





Interactions Across Abilities: Supporting Families of Children With Special Needs





PARENT HANDOUT

Although all children have similar needs, they differ in temperament, interests, abilities, and the surroundings they live in. It is these differences that make each child unique.

To better understand your child, it may help to ask yourself some questions. Is she shy or outgoing, easy-going or spirited, laid back or impulsive?

Your child needs to be accepted for who she is. Her personality and abilities differ from yours. For example, if you like sports, but your child does not, find out what her interests are and learn about them.

Recognize your child's uniqueness and accept her differences. This will help you recognize her strengths. Your attitude can go far in supporting your child and in affecting others' attitudes toward her.

All children have similar needs. These include physical safety (shelter, food, health care); emotional security (love, advocacy); relationships (friends, playful experiences); and self-esteem (acceptance, recognition).

Take a few moments to think about the ways you meet these universal needs for your unique child.

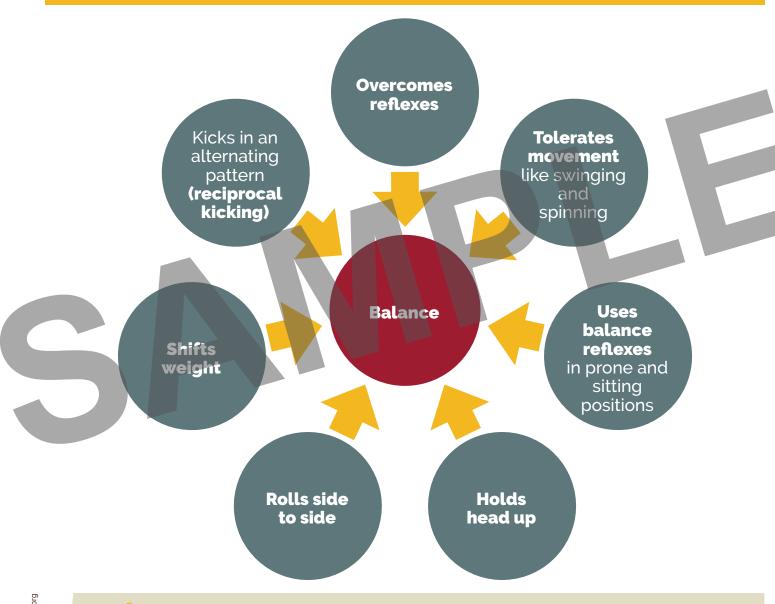
Universal needs



All children need love and understanding. Your child needs to be loved for who she is. Do not push her to be someone she cannot be. All children want to feel important. Help your child be successful each day. At the end of the day, reflect on whether there were more successes than failures. If not, make changes to help create balance. All children need direction. Your child needs to know what is acceptable and what is not. Limits and boundaries are important, as long as they are within reason. Like all of us, children need to be given enough opportunity to make choices. All children learn when they are ready. Consider when it's best to introduce new opportunities to your child. What is the best time of day? Children learn bestwhen they are happy and alert, not hungry or tired. All children learn in different ways. Let your child see, touch, handle, use, taste, and smell things. She is learning to explore and find success or make mistakes. She needs to know that mistakes are OK! She may need more time to learn at her own rate or adjustments to learn in her own way. Some children learn best with visual or picture directions. Others learn best when they are shown how to do something.

Balance: What Goes Into This Skill?







Which of these underlying skills does my child already do?

What are some other ways my child uses these same skills?

What have I noticed about the skills that are still developing?

Next steps

We can try ...

My child approaches this learning ...

Encouraging movement: Watch your child move. Are his movements voluntary (he controls them) or involuntary (beyond his control)?

Notice how he responds to movement. What does he do when his arms or legs move? What does he do when he begins to tip or fall?

Respond encouragingly to his reactions and support him as he learns to control his movement.

Dancing: Hold your child in your arms. Put on some music and dance, swing, and sway to the beat. How does he react? Does he enjoy the movement?

Swaving and dancing with your child helps improve his balance. Continue to move with your child as long as he is interested.

Doing tummy time: Place your child on his belly and put some interesting toys or objects in front of him. This is called tummy time, and it helps improve your child's balance and strengthens the muscles in his arms, shoulders, and neck.

While he's on his belly, does he lift his head to look around? Does he stretch his arms to reach? Is he interested in the sounds? Does he look toward them?

Talk, sing, or make noise to attract his attention and encourage movement during tummy time.

Rolling gently: Lay your child down in the center of a blanket or towel. Grab both sides of the blanket and gently roll him from side to side.

Observe his reaction. Does he enjoy it? How can you tell?

Kicking: Make a kicking toy for your child. Hang several interesting toys or objects from a piece of yarn or string.

Lay your child on the floor or in his crib. Hold or tie the string above his legs and encourage him to kick and move the toys.

Circles of Support



PARENT HANDOUT

Decide who is in the center, you or your child. Write in people who support or influence you or your child. Use dotted lines and arrows to show how energy and information flow between parts of the circle.







PROFESSIONAL RESOURCE

When one family member has a serious illness, medical condition, or disability, the entire family system is affected, including siblings.

