know if the candidate is reliable and easy to work with, as well as whether or not the person is honest and safe to hire.

- How long did the applicant work for them?
- Is he dependable, reliable, and trustworthy?
- Was she on time or often late?
- Did he often call in sick?
- Was she good at working independently and as part of a team?
- Was he flexible and able to learn and do the job the way the employer wanted?
- Did she take constructive criticism well?
- Did he show a creative streak?
- What were her most positive attributes, and her least positive?
- Would they recommend him for the position you have in mind?

Face-to-face interview. After you have screened by phone the applicants you are interested in, it is time for the interview. Schedule it at a time convenient for you and your child. If possible, do it when someone else is home working with your son. First, interview the person face-to-face, asking her questions to find out more about what kind of person she is. For example:

- What did she like about the jobs she's had in the past?
- What does he hope to pursue as a career?

- What hobbies or other interests does she have?
- Why does he want this position with your child?
- How long can she commit for?
- What schedule constraints does he have?
- Does she have any questions for you?

Then bring your child into the room (without the other tutor) and see how he reacts to this other person, and how this person acts toward your child.

- Does the applicant try to make contact with your child?
- Does she appear respectful of your child?
- What kind of approach does he have?
- You know your child. Does it appear that he likes this person?

If you think this could be a match, go to the child's room with the applicant. Have her watch you or the other nanny or tutor play a game or do a puzzle with your child, and then ask if she would like to try. Watch how she gets on, then give her a few directives and see how she responds to that; is she able to change what she is doing by listening to your suggestion? Again see if your child feels comfortable with this person. After she leaves, if your child is able to tell you, find out if he liked her.

FOOD FOR THOUGHT

Tips for Hiring In-Home Service Providers

BY NORA J. BALADERIAN, PHD

When hiring someone to work with your child (adult or minor), there is no “magic miracle” that will 100 percent ensure that the person you hire will not

attempt to do harm. However, there are guidelines that can be followed both prior to employment and during the employment period.

Perpetrators, sadly, are seldom identified, reported, arrested, or convicted. Knowing this is very important, because many people believe that conducting a check of legal actions (background check) is sufficient to identify perpetrators. This is not true. Why? Most abuse is not reported. Most reported abuse does not result in a conviction, which is required prior to a person's name appearing in a background check.

Thus, other measures must be used. First, do as thorough an employment background check as possible. Second, monitor their work. Third, ask your child how he or she likes the time spent with this employee, as well as monitor your child's responses when saying that this employee will be coming. Your child may not say or do anything that indicates anything is wrong, but they may, so if there is an indication they are not comfortable with a planned visit, pay keen attention to this. It may be nothing, but it may be important.

When hiring:

1. Have the person complete a written employment application. Include the "usual questions" and obtain a copy of at least two pieces of identification (make sure to check the expiration dates, if any) that have their picture on it.
2. Ask for at least five years' employment history with start and end dates, including the name of the employer, duties fulfilled, and contact information for the employer.
3. Include a space for the applicant to state why they left each employment position.
4. Ask for information on their education and training for the position, including the agency that provided the education, the dates of certificates, diplomas, continuing education, or other indication of successful completion. Make sure they include the address, phone, and email or website of the provider of training.
5. Questions should be included such as whether or not they have ever been convicted of a crime, such as driving under the influence of a substance (drunk driving, for example), drug use, or dealing drugs. *Keep in mind:* You cannot ask if they have ever been arrested, but you can ask if they have been convicted.
6. Ask for personal references. Although these may be the applicant's family member or best friend or paid informant, at least the asking for character references may deter the applicant from providing false information.

Tell the applicant that you will check out all of the information they provide. Then do so. Conduct a telephone interview with all prior employers. Employment law restricts what former employers are allowed to tell you, but it does not restrict what you can ask. Engage in a friendly conversation with all listed employers and character references.

Prior to your call, prepare your list of questions that you want to ask. These can include:

1. What were the dates the person worked for the employer?
2. What was the reason employment was terminated?
3. Was the employer satisfied with the work of the applicant?
4. What were the work duties of the applicant?
5. Did the employer believe that the applicant had the appropriate work skills?
6. Did they employer believe the applicant had an appropriate communication and social interaction skill set for working in their home/agency?
7. Would the employer hire the applicant again?

When you feel confident that the applicant is a good fit to work with your family and your child, notify the applicant for a pre-employment discussion that includes information about your child and your family. Not only do you want to hire someone qualified for the job, but you are interested in making sure that those you hire will not harm your child in any way. The best way to do the latter is to design and implement a plan for the safety of your child when he or she is alone with the service provider.

One of the pieces of your safety plan should be your openness about your plan. Perpetrators have a plan, which is to get into a relationship with a victim and victimize that person. You should have a plan, too! The book I wrote on abuse risk reduction (*Abuse of Children and Adults with Developmental Disabilities*, available at norabaladerian.com/books.htm) provides the basics for those who want to know how to build a plan. For now, however, it is sufficient for any parent to advise a new employee that the parents are aware that abuse happens, and thus the parents have adopted an “abuse awareness and reporting policy.”

This policy includes not only the employment background check that they have already completed at this point in the employment process, but also that they know the signs and signals that abuse has occurred, and that the policy is to immediately report suspicions of abuse to the police. The police can conduct a thorough investigation. Employers should not attempt to do their own investigation, first, because they are not qualified, and second, because any actions they take could void the findings of a police investigation.

It is possible that the simple act of telling prospective employees that one is aware of the signs and symptoms of abuse, that abuse of people with disabilities is a fact of which they are aware, and that the parents quickly report their suspicions of abuse to the police may deter perpetrators from continuing with the application process. They may offer some reason such as they “just got approved for another job.” The reason for declining your job offer does not matter, but it is possible that your “abuse awareness program” saved you from hiring someone who did not want to risk discovery.

It is often said that perpetrators “seem like such nice people.” That is true. That is how they gain the trust of parents and access to the individual whom

they see as vulnerable. They know that by behaving in ways that create an appearance of kindness, trustworthiness, dependability, and likeability their opportunities to have access to vulnerable persons is increased. It is recommended to use the motto “trust and verify.” It is not recommended to distrust everyone, but to trust others as well as verify information provided to you and monitoring their work performance.

It is a good practice to write out the job description and the tasks you want accomplished with your child, as well as specifics about your child that are essential, such as communication, behavior, nutrition, sun exposure, and other sensitivities.

Although using these practices may not be 100 percent foolproof, they create a level of protection for you and your loved ones.

Dr. Nora J. Baladerian is a licensed clinical psychologist in Los Angeles, California, and the founder and director of the Disability and Abuse Project in Los Angeles (disabilityandabuse.org). Nora has been working in the area of abuse of people with developmental disabilities since 1972, and has developed and conducted training materials and programs for parents, as well as professionals who respond to reports of abuse. In 2008, she was awarded the National Crime Victim Services Award by the U.S. Attorney General and the Office for Victims of Crime (OVC). She is frequently called upon by attorneys to provide expert assistance for cases involving individuals with developmental disabilities.

If you are comfortable with this person, then call her to come back when a tutor or nanny is around to overlap. Spend some time again with your child and the applicant, then have the applicant spend some time alone with the other person and your child. This will provide the opportunity for the applicant to ask questions of a non-family member who knows the child. It's not always easy to work for someone in their home, and you want to make sure she knows you can be trusted as an employer. Also, you will be able to get your tutor or nanny's point of view on the applicant, which is a good thing to have. They may have noticed some things you didn't. At the end of this time, talk with the person, and if you are interested in hiring her, find out if she is still interested in working with your child.

The applicant will have had two opportunities to meet your child and a chance to talk to someone in the position she will be filling. By now she should have a concrete idea of whether she really wants to work with your child.

No matter how nice or trusting the person appears, do not forgo following Dr. Baladerian's advice above. Better to be safe than sorry.

How to Supervise and Keep Good People

Somehow, our house acquired the reputation of being a good training ground for tutors and respite workers. I often got calls from special education administrators, parents, service providers that supervise home programs based on ABA, and social workers. They would call asking if anyone currently working in our home or who had worked in our home was available for working elsewhere as well. This was mostly due to Jeremy and his pleasant personality, which was so endearing.

However, in asking people why they enjoyed working for our family so much, the number one response after their love of Jeremy (and his sister, Rebecca) was that we were organized. This does not mean our house was particularly clean or neat, as we do not have the time it would take to earn the Good Housekeeping Award in our neighborhood. We do the minimum amount of cleaning so we will not be cited by the Health Department. Jeremy was particularly talented at "redecorating" the house ("Uh-oh, Jeremy's doing a 'Martha Stewart' again!"), and although we attempted to teach him that he can only redecorate his own room, what he has learned is to redecorate when no one is watching.

Being "organized" in this case means that the wonderful people working in our home knew what they are supposed to do, when they were supposed to do it, where everything was, and where to put it back. Here are some guidelines to make life easier for all of you:

- Make sure responsibilities are clear. Draft a contract that outlines your responsibilities toward the person you are hiring and their responsibilities toward your child and you. The contract should cover how much they are getting paid, how often they are getting paid, whether or not you are paying sick leave and holiday pay, when pay raises will be given, and, if they will be driving your child anywhere, what they will be compensated for using their car, or any insurance details if you are providing one.

- Make sure that the hours and times they are to be present are clear. Make sure they know they are responsible for those hours, and make it clear that if they need to make a change, they are responsible for communicating that to you as soon as possible. If there are several tutors, you may wish to make it their responsibility to find someone else to work their hours.
- Make a calendar and hang it in an easily accessible area so people can see special appointments or make changes in scheduling.
- Make sure appropriate notice is given if you have a change in schedule because of a doctor's appointment, or if your child is ill.
- If you expect some degree of flexibility on their part in terms of changes in work hours, be prepared to be flexible when necessary in regard to their schedule.
- Make sure you have everything they need to do their work, and that everything has a specific place so things are easily found.
- Have a communication book located near the phone or in the kitchen where notes to each other can be quickly jotted down if need be. There are different online project management tools and apps that can be used for parents and staff members to communicate with each other, for example, Basecamp. This is a good place to keep a schedule and have all information posted, so that everyone can access the information all in one place.
- In the home environment, it is important to remember the boundaries of the work relationship and keep them clear.
- Remember that they are there to help your child and not to be your counselor. Give them information that they need to know for working with your child, but do not overburden them with the emotional issues, school issues, or legal issues that are on your mind. Those are for you to handle and get help with from someone else. The people working with your child need to concentrate on your child and helping him learn, not think about your problems.

- If your tutor is working with your child at a school, clarify what their responsibility at the school is.
- Keep your rapport with the tutors respectful and professional. Never discuss any issues that are not their concern, such as any disagreements you may be having with the local school authority or another professional. Never speak negatively about other tutors or nannies who are currently working or have worked in your home.
- Make your expectations of the tutors or sitters clear.
- Do not expect them to do things you would not do yourself.
- Have high expectations of their job performance, but give them what they need to do their job well.
- Make sure any new babysitter or tutor feels comfortable enough with your child to be able to handle any behavioral situations that may come up, before sending them out in public with him.
- If you have any behavior plans for your child or if you are working on any particular behaviors, make sure everyone who helps or works with your child knows what to do and ensure that everyone is handling behaviors in the same manner. This will make life easier for everyone—most of all your child—and be of great benefit to your child.
- Give people working with your child information about his likes and dislikes, as well as any other pertinent information. Having this written down somewhere is helpful. This makes tutors and nannies feel comfortable with your child, and they will know more about what they can use to motivate him. Your child will feel more comfortable with someone who knows about what is important to him.
- If you are running a home program, keep up to date and know what is being worked on. Give support when needed. When tutors are new and having problems with a behavior or noncompliance, or when new behaviors come up, they need to know you are knowledgeable enough to help them figure things out until they feel they can analyze it and handle the situation themselves.

- If you have any concerns or comments to make about what they are doing, talk to them privately. Explain to them your concern and ask if there is anything you can do to help. For example, think about why you have that concern and bring it up in a positive, constructive manner and not as a criticism. If you notice that one person always asks you for materials and never puts them away afterward, do not assume they think it is part of their responsibility to get them out and put them away. Or perhaps the needed items are not in a clearly designated area, and they do not want to root around in your things looking for them. Do not wait until you are frustrated and confront the person. After this has happened a few times, say something like, “Do you know where the items are located? It would be helpful to me if you could get the materials out and then put them away when you are done. Let me show you where they are.” Perhaps they are not thinking, but perhaps you have not made it clear that you are expecting them to do that. If that is the case, make sure you make the responsibilities clear to them.
- Feedback is always appreciated. Show appreciation of the effort they put into their work by commenting favorably on progress your child has made related to work they are doing with him, or thank them for something you noticed they did that has been helpful to you.
- Showing appreciation on birthdays and holidays is always a good way to keep them feeling that they are important to the family.
- Holding a dinner party and inviting all the past and present tutors and sitters is a fun thing to do. Over the years, the nannies and tutors get to know each other, and it’s nice to have this time to catch up with each other as well as get tips about college and jobs.

For more information on hiring in-home support, read *A Stranger Among Us: Hiring In-Home Support for a Child with Autism Spectrum Disorders or Other Neurological Differences* by Lisa Ackerson Lieberman.

For information about what in-home support staff need to know and how to organize the information, read *Sharing Information About Your*

Child with Autism Spectrum Disorder: What Do Respite and Alternated Caregivers Need to Know? by Beverly Vicker, MS.

What the General Public Should Know About ASD

As ASD becomes more and more common, it is important for retailers, emergency responders, recreation leaders, daycare providers, law enforcement officers, bus drivers, designers of public spaces, and anyone who works with the public to have an understanding of these individuals as they are your neighbors, your clients, the person you may be called on to help one day. In order to help your fellow citizens and to avoid potentially dangerous situations, you need a basic understanding about ASD. You may not need to know everything in this book, but you can get a good introduction by reading the following sections:

- “Characteristics of Autism Spectrum Disorder” on pages 21–27
- “Why People with ASD Act the Way They Do” on pages 50–56
- “Myths About Autism Spectrum Disorder” on pages 2–8 will also be helpful in dispelling some of the false assumptions you may have.

Parents may want to use this section as a guideline on what information to convey to people who will encounter your child in the neighborhood and beyond:

- “Public Environments and Sensory Processing Issues” on pages 276–286
- Another short read that answers the most common questions asked about autism is my book *What Is Autism? Understanding Life with Autism or Asperger’s*.

Once you have a general overview of what autism looks like and why, you will appreciate the concerns about safety in the community for people

with ASD. For some, it is as elementary as not having any notion of physical safety. They may take off in the middle of traffic to check out something interesting on the other side of the street, or head for a pond, river, or pool because they are attracted to water. For others, it may be not understanding about personal space and not recognizing when people are being “too friendly,” or whom to approach when lost and needing directions. Many safety concerns and skills may be taught to some individuals with ASD, but for others they are extremely difficult.

Another concern is that if emergency responders are not knowledgeable about behaviors exhibited by some individuals, they may not know how to respond in the line of duty when faced with autism. For example, many children with autism do not reply to their name, nor do they follow directions, which can be a life-and-death situation in case of a fire, when the firefighter is trying to give instructions that need to be followed. Many people with autism do not like to be touched or do not tolerate loud noises, and they become tense. A very able person with autism or Asperger’s may take everything literally, and does not understand expressions the rest of us take for granted. For example, the expression “spread eagle” means just that: a spread eagle; and the person will not understand that the peace officer is telling him to take a particular pose. The peace officer will need to tell him exactly what to do (i.e., “Stand against the car, and put your hands on the top of it”). A peace officer may be called because someone is reported to be peering into windows. Perhaps this person has autism and is staring at reflected light in the window, not looking inside, and has no idea what the fuss is about. Thankfully, there are now many initiatives under way across the country for first responder (including police) training.

In the autism community, people are working hard at determining better ways of teaching safety issues to people with autism, as well as getting people to display stickers in their front windows explaining that someone with autism lives there and making sure people carry ID including the word “autism” and an explanation. Yet we really need the help of the community in keeping our children and teenagers, as well as adults with autism, safe. Being able to recognize some of these behaviors and how to deal with them is one way you can help. Here are three excellent sources of information on safety, for general use, for the prevention of senseless tragedies, and for training emergency responders:

National Autism Association Safety Initiative: autismsafety.org

Autism Speaks Safety Project: autismspeaks.org/family-services/autism-safety-project

Autism Society of America: autism-society.org/living-with-autism/how-we-can-help/safe-and-sound

Public Environments and Sensory Processing Challenges

In recent decades, we have seen more and more cases of asthma, hyperactivity, ASD, behavior problems, and allergies than ever before. Children are routinely given medication for hyperactivity and behavior problems.

In Chapter 3, some of the behaviors of people with ASD and what they could mean were discussed. Many of those behaviors can be indicative of allergies and problems with sensory integration. Every book by a person who has ASD contains references to sensory processing difficulties, the sensitivity they have, and the pain they experience from overstimulation.

In Chapter 5, some helpful treatments and therapies are discussed in regard to sensory processing challenges. Parents of children on the spectrum and adults on the spectrum can find resources to help.

Fluorescent Lighting

Temple Grandin, Donna Williams, Stephen Shore, and Liane Holliday Willey all write about how terrible they find fluorescent lighting. But it is not only people with autism who are affected.

In her book *Is This Your Child's World? How You Can Fix the Schools and Homes That Are Making Your Children Sick*, Doris J. Rapp, MD, discusses the subject. As would be expected, natural lighting is best. Fluorescent lighting appears to be a major source of trouble for many people. A study of one classroom showed a decrease of hyperactivity by 33 percent when the fluorescent lighting was replaced by full-spectrum

lighting. Germany banned fluorescent lighting in its schools and hospitals years ago, whereas in other countries such as the United States, people seem to prefer the use of the drug Ritalin to counteract hyperactivity rather than looking at possible environmental factors that contribute to the disorder.

In his book *Health and Light*, Dr. John Ott discusses the possible health effects of different wavelengths of light. Dr. Ott videotaped students using time-lapse technology, and these videos demonstrated the increase in hyperactivity in some of them when fluorescent lights are used.

FOOD FOR THOUGHT

The Curse of the Fluorescent Light

Fluorescent lighting has got to be one of mankind's worst inventions. I always hated going shopping—after ten minutes I would become irritable, feel restless, and get a major headache. Once home, I would be so exhausted I would have to lie down. While shopping, my husband would ask me, “Are you hungry? Are you tired? Why are you so cranky all of a sudden?” I could never figure out why my mood would change so suddenly and how I could feel so physically bad so quickly. It was not until years later when I lived in France that I realized it was the fluorescent lighting that did it to me.

Most of the time in Paris I shopped at the wonderful food markets or local shops, but every once in a while it was necessary to go to a supermarket for sundry items. The small supermarket closest to our apartment had these horrendous fluorescent lights that you could actually see flicker and hear buzz. It was horrible. The checkout girl who worked there looked poorly and so depressed all the time. One day I asked her if she was okay, she looked so ill. She told me she had constant headaches and felt nauseous at work, and she thought it had to do with the lights.

Then all of a sudden it clicked. Looking at my past behavior patterns, I could see a connection between the kinds of stores that made me feel ill and the ones that didn't. I then started asking people around me and was surprised to find that many people suffer from the curse of the fluorescent light.

Once I realized what was causing my discomfort, I limited my outings to those kinds of stores and never planned a shopping day where I would hit more than one big shop (such as a Costco or Ralph's) in a day. My husband is now the designated supermarket and department store shopper in the family (he has a natural talent for this; at one time he worked in procurement). But mostly, we have taken our business elsewhere, avoiding major shops and spending money where people are more cognizant of making a comfortable working and shopping environment.

In the United States, smoking is prohibited in most public places, and in some places even in restaurants and bars, and this was done to protect the workers behind the counters as well as the customers. And of course, new buildings have to be designed with easy access for people in wheelchairs. So how about a law banning the use of fluorescent lighting?

Think of all the checkout men and women and shelf stackers working in supermarkets. And what about the teachers and physicians who are obliged to spend long hours under those lights? Perhaps sensory integration dysfunction should be labeled a handicapping condition and no new buildings should be designed with fluorescent lighting. Then, perhaps, students will finally have a proper environment to learn in.

Sensory Processing Disorder (SPD)

Sensory processing challenges stem from the brain's inability to correctly process information received through our senses of taste, touch, smell, sight, and sound. People can be hyposensitive in some areas (meaning they fail to pick up cues) and hypersensitive in others (meaning that they are overly sensitive to stimulation of a sense).

When a person's senses are over- or understimulated, it affects their behavior as they try to compensate for a lack of stimulation or for overstimulation. Some individuals with sensory integration problems are aware of these challenges; others are not. Once a person is aware, it is possible in some cases to learn to compensate in a positive way or to undergo desensitization over time. However, for many people, especially children, and people who are severely disabled by autism, it is difficult, as they are unknowingly put in situations where they have no control over their environment, which may lead to displays of inappropriate behaviors.

For an idea of what it is like to have sensory processing issues and live in today's man-made environment, read what some people with ASD have to say:

I also found many noises and bright lights nearly impossible to bear. High frequencies and brassy, tin sounds clawed my nerves. Whistles, party noisemakers, flutes and trumpets, and any close relative of those sounds disarmed my calm and made my world

very uninviting. Bright lights, mid-day sun, reflected lights, fluorescent lights; each seemed to sear my eyes. Together the sharp sounds and bright lights were more than enough to overload my senses. My head would feel tight, my stomach would churn, and my pulse would run my heart ragged until I found a safety zone.

—LIANE HOLIDAY WILLEY, *Pretending to Be Normal*

It came as a kind of revelation, as well as a blessed relief, when I learned that my sensory problems weren't the result of my weakness or lack of character. When I was a teenager, I was aware that I did not fit in socially, but I was not aware that my method of visual thinking and my overly sensitive senses were the cause of my difficulties in relating to and interacting with other people.

—TEMPLE GRANDIN, *Thinking in Pictures*

All daily transitions are very hard because I need to prepare my body and senses for what is coming up next. It is nice to have understanding staff, but frankly I dread transitions from one place to another. I have lots of strategies for transitions. Knowing what is happening next is important. The hope that the following activity will be pleasant is a great motivating tool to help me through transitions. Being reminded of the rules we write together is necessary. Carrying a magazine or book is necessary.

—JEREMY SICILE-KIRA, *A Full Life with Autism*

Sensory processing disorder is not experienced only by people with ASD. *The Out-of-Sync Child* by Carol Stock Kranowitz describes how some children may be labeled as inattentive, clumsy, and oversensitive when they are really suffering from sensory processing disorder.

Creating People-Friendly Environments

Granted, there are some environments that people with sensitivities need to and should learn to tolerate for short periods of time. However, when designing an environment where people are expected to learn or work for long periods of time, or where people are going for medical treatment and are already not well, doesn't it make sense to look at environmental issues?

Dr. Rapp's book *Is This Your Child's World?* should be required reading for all school and hospital administrators responsible for having their buildings renovated or constructed. There are many toxins in ordinary classrooms that could easily be eliminated.

FOOD FOR THOUGHT

Sensory Processing Challenges: Tips from Temple Grandin

Over two phone conversations, Temple shared the following important information about sensory processing and environments for people with ASD.

All people with ASD have sensory processing problems. Some of them may be auditory, some of them may be visual. Recently scientists have been able to map out the circuits in the brain for the separate visual and auditory areas, and they see that those corresponding areas are differently wired in people who have visual or auditory processing difficulties. Temple emphasizes that there are individual variations in the severity of the processing problems, and variations also depend on how tired the person is: the more tired the person is, the greater the risk of sensory overload. People with ASD usually cannot multitask, as they usually can only fix on one sensory process at a time.

For each individual and for each sensory processing issue there is a balance to be found between adapting the environment to fit the need of the person, and adapting the person to the environment that already exists.

If you are a parent or caregiver of someone who you suspect has sensory processing difficulties, but who is unable to communicate that to you, Temple suggests doing the "supermarket test." Take the person to the supermarket and see how he behaves, using the behaviors listed on pages 24–27 as a guideline.

The number one worst enemy for people with visual processing problems is fluorescent lighting. Some people with autism can see the flicker of sixty-cycle electricity. It has the same effect that being in a disco with strobe lighting has for neurotypical people. Unfortunately, because of its low cost, fluorescent lighting is present everywhere.

For people with auditory processing issues, fire bells can be particularly painful. They are very loud and you do not know when they are going to go off.

Department stores and supermarkets are particularly challenging to people with sensory processing issues, not only because of fluorescent lighting but also because of the overstimulation provided by the colors, stripes, and mosaic patterns on the displays; the smells from perfumes, detergents, and cleaning products; and the noise level due to hard flooring.

So there are many questions that come to mind. For those individuals unable to communicate, how do you know what is creating the overload, and what can you do about it? Temple suggests observing the person's behavior.

Those with visual processing problems:

- Use peripheral vision, with which they can see better (i.e., they look from the sides of their eyes and avoid looking directly at people or objects)
- Flicker their fingers or other objects in front of their eyes
- Avoid escalators in stores and appear afraid of them
- Have difficulty negotiating stairs in places unfamiliar to them

If you have visual processing problems, here's what you can do (or help someone else who has them to do):

1. Go shopping earlier in the day when you are not tired.
2. For a temporary fix in areas that you cannot control, such as supermarkets, try wearing a hat with a brim, or a visor.
3. Wear colored lenses such as sunglasses or Irlen lenses. Some people with visual processing issues report that the lenses help not only with seeing, but with training the visual processing so that in some cases they need lighter and lighter lenses as time goes by. From what Temple has heard from people who use colored lenses, the brownish, purplish, and pinkish lenses seem to work the best against fluorescent lighting.