Sibling relationships in a family with a child who has a special need are just like any other sibling relationships. They are impacted by individual personalities, temperaments, age differences, and preferences. The bond between siblings is one of the most intense interpersonal relationships most people experience throughout their lives (e.g., Dunn, 1983; 1993; University of Wisconsin Pediatric Pulmonary Center, n.d.).

Because family roles are reciprocal, a change in one can alter the others. This is true no matter the unique characteristics of those involved. For example, all toddlers may have similar responses to a new baby in the family – feelings of abandonment, resentment, loneliness, being left out, fears that he is bad, or upset at changes to his normal schedule (Parents as Teachers National Center, 2015). These emotions typically subside over time as the child adjusts to his new sibling, whether she has a disability or not. Younger children may have an easier adjustment, because they have never known a different dynamic.

Parents may worry about the impact their child's disability has on their typically developing children. A great deal of variability exists; more than half of siblings are at risk for negative outcomes, while about a third report positive outcomes (UWPPC, n.d.).

Some of the factors that impact a sibling's response include whether the diagnosis is new or existing, birth order, gender, the parents' mental health, the number and immediacy of adjustments the family must make, and the sibling's ability to understand the diagnosis (e.g., Knecht, Hellmers, & Metzing, 2015; Dauz Williams et al., 2010; UWPPC, n.d.). Generally, the quality of interactions between siblings will be influenced by their individual relationship.

Siblings experience many of same stresses parents have about a child's special needs. They too are directly impacted by changes to routines, hospital stays, or lack of resources - physical or emotional - due to the condition or disability. They may have many of the same emotions as their parents, such as shock, anxiety, and fear. Additionally, siblings may also have conflicting emotions, such as jealousy about the attention the child with special needs receives, combined with guilt over those feelings. Thus, they may be confused by these conflicting emotions (Strohm, 2006).

Parent handouts

Growing Up With a Sibling With Special Needs

Coping With Diagnosis and Adaptation

Circles of Support

Reflecting on Myself and My Family

Organization and Time Management

Discipline Basics

Ideas for Encouraging Positive Behavior

Understanding Challenging Behaviors

Helping Your Child With Grief and Loss

Parenting Multiples With Special Needs

Tuning In to Your Child



While research on siblings of children with disabilities is generally lacking, and what has been done is often inconclusive, it is generally known that growing up with a sibling who has a special need has both positive and negative effects (Fisman, Wolf, Ellison, & Freeman, 2000, as cited in Hallberg, 2013). Further, negative effects tend to be short-term, while the positive effects become evident over the long term, in adolescence or adulthood (Rossiter & Sharpe, 2001, as cited in Hallberg).

It is a relatively new concept for community supports for children with special needs to look at the whole family instead of the individual child. Professionals and therapists who work with children with disabilities are increasingly called on to consider all family members including siblings – as part of their care. Stressed parents and siblings impact the health and well-being of the child with disabilities and vice versa. Family support professionals are encouraged to recommend counseling services and sibling groups to help families with adjustment.

Challenges to family systems

Some children have difficulty coping with their sibling's needs. It is common for them to have many conflicting emotions. They may feel (Boyse, 2009):

- Worried about their sibling.
- Scared that she will die from her condition.
- Angry that they aren't receiving attention.
- Resentful about being expected to care for or stick up for her.
- Resentful about the things they miss out on due to their sibling.
- Embarrassed of their sibling and how she is different.
- Pressure to do all the things their sibling can't.

Guilty for being a typically developing child.

Some typical responses to having a sibling with special needs include feelings of isolation. anger, resentment, embarrassment, fear, guilt, and grief (Strohm, 2006). Siblings are less likely to share their feelings with parents because they don't want to burden them. It is vitally important that parents keep lines of communication open and allow them to vent their feelings in constructive ways.

Siblings may feel like the family's focus is never on them and that they no longer have their parents' attention. Parents may have to miss their typically developing child's game or school performance because of doctors' appointments or the need to stay with their child if she is not able to come along.

Some parents attempt to "shield" their children by not discussing their sibling's condition with them. However, this is not found to be helpful (Heller et al., 2008; Strohm, 2006). Instead, parents should openly communicate with their children about their sibling's condition in developmentally appropriate language.

Siblings who are not informed may have increased anxiety and worry or may believe that they caused their sibling's condition (Heller et al., 2008; Strohm, 2006). "Some of the key ways of supporting siblings include giving them information, listening to them, and helping them express their feelings. Parents can give children 'permission' to express their feelings, and set an example by showing it is OK to share difficult feelings" (Strohm, 2006, p. 7).

Just as in families who are not affected by a diagnosis or disability, parents may not always be aware of how their children feel. For example, many children feel protective of their sibling with a disability. They may naturally defend her against bullying or abuse from other children. At the same time, they may become targets of teasing or bullying because they have a sibling with special needs.

Most siblings adapt well to their family dynamics, but a minority have difficulty adjusting (Cuskelly & Gunn, 2006; Fisman et al., 2000; Giallo, Gavida-Payne, Minett, & Kapoor, 2012; Levy-Wasser & Katz, 2004; Pitten Cate & Loots, 2000; Rossiter & Sharpe, 2001, as cited in Hallberg, 2013). Some children may develop problems in school or have decreased self-esteem. Others may begin acting out, have difficulty interacting with peers, seek attention by trying to please others, or show signs of anxiety or depression (Strohm, 2006).

In some cases, children will need professional help to cope with their intense emotions. Experts suggest that families refer to a health care professional if any of these warning signs are observed (Boyse, 2009):

- Changes in sleeping or eating.
- Frequent complaints of headaches or stomachaches.
- Hopelessness.
- Perfectionism.
- Poor concentration.
- Poor self-esteem.
- Talk of hurting himself.
- Difficulty separating from parents.
- Lack of interest in activities.
- Frequent crying or worrying.
- Withdrawal.

Parental influences on family culture

Parents naturally worry about their role with all of their children. They wonder, "Am I doing enough?" or "Am I providing everything they need?" When one child in a family needs a lot of extra support in terms of medical care, therapy, or assistance with daily tasks like dressing and feeding, parents may attempt to ignore the reality that there is only so much one person can do. In these situations, it is impossible to offer all siblings "equal" attention.

Parents set the tone for how all children in the home respond to a child's special needs. It's important that they have realistic expectations first of all for themselves and also for their children. Siblings often feel their own internal pressure to step up and help. When appropriate, parents can to find ways to include all family members in caring for their child. For example, if a child's therapy includes block play, asking her brother to participate will help him feel included as well as teach him how to interact with his sibling in a positive way.

Learning when to draw the line and not allow siblings to take on too many caregiving responsibilities is also important – especially if the responsibilities are beyond their developmental ability. Siblings of a child with a disability frequently take on caregiving tasks of their own volition. Parents may need to find healthy ways to step in and assure siblings that, while they appreciate their help, they've "got this "

"It is easy to see the issues that cause stress for siblings: confusion and embarrassment about their sibling's behavior, disappointment about not having a sibling to play with, being the target of aggressive behavior, resentment over not having more attention and time from mom and dad, worry about the future and feeling responsible for future caregiving, feeling a need to not ask for much in order not to additionally stress parents who they often worry about" (Harris, 2012).



Children learn how to cope from their parents' example. "The meaning that parents assign to the special needs of a child will influence how a sibling views what is happening within his or her family" (Strohm, 2006, p. 5). Whether parents perceive having a child with a special need to be a punishment, a blessing, or a challenge influences how their other children - and extended family members - react.

Learning to cope with the added stress that often comes with caring for a child with a disability includes learning how to work with a spouse or partner. The parent handouts Discipline Basics, Ideas for Encouraging Positive Behavior, and Understanding Challenging Behaviors are designed to support sensitive conversations about topics that arise in every family, regardless of its dynamics.

Having a strong support network in place allows parents to carve out time for quality interactions with each of their children. One-onone time not only enables parents to check in, it lets siblings know they are important and builds their self-esteem. Family, friends, or neighbors may provide care so parents can help their typically developing child with homework, grab dinner, or attend a school event.

One of the dangers when parents are under extreme emotional stress is that they may lean on their other children for support. This is understandable, as many parents feel no one can relate better to the family situation than family members themselves. Parents often feel that even extended family, no matter how supportive they may be, just do not understand what they are going through. But young children are not developmentally able to be an emotional support to their parents. This can lead to issues like anxiety or feeling that they cannot speak about their own feelings.

Parents who have a child with special needs often feel overwhelmed and judged by those around them (Hebert, 2014). This may make

them reluctant to share their concerns with others, and yet it is crucial for them to do so.

The silver lining

Overall, siblings regard their experiences positively. "Siblings report affection and positive regard for their brothers and sisters with disabilities, attribute high levels of empathy and altruism as deriving from their relationship with siblings, and on the whole, appear to be as well-adjusted and successful as individuals who have typically developing brothers and sisters" (Heller, Kaiser, Meyer, Fish, Kramer, & Dufresne, 2008, p. 7).

Children who grow up in a family with a child who has a disability or special health need are more likely to develop a number of positive characteristics. These include (Boyse, 2009; Eames, 2013):

- Patience.
- Dependability and loyalty.
- Kindness and supportiveness.
- Compassion and helpfulness.
- Empathy for others.
- Insight on coping with challenges.
- Greater acceptance and understanding of differences.
- Confidence, especially in response to adversity.

How siblings adjust to news of a diagnosis or disability is highly influenced by how well their parents have adjusted. The way in which parents express their own feelings and convey information can be a big factor in how siblings adjust (Strohm, 2006). "How parents handle the situation – whether it is a temper tantrum in public, other annoying behaviors or daily behavioral interventions – is extremely important" (Macks & Moskowitz, as quoted in Mishori, 2012). The mental health and coping

skills of parents are often a predictor of how siblings will handle the same situations.