Usually when a person in the family has sensory processing issues, a parent may have them, too, to a lesser degree, so for people unable to communicate, the parent could see what color works for them and start with that. Another way to see what is helpful is to try different-colored lightbulbs or transparencies to overlay on written work, and see how the person works, learns, or acts under those circumstances. Temple warns, however, that many sunglasses may be too dark to help with reading. She also reports that Blue Blockers sunglasses work well.

4. In areas you can control, such as your home, do not use fluorescent lightbulbs; use the old-fashioned incandescent kind.
5. Unfortunately, fluorescent lighting will not be replaced everywhere because of its low cost and efficiency. Schools that have students with ASD should definitely remove these types of lights. In the meantime, for

a quick fix for an individual workstation or desk, use a desk lamp with incandescent lightbulbs to offset the fluorescent lighting.

6. Use laptops or the newer flat-panel computer screens. The larger, older computer monitors have a flicker much like fluorescent lighting does.

Because laptops and flat screens are expensive, try finding a big company near you that frequently upgrades its equipment. Normally the used computers are donated or sent out to be broken up and recycled, and so you may find a sympathetic company happy to give you one of their throwaways.

Those with auditory processing problems:

- Cover their ears or leave the room when loud noises go off
- Cannot tolerate loud noises such as fire bells or school bells
- Cannot talk on the phone in large places such as airports due to the echo and resonance of the noisy crowds
- Move as far away as they can when there are too many people near them in the room talking
- Cannot pronounce the consonants of words because they are unable to hear them properly (hearing tests do not measure auditory detail that they may not be hearing; the hearing threshold may appear normal, but in fact they may only be hearing vowels, so they cannot produce the sounds of consonants)

If you have auditory processing problems, here's what you can do (or help someone else who has them to do):

1. Go to noisy places earlier in the day when you are not tired.
2. Get auditory training to help you tolerate the frequencies that may be causing discomfort.
3. For a temporary fix for supermarket shopping, wear earplugs, white-noise busters, or listen to music. Temple warns that although ear plugs and noise cancellers are okay for getting through an experience such as a trip to the supermarket, they should not be used on a regular basis, as the auditory system needs to learn to get used to and tolerate some amount of the noise which is around in the everyday environment.
4. To get desensitized to the sound of fire bells, Temple suggests taping the sound of a fire bell and listening to it, controlling the volume and length of play. Every time you listen to it, the volume can be adjusted as well as the playing time, yet always under the control of the person who is getting desensitized.
5. To ease the noise of scraping chairs on hard floors, pad the bottoms of the chair legs. You could use old tennis balls: Make a slit and fit them onto the bottoms of the chair legs.

6. For soaking up sound, put carpeting on floors and also on the walls of rooms (or insulate the walls). A good cheap way to get carpets is to ask carpet stores for remnants as donations, or contact major hotels, which redecorate often, and see if you can get the carpet they are removing and throwing away. (You will have to clean it.)
7. To teach the consonants to a person who can't hear them well, emphasize them very strongly, putting the accent on them, so the person can hear them.

Some people with autism have body boundary issues. Most people can tell where they are in a space. Normally, a person can close his eyes standing in front of a wall, and put his hand on the wall, knowing where his hand ends and the wall begins. For those who have body boundary issues, they are unable to "feel" this. Temple says that lots of brushing, massage, and deep pressure can help people feel their body boundaries.

Many people with sensory processing difficulties seek relief from too much or too little stimulation by rocking their chair. A therapy ball can help, but to avoid the cost of a therapy ball (or to avoid a child playing on it and not concentrating), make a T-stool with two pieces of plywood. The person will have to rock slightly on it to keep their balance.

Here is some advice for designing environments:

My ideal educational environment would be one where the room had very little echo or reflective light, where the lighting was soft and glowing with upward projecting lighting. It would be one where the physical arrangements of things in the room was cognitively orderly and didn't alter and where everything in the room remained within routine-defined areas. It would be an environment where only what was necessary for learning was on display and there were no unnecessary decorations or potential distractions.

—DONNA WILLIAMS, *Autism: An Inside-Out Approach*

Imagining that one's senses are 1,000 times more sensitive than reality can help a person to design environmental accommodations for those on the autism spectrum. Considering each sense individually can assist with organization of both the issues caused

by the sensitivity and the remedies for relief. In considering the sense of sight, a person with a vision hyperacuity might be bothered by the presence of fluorescent lights, because the lights cycle on and off 60 times per second in timing with the Hertz of alternating current. In such cases, a different form of illumination should be used. It is also possible that the humming from the ballast of a fluorescent lamp is irritating to individuals who are sensitive to sound.

—STEPHEN SHORE, *Beyond the Wall*

9

Adults Living and Working with Autism Spectrum Disorder

Once you become an adult, usually at twenty-one at the most, nobody is obligated to take care of you anymore. After that, where you live and how you live, more than anything else, depends on you and what you make of your abilities.

It will be easier for you if you prepare to accept an eventual change in where you live before failing health or death of your parents forces this reality on you. I am grateful to my parents for what they did but I have to say that I live more independently and fully now that they are gone. I had no choice.

—JERRY NEWPORT, *Your Life Is Not a Label*

The problem of long-term care plagues all parents of people with cognitive difficulties. People with cognitive disabilities are so vulnerable. . . . What parents want for their children and what they get are two completely different things. The government offices and private agencies responsible for serving them make for a huge, complicated system. . . . Parents have mixed feelings. They know what they want in a general way, but don't know how to go about achieving it.

—LINDA J. STENGLE, *Laying Community Foundations for Your Child with a Disability*

FOR a short while I worked as a case manager for one of California's regional centers, providing resources to individuals with developmental disabilities. Some of my older adult clients who required a lot of support

were still living at home with elderly parents. When I visited them, I could feel the anxiety, hear the tremor in the parents' voices, sense their exhaustion, knowing they were concerned not only about today, but the future, when they would no longer be around to look out for their child.

Then I had Jeremy. Now he is twenty-five, and I know that although he continues to learn, he will always need supports. He only has one sibling, and our relatives are spread out over the globe. The reality is that my husband and I are going to be aging parents, and we need to create with him options he is comfortable with. We can't imagine him living alone or in a residential facility or group home, where he knows no one and where he will be at the mercy of others unknown to us or even find his "home" sold like a business and run by others. He wants to live in his own community, with chosen roommates, just like any other young person. He would like to have a girlfriend and eventually get married. We want him to be surrounded by friends and people who love him, who can give him the support and strategies he needs to continue to learn and find his niche. We are exploring options, helping him prepare to move out into his own place, and making plans for the future.

The Reality of Life as an Adult with ASD

In *A Full Life with Autism: From Learning to Forming Relationships to Achieving Independence*, published in March of 2012, Jeremy and I extensively covered adult services, and you may wish to consult that book for more information than what is included here.

Meanwhile, in Chapter 7 of this book, we touched upon the need for preparation in high school for transitioning to the world of work or college. This chapter is written primarily for adults with ASD and their families or caregivers, but educators working with teenagers, prospective employers, and others working with adults with ASD will find a wealth of information as well. Those involved with transition planning from high school to real adult life would do well to read this for ideas and insight as well as resources for more information. (Those with ties to policy makers and purse-string holders could highlight the parts of this chapter that discuss the

lack of available services and the need for more funding, and send it on to them.)

Some adults with ASD are able to live and get what they need with little or no assistance. Others, although able, will need support throughout the process. Even more will need support and supervision twenty-four hours a day for most of their lives. In this chapter, services and ideas for different ability levels will be covered.

More is known about adults with ASD than ever before. Many of the more able people with ASD have written personal accounts of what their lives are like, and how they overcame challenges to make living in a neurotypical world easier. Their suggestions will be helpful to many readers. New ideas about possible living and working solutions have been put forth recently that may be helpful for those needing more supports.

The federal and state governments have a responsibility to all its citizens. In the United States, the Americans with Disabilities Act gives people with disabilities equal rights as others. However, although improvements have been made, equal access and opportunity is still “in progress.” Not enough opportunity—or supports to benefit from an opportunity—is available. However, there is hope as parents, professionals, and organizations work together to improve the situation and generate alternative solutions and creative funding mechanisms.

The Challenges of the Individual

Over the last few years, more and more adults with ASD have written books about living with autism or Asperger’s. It is very inspiring to read the accounts of their lives and how they overcame some of their challenges. The skills they developed in order to survive in a neurotypical world can give ideas to others like them or to parents and educators to help prepare teenagers and young adults. However, the stark reality is that most people with ASD, even those who are very able, do not enjoy the work and living environment that these authors do.

Why is that? First of all, these individuals are exceptional people, not only in their intelligence but in their determination and motivation to live a full life. These individuals have Asperger’s or are on the very able end of

the autism spectrum. Second, most of these individuals had strong, supportive mothers or fathers who were able to fight for what they thought their child needed while they were growing up, and who stood by them regardless of what label they had at the time for their difficulties. Thirdly, the parents raised them in such a way as to build a strong sense of self-esteem, and if they subsequently married, their spouse continued that support. These factors helped them to overcome the challenges they had and create a fulfilling life.

Unfortunately, all these factors do not always exist for most individuals. Even most neurotypical individuals do not have that drive and self-motivation to succeed against all odds. And not all parents have the knowledge, stamina, or conviction to go out and fight the powers that be for what their child needs as they grow up, and even less when they are young adults.

Options and Preferences

Some people on the more able end of the spectrum have found the college or university environment a comfortable place for them to learn and even work. Others have found that particular fields of work are more conducive than others. Dealing mainly with objects and data and less with people often appeals to those who have strong social impairments.

Many more will need help to find a job and coaching to keep it. Not only does the adult with ASD need to develop strategies to be a good employee, employers need to know how to make the job a good match with the employee. Good coaches will be needed to help put strategies in place to help those with inappropriate behaviors learn to keep them in check in the workplace.

Still others will need extensive supports and may be in volunteer or day programs learning skills and behaviors necessary for appropriate job placement.

Adulthood

BY PETER GERHARDT, EDD

One way of understanding the development of comprehensive programs of intervention and support for adult learners with ASD is to consider the difference between a disability and a handicap. A disability can be defined as a permanent reduction in the function of a particular body part or structure. A handicap, on the other hand, is defined by the challenges that the disability presents to the individual's participation in desired, life-relevant activities.

As such, any system of intervention or support first needs to identify the individual, environmental, instructional, and community conditions under which the disability of ASD may present an individual learner with less of a handicap.

Using this perspective, the adult with ASD becomes simply one target of potential intervention among a variety of targets (e.g., coworkers, cashiers, modifications to job requirements or the physical environment, the provision of community training, and support) designed to support increasingly greater levels of personal independence and competence. In this model, then, the goal is not to "fix" the adult learner with ASD but rather to simply view them as one of many potential targets for instruction, support, and growth, and in so doing, reduce the impact of potentially handicapping barriers while increasing the personal competence of all concerned.

Adulthood for learners with ASD needs to be understood as more than just a chronological state. For everyone, adulthood represents a time in one's life where there are increased levels of independence, choice, and personal control. Further, adulthood is generally recognized as a period of increased responsibility, commitment, and, more often than not, delayed gratification. It is during this time of life that we generally experience our greatest successes as well as some of our greatest difficulties. Adulthood, despite some popular perceptions, is a time of continued growth and learning and not a period of stagnation, and is, in many ways, the defining period of one's life. We may look back fondly on our childhood, but it is our accomplishments as adults for which we are generally most proud. Adulthood for the adult with ASD should be viewed as no different.

Peter Gerhardt, EdD, is the author and coauthor of articles and book chapters on the needs of adults with ASD, the school-to-work transition process as well as the analysis of intervention of problematic behavior. He has presented nationally and internationally on these topics. Dr. Gerhardt is the director of education at the Upper School for the McCarton School in New York City and serves as chairman of the Scientific Council for the Organization for Autism Research.

The concept of self-determination is taking hold in more and more states by people with disabilities and their families. It is about allowing people with developmental disabilities to make their own choices and supporting them as needed. This philosophy, which is about recognizing people's abilities rather than their disabilities, necessitates changes in state policy and local agencies in how they provide support for individuals.

Regardless of the ability level of the individual, the person's own preferences should be taken into account, and there are ways of trying to figure out what is important to even the least communicative of individuals. This is at the heart of person-centered planning, an approach discussed in Chapter 7 under the heading "Preparing for Life After High School" (page 240).