Siblings who grow up with a strong support network that includes positive interactions with extended family or friends, peers, school, community, and social support generally have a stronger sense that they are valued (Strohm, 2006). They also tend to have a better outlook about their family life. Likewise, siblings who are encouraged to talk about their feelings and express their emotions in positive ways fare better overall.

Your role

You may interact closely with parents and siblings of the children you serve. This puts you in a unique position to guide families in ways that support siblings as well as the child with special needs.

Help parents notice their attitudes about their child's disability and how they affect the outlooks of all their family members. Psychologist Sandra Harris at Rutgers University, an expert in autism and developmental disorders, suggests that parents (Vigo, 2012):

- Explain the condition to their children using developmentally appropriate language.
- Explain how the condition may affect the child's behavior.



- Sibling Support Project www.siblingsupport.org
- Sibshops (sponsored by local organizations to offer a place for siblings to connect) www.siblingsupport.org/sibshops
- Help the children form relationships and engage in play together.
- Make a point to have special one-on-one time with their typically developing child(ren).
- Find support for siblings online or in peer support groups.

When siblings come along to appointments, visits, or therapy sessions, interact with them. Say hello and acknowledge their presence to help them feel included.

Remember that many siblings are brought along out of necessity. If you notice any attention-seeking behaviors, think of ways you can include them in a session. Anything that increases the siblings' positive interactions will benefit the whole family.



"[T]he sibling relationship, forget disabilities for a moment, it's sort of the working definition of ambivalence. You know, siblings, you know, their relationship is characterized by hugging and slugging in the same 15-minute period. And when you add the dimension of the disability to it, it's like you've sprinkled monosodium

glutamate on the relationship.

The highs are higher, and the lows are lower. On one hand you'll have a sibling who will ascribe the personal problems that they have in their life because they grew up with a brother or sister with a disability, but you're also more likely to have people who say, you know, my brother taught me the meaning of unconditional love." Sibling of a child with special needs (National Public Radio, 2012)



Likewise, notice any behaviors or warning signs that the sibling is not adjusting well to the diagnosis. Encourage parents to seek ways for their child to express his emotions so they can better understand their source. Parents can encourage their child to share his feelings with a grandparent, aunt, uncle, close friend, or someone else in their Circles of Support.

If possible, connect families to parent support groups and sibling support groups in your area. Peer support helps families feel less isolated and connect all members with others who understand their unique situation. Sometimes online resources may be a good fit, especially for older siblings. One example is the blog series Autism and the Sibling's Perspective. Some organizations also offer classes for siblings of children with special needs.

Simple conversations about how everyone is doing, what they like to do in their spare time, and how siblings get along can open an opportunity to offer resources for all family members.

For example, with all the time and energy going into caregiving and therapy, families may need encouragement to engage in positive sibling interactions and play.

You may be able to help identify activities that everyone can participate in – including the child who is receiving services. Of those things. parents can reflect on which ones the sibling(s) enjoy. And of those, which ones do the parents enjoy most? This process will help them find a few things that everyone will enjoy together.

While one-on-one time with siblings is important, it can sometimes feel hard to carve out. Family play allows everyone to enjoy time together. If adaptations are needed so that everyone can participate, refer to the professional resource *The Parents' Role in Play* Adaptations.



Respite care

Caretakers of children with special needs often face extreme stress resulting from balancing the needs of their child with their own needs or those of other family members.

Respite care is designed to help families find temporary caregivers for their children with special needs. It can range from a few hours on a one-time basis to overnights or extended sessions. It can be used regularly or once in a while. It might be provided by family members, friends, care providers, or professionals.

The Lifespan Respite Care Program is a federally funded grant program that assists states with improving access to respite care and may provide financial assistance.

The ARCH National Respite Network Locator provides a directory of state and private programs, as well as a consumer guide to choosing a respite care provider.

Local organizations that may also offer respite programs include United Cerebral Palsy, Easter Seals, and local chapters of The Arc.



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PROFESSIONAL RESOURCE

Many children go through a "picky eating" phase – a commonly accepted part of childhood where they eat a limited number of foods, but those foods span all the food groups. However, some children have "serious food aversions and/or medical impairments that prevent them from eating a balanced diet" (Ernsperger & Stegen-Hanson, 2004, p. 3).

Most children are motivated to eat because of hunger and taste. However, some children don't have this inherent motivation. Unlike picky eaters, restrictive eaters are children on the extreme end of the eating spectrum who will not eat a food they avoid simply because they're hungry. Typically, this child avoids foods with certain colors or textures, has no appetite, eats very small portions, or becomes afraid to eat after an experience of choking or vomiting (Herrin, 2013).

In addition, children with a food intake disorder may avoid entire food groups and are "at greater risk for compromised physical and cognitive development" and may "develop slower, experience behavioral problems and even fail to thrive" (Kennedy Krieger Institute, n.d., para. 2). These children require professional intervention to expand their diets and get the nutrition they need to grow.

The Diagnostic and Statistical Manual of Mental Disorders (5th ed.) (DSM-V) defines avoidant or restrictive food intake disorder (ARFID) as a lack of interest in eating or food, avoidance of food based on sensory characteristics, or concern that a child is not getting appropriate nutrition (American Psychiatric Association, 2013). Restrictive eaters are on the extreme end of the eating continuum. These food aversions result in significant weight loss, nutritional deficiency. or the need for supplemental feeding. (Some young children may not lose weight, but they may not gain weight or grow as expected.)

Parent handouts

What to Do When Your Child Has Food **Aversions**

Overcoming Challenging Eating **Behaviors**

Understanding the Progression of Feeding Skills

Helping Your Child Accept New Foods

Ways to Expand Your Child's List of 'Preferred' Foods

The Six-Step Problem-Solving Method

Understanding Your Child's Temperament

Understanding Challenging Behaviors

Discipline Basics

Ideas for Encouraging Positive Behavior

My Next Visit

Activity pages

Grasping and Manipulating: What Goes Into This Skill?

Grasping and Manipulating: Where Does This Skill Lead?

Tactile - Sensory

Reality Check



It commonly develops in infancy or early childhood.

For older children, food issues may interfere with social development. They may avoid situations that involve food or may not get their schoolwork done because of the time it takes to eat (Center for Eating Disorders, n.d.).

There are a lot of reasons why children may have learned to eat less or to limit their intake of certain foods. Some have medical problems that make eating, or the mechanics of eating, difficult. Eating may be painful for these children, who have learned to eat less or to limit their intake of certain foods.

For other children, food is scary and strange and being asked to eat is stressful. Known as neophobia, fear of new foods is common at age 2 or 3 – or later in children with developmental delays - and most children outgrow it (Ernsperger & Stegen-Hanson, 2004). Other children may be extremely sensitive to the color, appearance, smell, taste, temperature, or texture of foods.

Sometimes children get used to certain foods or mealtime routines and have difficulty managing a change. When a child has had an unpleasant experience eating in the past, she is more likely to have trouble trying new foods in the future.

Feeding disorders in children take many forms. Characteristics of a restrictive eater include children who (Ernsperger & Stegen-Hanson, 2004; Kennedy Krieger Institute, n.d.):

- Eat fewer than 15 foods.
- Refuse to eat certain food groups.
- May refuse to eat any solids or liquids.
- May have oral motor and sensory problems.
- May have trouble accepting and swallowing different food textures.
- Have anxiety or tantrums when introduced to new foods.

- May choke, gag, or vomit when presented with new foods.
- May experience "food jags" (requiring one food, prepared in the same way, at all meals for a period of time).
- May depend on gastrostomy (g-tube) or naso-gastric (ng-tube) feeding.

There is a high correlation between children with disabilities and feeding problems (Ernsperger & Stegen-Hanson, 2004). Approximately two-thirds of children with ASD have severe food aversions (Marrs, n.d.). Feeding disorders are also common in children with cerebral palsy, intellectual disability, muscular dystrophy, oral motor problems, sensory processing issues, anxiety disorders, and attention-deficit hyperactivity disorder (e.g., APA, 2013).

Characteristics commonly associated with these disabilities can contribute to feeding issues (Ernsperger & Stegen-Hanson, 2004). For example:

- Communication delays and oral-motor issues are closely associated with delayed eating skills, which can lead to restrictive eating.
- Strict behavior patterns often seen in children with ASD or intellectual disability can manifest as rigid food routines.
- Parents focused on caring for their child's medical needs may not keep up with the natural feeding progression, such as introducing new textures or foods.

No child will like all foods, but all children can learn to like new foods. Food acceptance can be a very slow process. Children with a history of aversive eating are not likely to "outgrow" the behavior. Further, "the longer a child is allowed to eat the same foods, the less likely she is to increase to a variety of foods in the future" (Ernsperger & Stegen-Hanson, 2004, p. 8). The child needs help and support learning how to eat. Eating is an interactive process with many steps.



Stages of sensory acceptance of new foods

	Stage 1: Acceptance			
	Child tolerates	 Learning about new foods and the food groups. Being in the same room with a new food. Having a new food on the table. Allowing a new food on his plate. 		
	Child interacts with food by	 Helping prepare it. Using utensils or a container to stir/pour it for others. Using utensils or a container to serve it for self on his own plate. 		
	Stage 2: Touch			
	Child is willing to touch a new food with	 Fingertips. Whole hand. Arm or shoulder. Chest or neck. Top of head. Chin or cheek. Nose, underneath nose. Lips. 		
	Stage 3: Smell			
•	Child smells	 Food odor in the room. Food odor at the table. Food odor from his plate. Food by leaning toward it or picking it up. 		
	Stage 4: Taste			
	Child tastes by	 Licking a new food that is close in flavor and texture to a preferred food. Biting off a piece and spitting it out immediately. Biting off a piece, holding it in his mouth for "x" seconds, and spitting it out. Biting, chewing "x" times, and spitting out the food. Chewing the food, swallowing some, and spitting some out. Chewing and swallowing a whole bite with a drink. Independently chewing and swallowing a whole bite. 		

Trying a variety of flavors (salty, sweet, sour, and bitter).



Stage 5: Eat

Child ...

- Eats a variety of foods from each food group.
- Is not anxious when presented with new foods.
- Is able to eat in a variety of settings.