The State of Adult Services

The United States has many laws that protect, and services that provide for, the developmentally disabled. Sadly, it is not enough for all in need today—or for the epidemic numbers of children with ASD that will grow to be adults tomorrow. Currently, there is great concern in the autism community about the wave of children and teens who will need services as adults, and that we are wholly unprepared for the vast numbers, due to the increase in diagnosis as discussed earlier in this book. Due to the tenfold increase in the prevalence of autism during the past decade, the number of children with autism who will become adults is huge. Currently we are seeing the tip of the iceberg, but there are far greater numbers of older individuals—teens and young adults—who are in need of appropriate services than ever before. The reality is that services for adults with autism are not mandated in the way that special education services are required by the federal government. This means that when a teenager or young adult exits the school system or transition program, he or she may be eligible for services, but the local government is not legally obliged to expand their services and

provide for all. The individuals who are eligible are put on a waiting list until a spot opens for the service they are requesting.

In July 2001, the board of directors of the Autism Society of America (ASA) published “A Call to Action: Position Paper on the National Crisis in Adult Services for Individuals with Autism” (autism-society.org/upload/images/AdultServices). The author, Dr. Ruth Sullivan, is herself a parent of an adult with autism and a professional who has created living and working options for adults with autism.

Her paper is an excellent source of information in regard to the history of services in the United States, and where we should be heading, as well as a call to arms for parents and professionals and the government to create what’s needed.

There are some community agencies that serve people with ASD; however, in 2001, there were only about twenty-five agencies providing specialized programs for these adults. These agencies experience high turnover in staff, because the inadequate Medicaid reimbursement does not allow for paying decent salaries.

Staff turnover is high, and there are few college programs that train people about autism and strategies to work with adults with autism. Parents and professionals familiar with autism can attest to how difficult it is for staff to do their job—let alone how hard it is on the client with autism—if they have no training in the client’s form of communication or behavioral strategies.

The cost of autism-specific services is very high. Few families can afford the cost, no insurance company will cover it, and providers have limited financial ability to develop more programs.

This means that currently, there is not enough of anything to go around, and it is not going to get solved overnight with a prayer and a wish.

What must be done. To alleviate the enormous residential need we are currently facing, Dr. Sullivan suggests that in-home support be provided for those parents who wish to have their adult children live with them for as long as possible. Small group homes, apartments with support staff, and access to home financing should be provided for those who choose to live in their own home.

People with autism would be more effectively employed if they had access to job coaches who were well-trained and knowledgeable about

autism and could help them learn and maintain appropriate work-related behaviors. Taking the individual's interest into account when matching them to a job is also a key ingredient to successful employment, as it is for anyone.

The reality is, we cannot wait for the government to take action. Parents, professionals, and other organizations are taking the lead in many places and creating solutions: programs for adults regarding living arrangements and employment and college opportunities for those so inclined. These opportunities have been created out of frustration and need, which is a good example of taking a negative and turning it into a positive.

Some parents are joining together and creating group homes or nonprofit organizations to provide living arrangements.

Recently, more developmentally disabled individuals have become self-employed, which in turn pays for the supports they need in order to work in the position that has been created for them, based on their wishes.

Some undergraduate programs are creating supports specifically designed for college students with Asperger's or more able students with autism. Some colleges are designing integrated undergraduate programs specifically for the more academically able with ASD, and will provide necessary supports as well as opportunities to learn the skills a person may be lacking to be an independent adult.

FOOD FOR THOUGHT

Employment Tips from Temple Grandin

In her book *Thinking in Pictures*, Temple Grandin gives some useful information about how she was able to transition from college to work. Here are a few of the points she makes:

- It is important to make a gradual transition from an educational setting to the world of work. Starting a job or career part time while still attending a class or two can make this possible.
- The freelance route has been a way that many people with ASD have been able to exploit their talent area.

- Sometimes it is possible to get in trouble at a job by being technically correct but socially wrong. This happens to people with autism because they have a hard time being diplomatic and tactful. Temple learned by reading about international negotiations and using them as models.
 - Temple has had many mentors. These mentors, whether at college or at work, helped her by teaching her the social aspects she needed to be successful, such as how to dress and be groomed appropriately and how to put together a portfolio showing off her talents, explaining to her the social nuances she did not understand, and helping others to understand her behaviors and actions.
-

More recently, a national consortium called Advancing Futures for Adults with Autism (AFAA) was formed, facilitating the development of a national agenda affecting areas of adults with autism. Areas covered included housing, employment, and community life. Input was taken from many families and advocates all around the country in town hall meetings, and many autism advocacy organizations were involved. In 2010, this agenda was provided to federal policymakers who were urged to adopt key aspects of what the AFAA recommended.

In the area of employment, the AFAA identified many concerns in the autism community. The following are suggestions from the AFAA on how to improve the prospects for employment for adults on the spectrum:

- *Bridge the divide between the school years and adult life.* School districts and autism educators need to recognize that students with autism need to develop employment skills during the transition years from high school to college and beyond. There needs to be a continuity of support for young adults with ASD, their families, professionals, and employers.
- *Change the mainstream perception of adults with autism.* There needs to be a “presumption of employability,” which currently does not exist. As well, employers need awareness and training. When thinking of employment opportunities, the bar needs to be raised. Perhaps by making autism a diversity issue, it would be easier to place individuals

with autism in jobs, as employers understand and relate to the importance of diversity matters.

- *Improve the work conditions and career prospects for individuals on the spectrum.* Many such workers are underpaid and passed over for promotions. There needs to be equitable compensation and career opportunities that are mutually beneficial for employers and potential employees. As well, they must continue to maintain public assistance benefits—including transportation—even if they have jobs.
- *Provide continual social skills training and life-long support.* Without comprehensive help, people on the spectrum will continue to have low expectations for their career opportunities, and so will any potential employers. Technologically savvy and motivated people are needed to coach, teach, and support those preparing for employment.

For more information, visit afaa-us.org.

FOOD FOR THOUGHT

Do Your Best

The bottom line is this: If you ever want the kind of job that buys you a house, a limo and anything close to that, you will have to do every job before that one as if it were the greatest job in the world. Just make believe, if you wind up cooking hamburgers, that every burger will have a photo of you on the wrapper, saying “cooked by . . .” Do every job to the best of your ability because you are proud of who you are and always do your best. If you do that, you will get the most out of your working days.

—Jerry Newport, *Your Life Is Not a Label*

Where to Find Information and Possible Services

Meanwhile, it is apparent that regardless of the ability level of the person with ASD, there are challenges and barriers to overcome in order to get the services that are needed. Although the type of need may be different, any person with ASD who requires assistance, or their caregiver, should have access to information and advice. As mentioned earlier, there is not a federal mandate for services to be provided after the person leaves school. Every state provides differently, so you will need to find out what applies to your area. If you have made it this far, you are probably resourceful in terms of asking the right questions. Here are some suggested places to go for information:

- Apply for Supplemental Security Income (SSI). Adults considered disabled are eligible for SSI. Some states supplement the amount paid by the federal government. Contact the Social Security Administration (800-772-1213; ssa.gov) for more information.
- Contact your State Council on Developmental Disabilities to find out about adult services, and contact your state's protection and advocacy agency to find out your rights and what you may be entitled to in your state. You can find those agencies on the Administration of Intellectual and Developmental Disabilities website, acf.hhs.gov/programs/aidd.
- Refer to the free download "Life Journey Through Autism: A Guide for Transition to Adulthood," available on the website of the Organization for Autism Research (OAR), researchautism.org/resources/reading/documents/transitionguide.pdf.
- Visit the U.S. Department of Labor, Office of Disability Employment Policy, to find information about employment and disability at dol.gov/dol/topic/disability/index.htm. Also look for your state's agency online.
- To find out the contact information for the Statewide Independent Living Council (SILC) in your state, check out the Independent Living Research Utilization Project website (ilru.org).

- To find out about possible medical and Medicaid benefits, it is best to contact your state agencies; however, if you wish other information, contact the U.S. Department of Health and Human Services (hhs.gov).

Suggested Reading for All

More and more able adults on the spectrum are blogging and writing books about their experiences and their suggestions to make life easier for others like them. Granted, many people with ASD are not as able as these individuals, but the threads running through are very similar and can be applied to trying to understand the behaviors of others who are less able.

Some of these authors are listed in the Resources section of this book. As well, I have included input from many on the spectrum in *A Full Life with Autism*. People with autism might find it helpful to read some of these as well.

Employment and Careers

Jerry Newport has a great philosophy about work. He feels that no matter what job you have, you should do it well. In *Your Life Is Not a Label*, he gives many tips about work. He suggests that even entry-level jobs are important as they can teach you things that are necessary for all jobs, namely: how to follow instructions, how to be on time, how to dress appropriately, and how to work independently.

An excellent, practical book is *Developing Talents: Careers for Individuals with Asperger Syndrome and High-Functioning Autism* by Temple Grandin and Kate Duffy. This book explains how to prepare for an interview, how to prioritize work commitments, and how to deal with sensory overload. There is an informative and detailed section on the best jobs for people on the spectrum.

A book that might be useful for the more able adult wanting to explore possible career choices is the *Asperger Syndrome Employment Workbook* by Roger N. Meyer, who has Asperger's. This practical workbook includes useful worksheets that encourage readers to engage in an exploration of

their employment history, and to identify the work they are best suited for by analyzing their needs, talents, and strengths.

Temple Grandin suggests developing your special interest or obsession into an employable skill. Readers who have seen the Emmy Award–winning movie based on her life (titled simply *Temple Grandin*) will remember how Temple became successfully employed in this way. Even though social skills may be lacking, a person can impress someone with their talents, strengths, and abilities and be hired. People respect talent, and a person can focus on selling their skills instead of their personality. Employers will have to understand your needs in order for a job or career to be successful, but having a special ability will convince someone that you are worth employing. Employers should be reminded of the positive attributes that most people with ASD have, such as honesty and diligence, as well as the challenges you face.

Finding mentors can help a person develop their interests into marketable skills. Mentors can help the person figure out what kinds of jobs are available for people with a specific talent, practice social and interview skills, and help with contacts for possible job openings or clients.

Obviously, not everyone has the capabilities of Grandin or Newport; however, the concerns of finding a good fit, and a job that is interesting to the individual, are the same whether the person is more or less able.

Seeking Employment

Scott Standifer, PhD, of the Disability and Policy Studies department at the University of Missouri, has done research that shows many of the current practices in interviewing, training, and placing individuals with autism in jobs have been ineffective. In order to fill the existing gap of information available to state employment agencies, Standifer wrote a wonderful resource, which is free online: “Adult Autism and Employment: A Guide for Vocational Rehabilitation Professionals.” You may wish to provide this to vocational rehab offices you come in contact with if they do not demonstrate a working knowledge about autism and employment.

Each state may propose different opportunities, or use different labels to describe what is available, so check to see what is available locally. Here is

a glimpse at the usual options for finding and keeping a job:

- *Competitive employment.* These types of employment opportunities are usually good for people who can work at a job with some adjustments but who will not need support on a continual basis. People who have an employable skill will find it easier to find work. Networking through family members, friends, people from your church, or mentors you have had can perhaps lead to employment. If you are attending college, you may find a job through contacts made there: people who admire your abilities and know people who can use your talents. Local unemployment centers, the classifieds, and websites like Monster.com are also places to look for openings.
- *Supported employment.* This option provides assistance in areas where people with ASD need help: job finding, job coaching, skills training, and employment advice and guidance. The goal is to place the person in a job in the community that fits in with their interests and abilities. These kinds of programs, regardless of the ability level of the person, provide each person with the training and support to maintain employment in the chosen career field.
- *Sheltered employment.* This is an option for those who will need security in a work environment where people are knowledgeable about ASD. These jobs tend to be repetitious, and those who like structure and repetition may do well in them. However, there are concerns about the pay scale and about whether there are better options for many who are working in these types of arrangements.
- *Customized employment: job carving.* Some companies may be able to customize a job to fit the needs of a prospective employee who may be able to fulfill part of the job duties but not all. In this case, the job duties an employee can do are “carved” out, and the other duties are given to another employee. In this way, sometimes two people actually share one job.
- *Customized employment: self-employment.* Working as a freelancer in a particular area of interest is a possibility if the person has the

discipline that self-employment requires. However, if the social aspect of marketing is difficult, this will work only if there is someone who can refer work to the individual and do their marketing for them.

Mentors can be very helpful in this arena. For those who are on the more impacted end of the spectrum and would have a hard time getting and keeping a job, this can also be an alternative as it provides a way for the individual to earn money doing something he is interested in doing and not be constrained by what “the system” has or doesn’t have available for him.

As described in my book *A Full Life with Autism*, those on the spectrum who are successfully employed share one common trait: that wherever they work, they are accepted for who they are. Acceptance starts first at home with the parents recognizing and encouraging the talents and positive aspects of the differences of their child. These differences could be a basis for employment.