Adapted from "Chapter 9: Stages of Sensory Development for Eating" in Just Take a Bite; Easy, Effective Answers to Food Aversions and Eating Challenges by L. Ernsperger & T. Stegen-Hanson, 2004, and "Steps to Eating" by K. A. Toomey, 2010.

There is not a one-size-fits-all approach to treating feeding disorders. Further, there is disagreement among professionals about the nature of the disorder. Nutritionist and feeding specialist Ellyn Satter finds flaws in how the DSM-V definition of ARFID is perceived (Satter, 2015). She attributes the majority of feeding problems in children to the parentchild relationship (e.g., parents put too much pressure on their child to eat) and resulting power struggles.

The occupational therapy perspective takes issue with the cultural implications of Satter's "Division of Responsibility," namely that parents choose what, when, and where to eat and the child is responsible for deciding how much and whether to eat from what is provided. Expectations such as this around food and mealtimes can exacerbate the behavior of restrictive eaters and often keep concerned parents from seeking help because they may consider themselves to blame.

The child's health care provider will coordinate a feeding evaluation that takes into consideration the parent-child feeding relationship, the child's personality, and her overall health. Depending on the child and any underlying problems, feeding therapy might be provided by an occupational therapist (OT), speech-language pathologist (SLP), registered dietician (RD), or a gastrointestinal specialist. The best approach to restrictive eating is prevention or early intervention.



- **Academy for Eating Disorders** www.aedweb.org
- National Eating Disorders Association (NEDA)
 - www.nationaleatingdisorders.org
- Marcus Autism Center Pediatric **Feeding Disorders Program** www.marcus.org
- Eating Disorder HOPE www.eatingdisorderhope.com
- Avoidant/Restrictive Food Intake Disorder

http://eatingdisordersreview.com

Challenges parents face

It's easy to understand why parents become anxious and frustrated when they have a child who refuses foods. Because food is a source of pleasure for most adults, parents may have a hard time relating to foods being unpleasant for their child.

A child's refusal to eat what is served can disrupt family function and add stress to mealtimes (APA, 2013). This can cause parents to prepare different and sometimes separate



meals for their child. Aversive eating can be very challenging for all who work with the child. Family culture around food and discipline also plays a big role.

Stress

Having a child who won't eat is a big stressor for any family. Well-meaning parents that coax, bribe, or threaten their children to eat may exacerbate the problem they are trying to prevent.

Expectations from parents as well as extended family and caregivers can add stress to an already stressful situation. Ultimatums such as "You can't get up from the table until your plate is clean!" can turn mealtimes into a battle of wills that parents of restrictive eaters will not win.

Rules around manners, such as not touching your food or eating with your mouth full, may inhibit an already tentative eater (Ernsperger & Stegen-Hanson, 2004). Rewards and bribes around eating or coercing a child with severe food aversions to clear her plate are likewise ineffective. Some kids feel frightened or uncomfortable during mealtimes.

Parents may feel to blame for their child's feeding problems, especially if family culture emphasizes that parents are in control of what their children eat. Expectations such as "Don't waste it!" or "There are children who have nothing to eat!" are rarely helpful in these situations.

Parents will need to work closely with their child's therapist to address their own beliefs around eating and adapt how they present food to their child. They will also need to educate extended family and caregivers about how to

support their child in expanding her diet and learning not to fear foods.

Some families may need to adjust their routines, stop eating out with their child, or avoid eating in environments that distract or add stress.

Feeding therapy may or may not be covered by insurance, depending on the diagnosis, and the therapy can be costly.

Communication

Children communicate with the person feeding them through a combination of vocalization, verbalization, and nonverbal communication. For a child who has a difficult time with eating, developing a rapport with her parents and caregivers is critical.

Ideally the child will communicate wanting more, wanting something different, wanting the pace changed, being finished, or needing a change of position or environment. And, ideally, parents and caregivers will be in tune with the messages their child is sending.

Some children never ask for food but will eat when food is presented. Others seem to ask for food all the time. In both cases, children need help regulating and learning to recognize what hunger and satiety feel like. Labeling these sensations for them will help them learn to act accordingly.

Support

Parents may feel frustrated and exhausted by extensive efforts to motivate their child to eat. Or they may be worried about their child's failing health or nutritional status. Parents and caregivers - and their child - need ongoing support to help the child progress slowly



"Children with severe food aversions will likely struggle with these aversions through adulthood" (Marrs, n.d.).



through acceptance toward a wider variety of new foods. The parent handout Circles of Support can help families identify the people who help - and hinder - their efforts to address their child's feeding problems.

Throughout treatment, the child will need help feeling in control. A child with eating difficulties may feel out of control a lot of the time. One thing she can control is what goes into her mouth. Getting her input in the feeding intervention will greatly increase success. Parents should provide choices whenever possible. For example, ask her which new food she would like to try. Or offer opportunities to explore foods that don't involve eating, such as through science experiments or art.