There are now companies being created that create employment based on the talents of individuals on the spectrum. One of these is Specialisterne (The Specialists), a Danish for-profit social enterprise business that provides software-testing services. Specialisterne workers doing data entry are five to ten times more precise than other contractors, according to one of their clients. These employees with an autism diagnosis are paid competitive wages.

A good resource for those on the more able end of the spectrum is Asperger Syndrome Training and Employment Partnership (ASTEP). ASTEP promotes the inclusion of individuals with Asperger’s syndrome and high-functioning autism in competitive employment. Among other ways, they do this by establishing relationships between national employers and high-quality support programs for adults with autism, and awareness and training campaigns aimed at Fortune 1000 companies. For more information, go to asperger-employment.org.

There are now more opportunities available for those on the less able end of the spectrum. Successful work stories of individuals with developmental and intellectual disabilities can be found on realworkstories.org.

Positive Aspects of Hiring Someone with ASD

Prospective employers should know that there are positive benefits to hiring someone with ASD. According to the U.S. National Association of Colleges and Employers, Bureau of Labor Statistics, U.S. Department of Labor, the following are the top ten skills and attributes that employers look for in prospective employees:

1. Honesty/integrity
2. Strong work ethic
3. Analytical skills
4. Teamwork
5. Computer skills
6. Time management/organizational skills
7. Communication
8. Flexibility
9. Interpersonal skills
10. Motivation/initiation

Honesty, dependability (strong work ethic), analytical skills, computer skills, and motivation (provided the job is in an area of interest) are traits that can be found in abundance in the ASD population. The other skills are seen in many on the autism spectrum. For some, teamwork, flexibility, time management, and communication could be more of a challenge. But these are skills that can be taught or adapted. For example, if a person has a hard time working on a team because of sensory or communication challenges, one person on the team could be designated as the “go-to person” with whom the employee with autism interacts in regard to projects and information resulting from meetings.

But the most important traits—honesty and a strong work ethic—are in abundance with those with autism. Unless there is another comorbid

diagnosis, a person with autism is honest to a fault. If you ask, they will tell you truthfully what they think (e.g., “No, I don’t think that dress looks nice on you”). They won’t be the one stealing from the cash drawer. And they won’t be calling in sick because they had too many tequila shots the night before.

RESOURCES

Adult Autism and Employment: A Guide for Vocational Rehabilitation Professionals by Scott Standifer

A Full Life with Autism: From Learning to Forming Relationships to Achieving Independence by Chantal Sicile-Kira and Jeremy Sicile-Kira

Asperger’s on the Job: Must-Have Advice for People with Asperger’s or High-Functioning Autism and Their Employers, Educators, and Advocate by Rudy Simone

Asperger Syndrome Employment Workbook: An Employment Workbook for Adults with Asperger Syndrome by Roger Meyer

ASTEP: asperger-employment.org/employment-resources

Autism and the Transition to Adulthood: Success Beyond the Classroom by Paul Wehman, et al.

Autism Life Skills by Chantal Sicile-Kira

Disability Benefits 10: Working with a Disability in California:
DB101.org

JobTIPS: do2learn.com/JobTIPS/index.html

Real People Real Jobs: Stories from the Front Line—Institute for
Community at University of Massachusetts Boston:
realworkstories.org

Temple Grandin: hbo.com/movies/temple-grandin/index.html

College

There are different types of colleges: vocational or technical colleges, community colleges, and universities or four-year colleges. Vocational or technical colleges usually teach a skill in preparation for a specific job or employment goal. Community colleges are only two-year programs, with students transferring to four-year colleges or universities to complete their education.

Many of the more able people with ASD are successful at college. Some of the interests or obsessions they have can be pursued in a course of study. The challenge may well be translating that knowledge or degree into stable employment, but that is a challenge all students face. Some feel so comfortable at college that they develop their interests into a career on campus. Both Stephen Shore and Lars Perner in articles on the web describe college as being “heaven” either for themselves or for others they know on the spectrum. Where else can a person expound on their favorite topic without interruption for a few hours at a time? As well, the college campus can be a mini-society, making it easier and less stressful to manage than society at large.

There are more and more programs available to help college students with autism. Some cater even to those who need more academic supports and who need more help to learn life skills. Disabled Student Support Services at colleges are becoming more and more understanding about the types of supports a college student with autism may need.

Some students prefer community or local colleges as they can continue to stay at home. Dormitory living can be difficult unless the student has a private room. Living with unknown roommates in a rental unit also can be tricky. Community colleges usually offering two-year programs can be a challenge if the student wishes to continue at a four-year college. The student will have to make sure to plan carefully what classes to take to make sure they apply. Also, if adjusting to different environments is a challenge or stressful, the student will be going through that step twice.

Differences Between High School and College

It is important for both the parent and prospective college student to understand that they have different legal rights and responsibilities in college. While a student is still in high school or the transition program, he or she is protected under the Individual with Disabilities in Education Act (IDEA). Once a student graduates from high school with an academic diploma, or ages out of the school district (twenty-two to twenty-five, depending on the state), those protections end. The college student with a disability is protected under the Americans with Disabilities Acts (ADA) and other laws.

“Catching the Wave from High School to College: A Guide to Transition,” available online, is a great publication designed to help students with disabilities, parents, and high school educators understand the differences between being a student in high school and one in college. This is a good tool for preparing everyone involved for this important transition.

One of the major differences is that in high school, the parent is legally responsible and may advocate for their child at IEP meetings, and request needed accommodations and modifications. In college, the student must be able to ask for their own modifications and needed supports. A college student may sign a document allowing the release of information to the parent, but is not obliged to. The amount of contact or input a parent has is really up to the discretion of the college with permission from the student.

Another major difference between high school and college is that certain accommodations are possible under ADA, but modifications in the homework or coursework are not allowed. For example, a college student with a disability may request extended time for test taking or for completing assignments, but may not ask for a shorter test or to hand in a three-page paper instead of a six-page paper. For this reason, it is important that a high school student who wants to go to college not have modified school work the last year in high school.

It’s important for both the parents and the student to realize that college is a privilege, not a right. A student who struggles in a public high school is protected because the school is required to serve the student. This is not the case in college. It is up to the student to ask for and get the help he or she needs; a college is not required to serve a student who is failing or having trouble adjusting.

For all the reasons above, it is important that the student learn self-advocacy skills while still in high school before reaching the age of eighteen or before exiting school district services.

Getting Support for a Successful and Enjoyable College Experience

Colleges offer services and supports for students with special requirements. Accommodations can be made as specified under the Americans with Disabilities Act (ADA). However, not all colleges are familiar with ASD and your particular needs. Here are some suggestions for making college a rewarding experience:

- Give information to those you think may need to know about the ASD and how it affects you, the challenges you face, and what strategies can be used to help you.
- Find a sympathetic school counselor or mentor. This person can help in many ways, for example, by helping you find a group on campus that shares your special hobby or interest.
- Ask your school counselor or mentor which teachers would be more accepting of your difficulties and willing to make you comfortable with learning in their class.
- The same kinds of support that helped in secondary school will be beneficial at college, and telling your guidance counselor what those were is a good idea. For the visual learner, written schedules, lists, and visual aids for studying such as graphs, charts, and videos are helpful. For the auditory learner, tape-recording lectures or having a note-taker works well. Textbooks on tape can be another useful tool.
- Test-taking accommodations can be requested such as a quiet room separate from other students and more time to take the test.

RESOURCES

Realizing the College Dream with Autism or Asperger's Syndrome: A Parent's Guide to Student Success by Ann Palmer

Students with Asperger Syndrome: A Guide for College Personnel by Lorraine E. Wolf, PhD, et al.

A Full Life with Autism by Chantal Sicile-Kira and Jeremy Sicile-Kira

Succeeding in College with Asperger Syndrome: A Student Guide by John Harpur, Maria Lawlor, and Michael Fitzgerald

Beyond Brochures: autismcollege.com/blog/2012/01/25/beyond-brochures

“Catching the Wave from High School to College: A Guide to Transition” edited by Carl Fielden, et al.: grossmont.edu/dsps/transition/transition00_default.asp

Financial Help for Disabled Students: disabled-world.com/disability/finance

Going to College: going-to-college.org

Indiana Resource Center for Autism: Academic Supports for College Students with an Autism Spectrum Disorder: iidx.indiana.edu/index.php?pageId=3417

Lars Perner's website: larsperner.com/autism/colleges.htm

Think College: thinkcollege.net

Living Arrangements

At some point in time, you may be leaving the family home. As Jerry Newport points out in his book, it is better to start that transition while your parents are still well. That way, you will still have the support of people who love and care for you and whom you trust during the period of transition that you will be facing.

Obviously, living arrangements are a personal and family decision based on comfort level, needs, and budgets. If anything other than a totally independent situation is being considered, then it is important that the individual with ASD and/or a family member look into the company that is providing or supervising the living arrangements. Make sure the company has a mission or philosophy that fits in with the needs of the prospective resident.

There is a lack of available housing for those on the autism spectrum. Research indicates that 69 percent of adults with a disability reportedly live with their parents and guardians. One study, titled “Opening Doors,” offered some ideas and solutions that could be created for those of different ability levels needing more or less supports. Some of the challenges uncovered in this study conducted by the Urban Land Institute Arizona, Southwest Autism Research and Resource Center, included a lack of consistency in the definition of residential options and in a lack of guidelines in terms of designing for those with autism. As well, there were challenges in obtaining needed capital for building and in terms of service providers.

There is general agreement among adults on the spectrum for the need for quiet and safe environments as well as the importance of color. For those who have sensory challenges and acute hearing, living in an apartment building can be a nightmare.

Some self-advocates in the autism community believe in a full-inclusion model; others believe that we need to be open to different options as some may prefer or need autism-specific accommodations.

It is important that whatever option is chosen, safety, communication, and personalized training of support staff be planned for. Whatever setting is chosen, the individual needs of each person must be taken into account.

FOOD FOR THOUGHT

Socializing

Many young adults meet each other at places that cultivate a common interest. These should not be “negative” sites such as night-clubs, which are notoriously socially threatening environs for our people. Places like a bookstore that

features poetry readings, health club, yoga club, running group, chess club, or any interest group are a good bet for our people, who have little problem expressing an interest in certain subjects. In these places, our extreme interest, which may not be appreciated ordinarily, might even come to be a social advantage.

—Jerry and Mary Newport, *Autism-Asperger's and Sexuality*

Housing and Support Options

There are different options available, depending upon the adult's functional living skills, whether the person likes being alone or not, as well as available funding from the government or the adult and his or her family. Not all housing models are available in all states. Below are some of the existing options:

Group homes. These are supervised and supported care facilities in more typical homes located in the community. They exist in every state and are small, residential homes usually owned by the provider agency, usually have eight or fewer occupants, and are staffed twenty-four hours a day by trained agency staff.

Supported living programs. These provide residential services to those who live in self-owned or leased homes in the community, and are designed to promote full inclusion of the person in the community as they work toward their long-term personal goals. The core philosophy here is that anyone, regardless of current skills sets, can benefit from supported living and that programming and instruction are directed by the resident and not by the program.

Supervised living programs. These provide services to individuals with more supervision and direction than might be provided in supported living programs, but less than in a group home structure. These residences may be small with usually no more than one or two adults with autism per residence, scattered throughout the same apartment building or housing complex, which allows for greater staff accessibility and oversight.

Transitional models. These are short-term living arrangements of usually one month to two years, with the goal of transitioning the person back to the previous environment or into a new residence. These are for those who are expected to live independently once they complete the program that provides intensive life skills, who are attending a college that provides support, or who have severe behavior disorders and require in-patient behavioral evaluation and intervention.

Agricultural community/farmstead programs. Farmstead programs typically combine residential living arrangements, usually several single-family homes or individual apartments in multi-unit dwellings, located on-site or in nearby locations, and include agricultural science and community-based employment.

Intermediate Care Facility for individuals with Mental Retardation (ICF-MR). The funding for this facility-based program, which includes the support services as well as the facility, stays with the facility, not the person. Programs range from large congregate settings to smaller community-based group homes. The ICF-MR usually serves individuals with complex needs, who are medically fragile and multichallenged.

Resources About Housing

- To find out about available housing services in your area, and to get on waiting lists, you need to contact local agencies in your area. If you are unsure of where to go for information, contact your state's protection and advocacy office.
- To find the contact information for centers for independent living (CILs) in your state, visit the National Council on Independent Living website (ncil.org).
- The FRED Conference is a national coalition of special needs professionals and families. Through collaborations, FRED advances adult living options for people with disabilities to live with meaning and purpose, which includes housing, employment, and recreation for

current and future generations. For more information, visit fredconference.org.

- For more information about housing and supports, visit Autism Speaks and download their free Autism Services Housing and Residential Supports Toolkit at autismspeaks.org/family-services/housing-and-residential-supports.