Understanding and following through with therapy

Depending on the child's behavior and type of feeding problem, different therapies will be used. Regardless of the treatment, parents need to take a long-term approach and understand that progress will likely be slow. They will need to stay in contact with their child's health care or therapy provider about any concerns or progress along the way.

Therapy may include weaning the child off of high-calorie food supplements or g-tube feedings, adjusting meal times and schedules, and reducing distractions. For children with oral motor or physical delays, parents may need to support their child's efforts to self-feed by allowing more time, offering easy-to-use utensils and cups, and allowing her to fail so she can learn from her mistakes.

Whatever strategies are advised by their child's therapist, parents will need to reinforce and follow through with them at home. If parents are unclear or get frustrated with the approach, they will need to circle back to their child's therapy provider and adjust the strategy until they can support it at home.

Your role

When a child develops a feeding disorder, an all-hands-on-deck approach is essential. Addressing restrictive eating behaviors requires a big commitment on the part of all that care for the child, including extended family. Evaluate parents' willingness to change their own behavior. Remind them that the long-term goal is to get their child to make progress - no matter how small.

Progress can be hard for parents to see when they are working through day-to-day feeing issues. Point out to them positive parenting behaviors they're using to address their child's feeding problems. Help them notice small improvements that they may not recognize. And reassure them that it is a long, slow process that will eventually result in progress.

Goals and perseverance

Talk with parents about their goals for their child. Help them pick small goals that will help bigger goals be achieved. For example, the first goal may need to be introducing their child to new textures. To accomplish this, it may be necessary to serve preferred foods, incrementally adding new textures. Once the child is eating new textures of familiar foods, unfamiliar foods can begin to be introduced. The parent handout *The Six-Step Problem-*Solving Method and the activity page Reality Check: Thinking About Expectations may help with this.

Because parents and caregivers control food, diet, and meal planning, it will be especially important for them to be on board with their child's therapy. Ensure they understand the strategies offered by the feeding specialist. Talk to parents about how feeding is going at



home and discuss what is and isn't working well. When things aren't working, help parents identify the most stressful triggers (mealtime routines, expectations from other family members, time).

Discipline

Ask the family to talk through common feeding scenarios with you. Listen for cues that parents are inadvertently punishing desirable behavior or rewarding undesirable behavior. Sometimes, when a child is learning to like new foods, the goal gets moved. The parents may get so excited when a small bite of a new food is accepted that they ask for "just one more." This actually punishes the child for performing as requested.

Likewise, parents may turn away and "take a break" after their child accepts a bite of food, thus ignoring their child's positive behavior. It can be tough for families to see where breakdowns in communication may occur while feeding their child.

Families will need to examine if and how they have disciplined their child around food and eating in the past. Is preferred food offered as a bribe? Is an incentive withheld if the child doesn't try a new food?

If they don't already have clear guidance on this from their child's therapist, encourage them to ask for direction. Brainstorm with them around what has and hasn't worked and what positive discipline strategies they might try from the parent handouts **Understanding Challenging** Behaviors, Discipline Basics, and Ideas for Encouraging Positive Behavior.

Encourage them to write down observations, feedback, and questions for the next therapy session, perhaps using the parent handout My Next Visit. Treating feeding problems is a long, ongoing process, and strategies may need to be adjusted along the way.



Reflective questions for parents

- Why are you concerned about your child's eating or growth?
- Have you discussed your concerns with her medical team?
- What changes would improve your family's life?
- What barriers does your child face that may be preventing her from progressing to a more balanced diet?
- What foods seem to cause the most problems? Are there themes related to texture, temperature, color, taste, volume, or timing?
- How often, when, where, and with whom does the behavior occur most frequently?
- What motivates your child?



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Snapshot of Early Intervention Possibilities



PARENT HANDOUT

Maybe you have a concern about your child's development. Or maybe a screening indicated a need for follow-up about your child's development, health, hearing, or vision. What happens next?

There are usually standard processes in place. First, you will be referred for evaluation to one of these three possibilities:

- Your child's primary health care provider.
- Early Intervention (EI), if it's before your child's third birthday. This falls under Part C of the Individuals with Disabilities Education Act (IDEA). The program is administered in each state by a lead agency appointed by the governor.

The agency/person to talk to is:				
The number is:				
The e-mail address is:				
Your family will be assigned a service coordinator who will explain the process and become your main contact. A screening or evaluation will take place.				



■ Early Childhood Special Education (ECSE), if it's between your child's third birthday and when he enters Kindergarten. This falls under Part B of IDEA. The program is administered by your local school district.

The agency/person to talk to is:
The number is:
The e-mail address is:

PARENT HANDOUT



If your child is eligible for services under Part C:

- You will meet with a team of professionals to figure out the level of service.
- Together, you will write an Individualized Family Service Plan (IFSP).
- Your child's services will begin in the least restrictive environment. This can be at your home, child care center, preschool, or other place your child is used to.
- Your child's development will be monitored. He will also be rescreened in areas not being addressed through EI.
- Before his third birthday, he will start the transition to Part B.