Helpful Strategies for Work, College, and Everyday Living

Adults with ASD face challenges in certain areas. For those who are not cognitively disabled, or who are on the mid to higher end of functioning ability, there are many strategies that can be put in place to help.

FOOD FOR THOUGHT

Partners of Adults with ASD

If you are in an intimate relationship with someone who has Asperger syndrome, you are one of the most important people in their lives. How you approach and cope with problems can make a difference to how he copes with many of the difficulties that having Asperger syndrome can present him with. This is not to say that you will have to take responsibility for everything your partner does, but it is important that you are aware that there are some things that you will be naturally better at than he is.

—Maxine C. Aston, *The Other Half of Asperger Syndrome*

For Challenges with Social Communication and Contact

Getting and keeping a job or career, or signing up for and attending college, can be difficult for people with ASD. The social skills that are necessary to

network, ask questions, and understand the true meaning (as opposed to the literal meaning) of what is being said, as well as to interpret nonverbal communication, are areas in which people with ASD may be lacking. However, there is much that can be done to overcome this obstacle:

- Much information can be accessed through the Internet now without dealing directly with another person. This can be a good way to make primary contact when trying to network for jobs.
- If possible, find mentors who admire your talent and know about your eccentricities and who can help you turn your talent into a career, or put you in touch with people who can help you find work or get through school.
- Decide who at work or college needs to know about your ASD and tell them how it affects you in the workplace. In his book *Beyond the Wall*, Stephen Shore has included a sample letter he helped develop for the Asperger's Association of New England. This letter, addressed to employers, explains the difficulties the person writing it has with reading nonverbal signs and understanding what it is like to be in someone else's shoes, and the situations that can result, as well as suggestions that would help the person.
- Practicing areas that you are not comfortable with, such as job interviews, discussion with teachers, or going on a date or outing with a peer, can be very helpful in relieving some of the anxiety.

For Problems with Finding Your Way Around

Many individuals with autism have difficulty going from one place to another, whether it's at school, on a college campus, or in shopping malls and big buildings. This can be a problem for getting to classes on time or accomplishing your job. What you can do:

- Go around the place you will be needing to learn how to navigate a few times before starting school or your job. It helps if you can have

someone with you who is already familiar with the building. In some areas you may need to ask permission for access. If possible, walk the route from one place to another that you will have to take.

- Take pictures or draw the different landmarks that are on the path from one place to another. List on a piece of paper or dictate into a mini-recorder the order of the landmarks, and where you need to turn or stop or take another direction.
- Make a small guidebook with the pictures and notes, including the times at which you must leave one place and go to the next.
- Draw a map if you think it will be helpful to you, of all the corridors or alleyways or streets and landmarks.
- Practice navigating through the areas you have mapped out. Using a bicycle can be a viable means of getting around large campuses or small towns.

For Daily Living

Keep in mind that the kind of strategies that help you with organizing your schoolwork or job will help you with your daily living skills. Perhaps you have already been using some of these while living at home. Some things that may be helpful are color-coding for files of paperwork and bills and schedules of your daily, weekly, and monthly activities and chores.

For example, some people find it helpful to do certain chores (laundry, vacuuming, food shopping) on certain days and have them marked on the calendar. Other responsibilities with a home that crop up less often, such as paying the bills, can be noted on the calendar to remind you when they need to be done.

For Sensory Processing Challenges

Both Temple Grandin (*Thinking in Pictures*) and Liane Holliday Willey (*Pretending to Be Normal*) have much information to share about sensory

difficulties. Getting an occupational therapist who has had sensory-integration training to develop a program to help you in this area can be very useful. Look at Chapter 5 for therapies that address sensory issues. Meanwhile, there are a few things you can do:

- Auditory sensitivity can be minimized for some through auditory integration training. Meanwhile, wearing earplugs may be helpful in curtailing your sensitivity to sound. Make sure you can still hear people talking to you, as well as emergency vehicles and signals such as fire bells. If it doesn't distract you from your work or studies, wear headphones and listen to music you enjoy at low volume. Temple cautions against using these strategies all the time, as some exposure to noise can help desensitize a person, and there is a need to get used to some everyday noise.
- For visual sensitivity, try wearing sunglasses, a hat with a brim, or a visor to minimize the amount of light reaching your eyes, making sure you can see well enough to safely continue with what you are doing.
- If you suffer from tactile sensitivity, tell those around you (at work, college, your living environment) that you do not like to be touched. Wear only fabrics that you like the feel of. If you enjoy deep pressure, there are weighted vests available. However, carrying a heavy backpack or shoulder bag or sewing pockets of little weights into your coat or sweater may work just as well and look better. Rub your skin with light or heavy pressure (depending on your preference) when you are alone, perhaps when getting dressed. If you feel the need to put things in your mouth, then chew gum.
- For those with olfactory sensitivity, put some of your favorite scent on a small piece of material, the inside of your elbow, or a cotton ball, so that you can smell this scent when others overwhelm you. If you can, tell those who are in close proximity to you all day long about your sensitivity and ask if they can refrain from wearing perfumes and other products with strong smells.

- If food sensitivity is an issue, think of the foods you can tolerate. Identify the restaurants or cafes that serve those foods. If invited to someone's home, you may wish to tell them you can eat only certain foods. If your food sensitivity is extreme and you are unlikely to find what you can eat in a restaurant or at someone's home, be prepared to make and carry your own foods when you are spending time outside your home.

Having a Social Life and Close Relationships

Leisure and Recreational Activities

Having a social life can sometimes be a challenge even for people who do not lack social skills. Some people are more gregarious than others, and those people tend to have more relationships and recreational activities. However, it must be remembered that it is not quantity but quality that counts.

For people with ASD, building relationships and participating in recreational activities can be even more difficult because of the impairment of social interaction skills, and the lack of knowledge that most people in the leisure and community services have when it comes to ASD. However, due to the increase in those being diagnosed with autism, people are at least becoming more aware of what they are. Rome was not built in a day, and even though laws protect your right to have access to leisure, recreational, and cultural activities in the community just like every other citizen, in reality people out there still suffer from a lack of knowledge. One way you can help in this area is by spreading knowledge of ASD.

When looking for leisure activities, think about the talents, abilities, and interests that you have and find out if there is a local group that meets around that subject. You may need to take any sensory-overload issues you have into consideration when looking at activities to join. Some activities may have more social pressure than you are ready to handle. Good places to start looking are local facilities such as leisure or sports centers, swimming pools, libraries, art galleries, and adult education classes. Other places

where you may find groups are bowling alleys and bowling greens, cinemas, ice and roller skating rinks, gyms, and local sports clubs.

Depending on your ability level and the level of support needed there are different ways to access activities. You may be able to do it on your own, or with a parent or family member to start off with. If you need a high level of support and live in a residential facility, paid staff may accompany you. Sometimes there are autism-friendly volunteer organizations or befriending schemes in your area. Parents may already be providing a “circle of support” of family friends and caregivers who can help you access recreational activities.

Social and Internet Groups

If you wish to socialize with other adults with ASD, some local chapters of national organizations listed in the Resources section have meetings and organized activities. Other organizations provide social outings, but are not necessarily ASD-specific.

The Internet has become a great resource for people with ASD. Some people prefer to develop relationships this way and can communicate with others through the Internet at any time that is convenient to them. There are online support groups, such as GRASP, among others. If you do not have access to a computer at home, visit your local library.

Close Relationships

Many people with ASD have close relationships and intimacy with others. Some get married and have children. There are difficulties that pose themselves, like in any marriage, and the areas of intimacy and responsiveness to the other are different for each person, depending on issues of sensory sensitivity and level of social exchanges that the partners are comfortable with. Reading some of the books by those with ASD who are married, to either another person with ASD or a neurotypical person, is useful. Some of the married authors worth reading are Michael John Carley, Brian King, Judy Endow, Stephen Shore, Mary and Jerry Newport, Gisela

and Christopher Slater-Walker, Liane Holliday Willey, Maxine Aston, and Donna Williams (see the Resources section for details).

Tips for All Who Know Someone with ASD

Some people with ASD manage well with little or no support. For others, social and communication issues, or perhaps learning disabilities, can get in the way of being as independent as possible.

The Challenges and What Can Help

Parents can help their children by instilling values and a sense of self-esteem and pride, encouraging them to see their individuality as something to be respected and appreciated, eccentricities and all. Parents can also help by creating networks of people who can be available for different areas of need for their adult child. Friends of the family or church members who have certain professional skills can help in their area of expertise. This is one way that community members can be helpful. Whether you are a plumber or an accountant, it would give peace of mind to a friend to know that you are willing to help if the need arises. Parents can also educate their child about safety, police, and emergency situations. (See Chapter 8 for more about establishing community ties.)

Depression in Adults

Many adults with ASD suffer at one time or another from depression or mental illness. This is not part and parcel of the ASD but can be exacerbated by the challenges they face in trying to find a place in our society. Some may also be suffering from PTSD as a result of having been bullied or abused when younger. Friends and family members need to watch for signs that all is not well in order to get them the counseling or support they need.

Partners of Adults with ASD

As ASD becomes more and more recognized and diagnosed, many adults are realizing for the first time that they are autistic or have Asperger's. Sometimes this happens after the person is already married; it may even be that being married provoked getting the diagnosis. The spouse may have chosen her mate because he was calm and reliable, but after some years came to think of her husband as cold, unemotional, and unromantic, and realized that something was amiss.

Finding out that a partner has ASD can provoke different feelings. One of them is anger at missing out on aspects of a marriage that you were looking forward to. Another feeling is relief that your partner is not trying to shut you out, he is just unable to give you the emotional response you need. Other feelings can be acceptance and understanding and letting go of the resentment you felt, because now you know he is not being thoughtless; he really does not get it. The positive aspects of having a spouse with ASD include the fact that he will most likely always be loyal and honest.

Maxine C. Aston in *The Other Half of Asperger Syndrome* and Liane Holliday Willey in *Asperger Syndrome in the Family: Redefining Normal* describe the differences between the expectation of the spouse with Asperger's versus the more neurotypical one, and how it is important for each spouse to recognize the differences and understand where they come from. *An Asperger Marriage* by Gisela and Christopher Slater-Walker is very good, as it gives the point of view of both spouses.

Two more recent useful books both by Rudy Simone are *22 Things a Woman with Asperger's Syndrome Wants Her Partner to Know* and *22 Things a Woman Must Know If She Loves a Man with Asperger's Syndrome*.

Closing Comments

I am a person who is autistic.

What I want to say is that the hardest part of autism is the communication.

Music is helpful.

I like that I can see colors in everything.

Help us by encouraging us.

—JEREMY SICILE-KIRA

*One's first step in wisdom is to question everything—
and one's last is to come to terms with everything.*

—GEORG CHRISTOPH LICHTENBERG (1742–1799)

EMILY Perl Kingsley wrote a wonderful story in 1987 titled “Welcome to Holland” in which she described how having a child with a disability is like planning a trip to Italy, but then landing unexpectedly in Holland. The point of the story is that Holland may not be Italy, but it is still a nice place to be. Years later, Susan F. Rzucidlo wrote “Welcome to Beirut (Beginner’s Guide to Autism)” about how having a child with ASD is more like landing in Beirut with bombs dropping everywhere, with occasional ceasefires, but never knowing when the next enemy attack will begin, or where it will come from, or who the enemy really is. I sympathize.

Much has changed since this book was first published almost ten years ago. I know more about autism than I ever thought I would. Some of my best teachers have been people on the spectrum.

My son, Jeremy, often likens his story to that of Helen Keller—and mine as Anne Sullivan, her first teacher. But, to be honest, it is my son who has taught me. He has taught me patience, compassion, and what is truly important in life. Jeremy is honest, real, and lives in the moment. He has no

preconceptions or judgment about people. This I find to be true of most on the spectrum. We can all learn from their honesty and realness.

As a person close to someone with ASD, your role is extremely important to him, even if he doesn't show it. Your main purpose will be to explain or translate to him the complexities of the neurotypical world and, in turn, to translate to the neurotypical world the eccentricities of the person with ASD. You will be a sort of United Nations interpreter; a most important role to fill. Just as a stranger in a strange land needs to have customs explained to him, so will the individual with ASD need explanations. And as the adopted country needs to have some understanding of the foreigner who has landed in their midst, so will the neurotypicals of our society need to learn from you about people with ASD so as to be more accepting and tolerant of differences.

Parents need to do all they can to help their children, and as early as they can. Some will be "recovered" and many will not be. The focus should be to teach them how to make sense of the world, and give them the tools to function in it so that they can grow up to live independent, fulfilling lives. Helping your child learn by focusing on his area of strength or passion can make life enjoyable for him and may pave the way for connecting with other people and possibly employment in future years.

As a parent you may have knowledge, but you will not always have control. You must learn to recognize that which you can change, and that which you cannot. And this advice holds true whether you are thinking about a behavior your child has or a policy your school district is sticking to. In some instances, the only thing you may be able to change is your attitude.

Professionals should recognize that autism includes the family. You may spend a few hours a day or month with this person, but for his loved ones, it is 24/7. You need to respect the fact that you may be an expert in your field, but while the person is growing up at home, the parent is still the expert on their child. Together you offer strong support and assistance to the person with autism.

Friends and extended family can lend support by learning about ASD, and being open-minded. Do not judge the person with ASD or the caregivers; realize that they may all be a bit overloaded. Continue to extend invitations and keep the lines of communication open. If you can help in

any way, offer to do so. The offer will be appreciated even if it is not taken up.

The general public can be instrumental in how a person with ASD or the caregivers feel in the community. Acceptance and a nonjudgmental attitude toward those who act differently will do wonders to ease the stress. We are all part of the same community, and it does take a village to raise a child and make the place we live into a neighborhood.

Some parents say that if it weren't for autism, they wouldn't have met the wonderful people they have come to know, that autism has given them a *raison d'être*. As for me, I tend to believe that even without autism in my life, I would have met some wonderful people and become committed to some worthy cause. This is not to speak disparagingly of all the fantastic autism-related friends my family has made over the years. It is more a comment about the fact that I could do fine without having to deal with the individuals who don't "get it" or all the added stress of administrative paperwork, phone calls, and resource-searching one needs to do in order to get any assistance.

What is certain, however, is that I have learned much about what is truly essential in life. I have learned how fortunate I am that my body and mind work in sync, and how much inner strength I possess. I have also learned literally to stop and smell the roses and to take pleasure in the simple moments of daily living between the bombs falling. I have learned that heightened senses can bring both pain and pleasure, and that passing the time of day by staring at dust particles in the sunlight, feeling the sand sift through your fingers, or your body floating weightless in a pool, doesn't seem so crazy after all. In fact, it's very relaxing. Try it sometime.

Resources

LISTED here are resources of two kinds: those that have been repeatedly mentioned in this book and merit being grouped here for easy access, and those that have not been mentioned but that are good additional resources. Other excellent resources appear throughout the book.

ASD-Specific National Organizations

There are many great nonprofit local and national organizations now active in the United States. Below are listed the ones with major national outreach.

Autism National Committee (AutCom)

autcom.org

AutCom is dedicated to social justice for all citizens with autism through a shared vision and a commitment to positive approaches, and encourages its individual members and organizational partners toward self-direction and self-empowerment.

Autism One

autismone.org

Autism One is a parent-driven organization that provides education and supports advocacy efforts for children and families touched by autism.

Autism Research Institute (ARI)

autism.com

ARI is a support network providing online and in-person educational events for parents and caretakers and continuing education credit for physicians, teachers, dietitians, and occupational therapists.

Autism Society of America (ASA)

autism-society.org

ASA exists to improve the lives of all affected by autism by increasing public awareness about the day-to-day issues faced by people on the spectrum, advocating for appropriate services for individuals across the life span, and providing the latest information regarding treatment, education, research, and advocacy. There are local chapters.

Autism Women's Network (AWN)

autismwomensnetwork.org

AWN is an online community of autistic girls and women, their families, friends, and supporters, and provides a place where all can share their experiences among a diverse, inclusive, supportive, and positive environment.

Autistic Global Initiative (AGI)

autism.com/index.php/tests

AGI, a project of the Autism Research Institute, is comprised of a committee of adults diagnosed with autism spectrum conditions and exists to foster the development of adults on the autism spectrum and those who work with and for them.

Autistic Self-Advocacy Network (ASAN)

autisticadvocacy.org

ASAN is run by and for autistic people, and activities include public policy advocacy, community engagement to encourage inclusion and respect for neurodiversity, quality of life-oriented research, and the development of autistic cultural activities. There are local chapters.

Autism Speaks

autismspeaks.org

Autism Speaks has grown into the world's leading autism science and advocacy organization, dedicated to funding research into the causes, prevention, treatments, and a cure for autism; increasing awareness of autism spectrum disorder; and advocating for the needs of individuals with autism and their families. There are local chapters.

First Signs

firstsigns.org

First Signs aims to educate parents, healthcare providers, early childhood educators, and other professionals to ensure the best developmental outcome for every child. Goals include improving the screening and referral practices and lowering the age at which young children are identified with developmental delays and disorders.

Global and Regional Asperger Syndrome Partnership (GRASP)

grasp.org

GRASP's mission is to improve the lives of adults and teens on the autism spectrum through peer supports, education, and advocacy with an emphasis on community outreach and individuals advocating for their own needs. There are local chapters.

National Autism Association (NAA)

nationalautismassociation.org

The mission of the NAA is to respond to the most urgent needs of the autism community, providing real help and hope so that all affected can reach their full potential. There are local chapters.

Organization for Autism Research (OAR)

autism.com

OAR uses applied science to answer questions that parents, families, individuals with autism, teachers, and caregivers confront daily.

Free downloadable resource guides on numerous autism topics are available.

Profectum

profectum.org

Profectum aims to create a community of caring families, clients, multidisciplinary professionals, and leaders in the field, and is committed to promoting treatment approaches that address the unique needs of the individual at any stage of development from early childhood to adulthood, integrating the best treatment models across disciplines and intervention approaches.

Talk About Curing Autism (TACA)

tacanow.com

TACA is dedicated to educating, empowering, and supporting families affected by autism. For families who have just received the autism diagnosis, TACA aims to speed up the cycle time from the autism diagnosis to effective treatments. There are local chapters.

Other Related Nonprofit Organizations—Not Autism Specific

FRED

FREDconference.org

The FRED Conference is a national coalition of special needs professionals and families. Through collaborations, FRED advances adult living options for people with disabilities to live with meaning and purpose, which includes housing, employment, and recreation for current and future generations. FRED is an annual event organized by Golden Heart Ranch (goldenheartranch .org).

National Council on Independent Living (NCIL)

ncil.org

NCIL advocates for civil rights and independence for people with disabilities worldwide.

Safe Minds

safeminds.org

Safe Minds exists to eliminate mercury from all medical products, including vaccines, and substantially reduce other environmental exposures to mercury.

Government Agencies

Administration of Intellectual and Developmental Disabilities (AIDD)

acl.gov/Programs/AIDD

Social Security Administration (SSA)

ssa.gov

State Council on Developmental Disabilities

acl.gov/Programs/AIDD/Programs/DDC/index.aspx

State protection and advocacy agencies. Find the one in your state on the Administration of Developmental Disabilities website.

U.S. Department of Education

ed.gov

U.S. Department of Health and Human Services

hhs.gov

BOOKS

Although I am a big fan of the Internet, books are often recommended over websites because:

- The reader knows who the information is coming from and can validate the source.

- Published books (unless self-published) have gone through a certain amount of scrutiny and fact-checking by different individuals other than the writer before being published.
- The book will exist indefinitely.
- Books can be downloaded or listened to on audio.

There are many excellent books currently available. Some classics are listed below, as well as some newer ones.

Memoirs by Those on the Autism Spectrum

Asperger Syndrome in the Family: Redefining Normal and Pretending to Be Normal: Living with Asperger's Syndrome by Liane Holliday Willey

Atypical: Life with Asperger's in 20 1/3 Chapters by Jesse A. Saperstein
Beyond the Wall: Personal Experiences with Autism and Asperger's Syndrome by Stephen Shore

Elijah's Cup: A Family's Journey into the Community and Culture of High-Functioning Autism and Asperger's Syndrome by Valerie Paradiz

Episodes: My Life as I See It by Blaze Ginsberg

Freaks, Geeks and Asperger Syndrome by Luke Jackson

Learning the Hidden Curriculum: The Odyssey of One Autistic Adult by Judy Endow

Thinking in Pictures: And Other Reports from My Life with Autism by Temple Grandin

Your Life Is Not a Label by Jerry Newport

Books Written by or Contributed to by Those Who Communicate by Typing

Autism and the Myth of the Person Alone edited by Douglas Bilken

Carly's Voice: Breaking Through Autism by Arthur Fleischmann and Carly Fleischmann

A Full Life with Autism: From Learning to Forming Relationships to Achieving Independence by Chantal Sicile-Kira and Jeremy Sicile-

Kira

*How Can I Talk If My Lips Don't Move? Inside My Autistic Mind and
The Mind Tree* by Tito Rajarshi Mukhopadhyay

*I Am Intelligent: From Heartbreak to Healing—A Mother and
Daughter's Journey Through Healing* by Peyton Goddard and
Dianne Goddard with Carol Cujec, PhD

Ido in Autismland: Climbing Out of Autism's Silent Prison by Ido Kedar
The Purple Tree and Other Poems by Sydney Edmond

Reasonable People: A Memoir of Autism and Adoption by Ralph James
Savarese and DJ Savarese

Memoirs by Parents

All I Can Handle: I'm No Mother Teresa by Kim Stagliano

Let Me Hear Your Voice: A Family's Triumph Over Autism by Catherine
Maurice

Raising Blaze: A Mother and Son's Long, Strange Journey into Autism
by Debra Ginsberg

The Siege and Exiting Nirvana by Clara Claiborne Park

*Strange Son: Two Mothers, Two Sons, and the Quest to Unlock the
Hidden World of Autism* by Portia Iversen

Parent and Family Support

F.A.M.I.L.Y. Autism Guide: Your Financial Blueprint for Autism by
Greg Zibricky, CFP, ChFC, CLU, CASL

*Grandparent's Guide to Autism Spectrum Disorders: Making the Most
of the Time at Nana's House* by Nancy Mucklow

One on One by Marilyn Chassman

*Sharing Information About Your Child with Autism Spectrum Disorder:
What Do Respite and Alternated Caregivers Need to Know?* by
Beverly Vicker, MS

*Special Children, Challenged Parents: The Struggles and Rewards of
Raising a Child with a Disability* by Robert A. Naseef

*The Special Needs Planning Guide: How to Prepare for Every Stage in
Your Child's Life* by John Nadworny, CFP, and Cynthia Haddad,
CFP

Steps to Independence by Bruce Baker and Alan Brightman
A Stranger Among Us: Hiring In-Home Support for a Child with Autism Spectrum Disorders or Other Neurological Differences by Lisa Ackerson Lieberman
Understanding Death and Illness and What They Teach About Life by Catherine Faherty

For Siblings

Everybody Is Different: A Book for Young People Who Have Brothers or Sisters with Autism by Fiona Bleach
Siblings: The Autism Spectrum Through Our Eyes by Jane Johnson
Siblings of Children with Autism: A Guide for Families (Topics in Autism) by Sandra L. Harris and Beth A. Glasberg
Sibshops: Workshops for Siblings of Children with Special Needs by Donald J. Meyer and Patricia F. Vadasy

For Children on the Spectrum to Read

All Cats Have Asperger Syndrome by Kathy Hoopman
Asperger's Huh? A Child's Perspective by Rosina G. Schnurr and John Strachan
Different Like Me: My Book of Autism Heroes by Jennifer Elder and Marc Thomas
I Am Utterly Unique: Celebrating the Strengths of Children with Asperger Syndrome and High-Functioning Autism by Elaine Marie Larson and Vivian Strand
The Survival Guide for Kids with Autism Spectrum Disorders (And Their Parents) by Elizabeth Verdick and Elizabeth Reeve, MD
What It Is to Be Me! An Asperger Kid Book by Angela Wine

Bullying and Risk Reduction re Abuse

Perfect Targets: Asperger Syndrome and Bullying—Practical Solutions for Surviving the Social World by Rebekah Heinrichs
The Risk Reduction Workbook for Parents and Service Providers: Policies and Practices to Reduce the Risk of Abuse, Including

Sexual Violence, Against People with Intellectual and Developmental Disabilities by Nora J. Baladerian, PhD
The Risk Reduction Workbook for People with Intellectual or Developmental Disabilities: How to Reduce the Risk of Abuse Including Sexual Abuse by Nora J. Baladerian, PhD

Educational Advocacy

The Everyday Advocate: Standing Up for Your Child with Autism or Other Special Needs by Areva Martin, Esq.
The IEP from A to Z: How to Create Meaningful and Measurable Goals and Objectives by Diane Twachtman-Cullen and Jennifer Twachtman-Bassett
Wrightslaw: From Emotions to Advocacy: The Special Education Survival Guide by Peter W.D. Wright and Pamela Darr Wright

Explaining Autism to Young Peers, Family, and Friends

Can I Tell You About Asperger Syndrome?: A Guide for Friends and Family by Jude Welton
My Friend Has Autism by Amanda Doering Tourville and Kristin Sorra
My Friend with Autism by Beverly Bishop
Since We're Friends: An Autism Picture Book by Celeste Shally and David Harrington
What Is Autism?: Understanding Life with Autism or Asperger's by Chantal Sicile-Kira

Books Specific to Girls and Women on the Spectrum

Asperger's and Girls by Tony Attwood and Temple Grandin, et al.
Aspergirls: Empowering Females with Asperger Syndrome by Rudy Simone
Girls Growing Up on the Autism Spectrum: What Parents and Professionals Should Know About the Preteen and Teenage by Shana Nichols
Girls Under the Umbrella of Autism Spectrum Disorders: Practical Solutions for Addressing Everyday Challenges by Lori Ernsperger and Danielle Wendel

Parenting Girls on the Autism Spectrum: Overcoming the Challenges and Celebrating the Gifts by Eileen Riley-Hall
Safety Skills for Asperger Women: How to Save a Perfectly Good Female Life by Liane Holliday Willey

Puberty/Sexuality

Asperger's Syndrome and Sexuality: From Adolescence Through Adulthood by Isabelle Henault
Autism-Asperger's and Sexuality: Puberty and Beyond by Jerry and Mary Newport
The Boys' Guide to Growing Up: Choices and Changes During Puberty by Terri Couwenhoven, MS
The Girl's Guide to Growing Up: Choices and Changes in the Tween Years by Terri Couwenhoven, MS
Intimate Relationships and Sexual Health: A Curriculum for Teaching Adolescents/Adults with High-Functioning Autism Spectrum Disorders and Other Social Challenges by Catherine Davies and Melissa Dubie
Taking Care of Myself: A Hygiene, Puberty, and Personal Curriculum for Young People with Autism by Mary Wrobel

Health Related

Advice for Parents of Young Autistic Children (2012) by James B. Adams, PhD, et al.
The Autism Revolution: Whole Body Strategies for Making Life All It Can Be by Martha Herbert, MD, PhD, with Karen Weintraub
Autism Solutions: How to Create a Healthy and Meaningful Life for Your Child—Innovative Strategies for Developing the Right Treatment Plan by Ricki G. Robinson, MD, MPH
The Autistic Brain: Thinking Across the Spectrum by Temple Grandin and Richard Panek
Breaking the Vicious Cycle: Intestinal Health Through Diet by Elaine Gottschall
Digestive Wellness: Strengthen the Immune System and Prevent Disease Through Healthy Digestion by Elizabeth Lipski

Just Take a Bite: Easy, Effective Answers to Food Aversions and Eating Challenges by Lori Ernsperger and Tania Stegen-Hanson
Ketogenic Diets by Eric H. Kossoff, MD, et al.
The Kid-Friendly ADHD and Autism Cookbook by Pamela Compart, MD, et al.
Nourishing Meals: Healthy Gluten-Free Recipes for the Whole Family by Alissa Segersten and Tom Malterre
Nutritional Supplement Use for Autistic Spectrum Disorder by Jon B. Pangborn, PhD
Special Diets for Special Kids by Lisa Lewis, PhD
“Summary of Dietary, Nutritional, and Medical Treatments for Autism —Based on Over 150 Published Research Studies” by James B. Adams, PhD
Treating Autism: Parent Stories of Hope and Success edited by Stephen M. Edelson, PhD, and Bernard Rimland, PhD
Why Your Child Is Hyperactive by Dr. Ben Feingold

Practical or Educational

Activity Schedules for Children with Autism: Teaching Independent Behavior by Lynn E. McClannahan and Patricia J. Krantz
Adolescents on the Autism Spectrum: A Parent's Guide to the Cognitive, Social, Physical, and Transition Needs of Teenagers with Autism Spectrum Disorders by Chantal Sicile-Kira
An Early Start for Your Child with Autism Using Everyday Activities to Help Kids Connect, Communicate, and Learn by Sally J. Rogers, Geraldine Dawson, and Laurie A. Vismara
Apps for Autism: An Essential Guide to Over 200 Effective Apps for Improving Communication, Behavior, Social Skills, and More! by Lois Jean Brady
Asperger's from the Inside Out: A Supportive and Practical Guide for Anyone with Asperger's Syndrome by Michael John Carley
Asperger Syndrome and Difficult Moments: Practical Solutions for Tantrums, Rage, and Meltdowns by Brenda Smith Myles and Jack Southwick

Asperger Syndrome and the Elementary School Experience: Practical Solutions for Academic and Social Difficulties by Susan Thompson Moore, MEd

Autism: An Inside-Out Approach by Donna Williams

Autism Life Skills: From Communication and Safety to Self-Esteem and More—10 Essential Abilities Every Child Needs and Deserves to Learn by Chantal Sicile-Kira

The Complete Guide to Asperger's Syndrome by Tony Attwood

Don't We Already Do Inclusion?: 100 Ways to Improve Inclusive Schools by Kaula Kluth

The Hidden Curriculum: Practical Solutions for Understanding Unstated Rules in Social Situations by Brenda Smith Myles, Melissa L. Trautman, and Ronda L. Schelvan

How Your Child Is Smart: A Life-Changing Approach to Learning by Dawna Markova and Anne Powell

I Am Special: A Workbook to Help Children, Teens, and Adults with Autism Spectrum Disorders to Understand Their Diagnosis, Gain Confidence, and Thrive (2nd edition) by Peter Vermeulen

Outsmarting Explosive Behavior: A Visual System of Support and Intervention for Individuals with Autism Spectrum Disorders by Judy Endow

Practical Solutions for Stabilizing Students with Classic Autism to Be Ready to Learn: Getting to Go! by Judy Endow

Seven Keys to Unlock Autism: Making Miracles in the Classroom by Elaine Hall and Diane Isaacs

“Understanding Autism: A Guide for Secondary School Teachers” (video) by Organization for Autism Research

You're Going to Love this Kid!: A Professional Development Package for Teaching Students with Autism in the Inclusive Classroom by Paula Kluth

Sensory Processing Related

The Out-of-Sync Child and *The Out-of-Sync Child Has Fun* by Carol Stock Kranowitz

Raising a Sensory Smart Child by Lindsey Biel, OTR/L, and Nancy Peske
Reading by the Colors by Helen Irlen
The Sound of a Miracle: The Inspiring True Story of a Mother's Fight to Free Her Child from Autism by Annabel Stehli
Visual/Spatial Portals to Thinking, Feeling, and Movement by Serena Wieder, PhD, and Harry Wachs, OD
A Work in Progress: Behavior Management Strategies and a Curriculum for Intensive Behavioral Treatment of Autism by Ron Leaf, John McEachin, and Jaisom D. Harsh

Skills-Based Teaching Approaches

Engaging Autism: Using the Floortime Approach to Help Children Relate, Communicate, and Think by Stanley I. Greenspan and Serna Wieder
Feelings: Anxiety: Cognitive Behaviour Therapy to Manage Anxiety by Tony Attwood
Teaching Developmentally Disabled Children: The ME Book by O. Ivar Lovaas
Understanding Applied Behavior Analysis: An Introduction to ABA for Parents, Teachers, and Other Professionals by Albert J. Kearney
The Verbal Behavior Approach: How to Teach Children with Autism and Related Disorders by Mary Barbera, PhD, RN, BCBA-D

Communication/Relationships

An Asperger Dictionary of Everyday Expressions by Ian Stuart-Hamilton
The Autism Social Skills Picture Book by Jed E. Baker
Autistics' Guide to Dating: A Book by Autistics, for Autistics and Those Who Love Them or Who Are in Love with Them by Emilia Murry Ramey and Jody John Ramey
Comic Strip Conversations: Colorful Illustrated Interactions with Students with Autism and Related Disorders by Carol Gray
Crafting Connections: Contemporary Applied Behavior Analysis for Enriching the Social Lives of Persons with Autism Spectrum

Disorder by Mitchell Taubman, Ron Leaf, and John McEachin
Developing Communication for Autism Using Rapid Prompting Method: Guide for Effective Language by Soma Mukhopadhyay
Incorporating Social Goals in the Classroom: A Guide for Teachers and Parents of Children with High-Functioning Autism and Asperger Syndrome by Rebecca A. Moyes and Susan J. Moreno
The Incredible 5-Point Scale: Assisting Students in Understanding Social Interactions and Controlling Their Emotional Responses (2nd edition) by Kari Dunn Buron and Mitzi Curtis
The New Social Story Book : Over 150 Social Stories That Teach Everyday Social Skills to Children with Autism or Asperger's Syndrome and their Peers by Carol Gray
Social Skills Training for Children and Adolescents with Asperger Syndrome and Social-Communications Problems by Jed E. Baker
Strategies for Building Successful Relationships with People on the Autism Spectrum: Let's Relate! by Brian R. King
Thinking About YOU Thinking About ME by Michelle Garcia Winner
Understanding Autism Through Rapid Prompting Method by Soma Mukhopadhyay

Transitioning to Adult Life

Autism and the Transition to Adulthood: Success Beyond the Classroom by Paul Wehman, et al.
A Full Life with Autism: From Learning to Forming Relationships to Achieving Independence by Chantal Sicile-Kira and Jeremy Sicile-Kira
Life and Love: Positive Strategies for Autistic Adults by Zosia Zaks
Living Independently on the Autism Spectrum: What You Need to Know to Move into a Place of Your Own, Succeed at Work, Start a Relationship, Stay Safe, and Enjoy Life as an Adult on the Autism Spectrum by Lynne Soraya

Self-Advocacy

Ask and Tell: Self-Advocacy and Disclosure for People on the Autism Spectrum, edited by Stephen Shore

The Integrated Self-Advocacy ISA Curriculum: A Program for Emerging Self-Advocates with Autism Spectrum and Other Conditions by Valerie Paradiz, PhD

College

Aquamarine Blue 5: Personal Stories of College Students with Autism,
edited by Dawn Prince-Hughes

Catching the Wave from High School to College: A Guide to Transition,
edited by Carl Fielden, et al.

Realizing the College Dream with Autism or Asperger's Syndrome: A Parent's Guide to Student Success by Ann Palmer

Students with Asperger Syndrome: A Guide for College Personnel by
Lorraine E. Wolf, PhD, et al.

Succeeding in College with Asperger Syndrome: A Student Guide by
John Harpur, Maria Lawlor, and Michael Fitzgerald

Employment

Adult Autism and Employment: A Guide for Vocational Rehabilitation Professionals by Scott Standifer

Asperger's on the Job: Must-Have Advice for People with Asperger's or High-Functioning Autism and Their Employers, Educators, and Advocates by Rudy Simone

Asperger Syndrome Employment Workbook: An Employment Workbook for Adults with Asperger Syndrome by Roger Meyer

Business for Aspies: 42 Best Practices for Using Asperger Syndrome Traits at Work Successfully by Ashley Stanford

Developing Talents: Careers for Individuals with Asperger Syndrome and High-Functioning Autism by Temple Grandin and Kate Duffy

The Hidden Curriculum of Getting and Keeping a Job: Navigating the Social Landscape of Employment—A Guide for Individuals with Autism Spectrum and Other Social-Cognitive Challenges by Judy Endow, MSW, Malcolm Mayfield, and Brenda Smith Myles

For Partners of Those on the Spectrum

An Asperger Marriage by Gisela and Christopher Slater-Walker

The Other Half of Asperger Syndrome: A Guide to Living in an Intimate Relationship with a Partner Who Has Asperger Syndrome by Maxine C. Aston

22 Things a Woman Must Know If She Loves a Man with Asperger's Syndrome by Rudy Simone

22 Things a Woman with Asperger's Syndrome Wants Her Partner to Know by Rudy Simone

Other Media

Autism Media Channel

autismmediachannel.com

Autism One Radio

autismone.org/content/autismone-radio

Movies

Autism Is a World (written by Sue Rubin)

Autism the Musical

Temple Grandin

The United States of Autism

Wretches and Jabberers (about Larry Bissonette and Tracy Thresher)

Online Networks

Autism Brainstorm: autismbrainstorm.org

Interactive Autism Network: ianproject.org

Magazines/Newspapers

Age of Autism: ageofautism.com

Autism Asperger's Digest: autismdigest.com

The Autism File: autismmediachannel.com

Autism Spectrum Quarterly: asquarterly.com

Autism World Magazine: autismoz.com

Schafer Autism Report: www.sarnet.org

Other Online Resources

Adolescents on the Autism Spectrum

autismcollege.com

AGI Residential/Daily Living Support Course

houltoninstitute.com/programs/agi-residential-daily-living-support-course

The Autism Calendar

sarnet.org/events

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About the Author



Chantal Sicile-Kira is a parent, an advocate, a speaker, the award-winning author of five books, and the founder of autismcollege.com, which provides practical information and training online. Chantal's first experience with autism was teaching self-help and community living skills to severely

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Chantal has received numerous awards including the Autism Society of America Literary Work of the Year Award; San Diego Book Awards; Cure Autism Now Local Hero Award; and the 2012 Baron Inspiration Award. Chantal and her family have been featured in the MTV documentary *True Life* series, *Newsweek* (cover story), NPR, PBS, the *Chicago Tribune*, and Fox News. For more information, go to autismcollege.com.

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