If your child is eligible for services under Part B:

- You will meet with a team of professionals to figure out the level of service.
- Together, you will write an Individualized Education Plan (IEP).
- Your child's services will begin.
- Your child's development will be monitored. He will also be rescreened in areas not being addressed through ECSE.

If your child will not receive services under Part C or Part B, you could:

- Be referred to other community agencies.
- Receive suggestions for activities and/or resources to help with the areas of concern.
- Set up a plan for monitoring your child's development, health, vision, or hearing.
- Have your child rescreened.

Explore Emotions With Books



PARENT HANDOUT

Books can help your child recognize her feelings and learn to find acceptable outlets for them. Listening to stories about others gives her safe emotional distance from her own experiences. It also gives her ideas for ways to resolve and cope with them.

Strong emotions can be frightening to children who have not had the experience and maturity they need to deal with them in a healthy way. Talking about them with adults can help. Books are a way to encourage this communication.

Relieve stress with books

Books can help your child overcome feelings like anxiety and fear. You can read books with your child to work through situations like:

- Separation from loved ones.
- Changes in daily routines.
- New child care provider, center, teacher, or school.
- Conflict or tension in the home.
- Feelings of being unloved.
- Fears (real or imagined) such as strangers, abandonment, darkness, closed doors, isolation, and monsters.
- Family changes (a new baby, moving, absence of a parent or sibling, divorce, remarriage, death, or a parent's new job).
- Need for additional independence, more activity, or a less constraining environment.

Resiliency and coping skills

Resiliency is the ability to rise above the pressures of stressful situations. A child who has the emotional understanding and strength to interpret and respond to the events in her life is more likely to have resiliency.

Books and stories can provide examples of problem-solving skills and acceptable social behaviors. They can give children a sense of hope for the future. These are all factors that lead to resiliency.

When selecting books that promote resiliency, look for the main character to:

- Demonstrate high self-esteem.
- Resolve problems in healthy ways.
- Have the confidence to solve problems on her own but also accept help when she needs it.
- Use creative resourcefulness and peaceful conflict resolution.
- Not harm or detract from anyone else's abilities or self-esteem.
- Model a relationship with a significant adult figure for guidance and emotional support.



PARENT HANDOUT

Social stories are used to help young children grasp some complex concepts by using print, related pictures, and easy to understand language. Social stories can be adapted to your child's developmental stage.

Social stories can address many areas in your child's daily life, especially if she is unable to read. They can help her learn new ideas, practice routines, and solve problems.

Social stories can be used for:

- Giving alternatives to problem behaviors.
- Showing steps of personal care.
- Helping with social situations.
- Defining emotions.
- Addressing uncomfortable topics.

Social stories and interaction

You can address virtually any situation through your social stories. Create them together with your child for familiar routines and situations. Be creative by including pictures of your child doing different tasks.

Think about a new challenge your child might face. Discuss with your family how to make a social story about it. Role playing ahead of time can help your child practice how to respond if it is an unpredictable situation.

Once you have several social stories, make a book out of your child's collection. Use a binder to arrange the individual stories and refer to them when your child needs to prepare for a situation.

More examples of how to be creative with social stories are:

■ Create cards that give your child some ideas of conversation starters, like when she meets new friends.



- Post code words and phrases in different places around your home to prompt different behaviors. For example: STOP. BREATHE. SMILE.
- Make simple videos that show different scenarios. Show them to your child when she needs a visual reminder.

There are many media applications and websites that show more good ideas for social stories.





- Child-safe items from the kitchen (wooden spoons, rubber spatulas, teaspoons, measuring cups, metal bowls)
- Sturdy, flat surface (table, high chair, or floor space)
- Uncooked beans or rice (optional)



I wonder what will happen ...



- 1. Place the kitchen items in front of your child. Give him plenty of time to explore them with all his senses.
- 2. Describe what he's doing while he plays. "You turned the spoon over." This is called parallel talk.
- 3. Prompt your child to make new discoveries by asking questions. "Which one makes a loud noise?" or "Do you have something shiny?"
- **4.** Encourage him to use two items at a time. "Can you put one inside the other?"
- 5. Use words to compare size and shape by asking which is bigger, smaller, shorter, or longer.
- 6. Continue asking questions to prompt your child's exploration. Play as long as he is interested.



Reflection

How did this activity go for my child?

I noticed that our play together ...



If we do this again in the future, we might ...

Try it another way

Add new materials. Use measuring cups to pour beans, rice, or water into a bowl.

Add it to our routine

Keep some kitchen tools in a container or low cabinet where your child can easily get to them while you're cooking or cleaning up.

Burning Questions: Advocating for Your Child





My perspective ...



- Blank paper
- Pen, pencil, or marker
- Sticky notes



- Draw a fire on the paper.
- 2. Think about your "burning questions" what do you want answered, need more information about, or want more clarity on? They might be about medical, insurance, education, or legal issues.
- 3. Write each question on a sticky note. Put the sticky notes into the "fire."
- 4. Next, choose one of the questions. With your family support professional, complete the reflection prompts on this page around the topic of your question.
- 5. Think about who can help you answer it (for example, your child's therapist, child care provider, or school district). If you want more information about your child's diagnosis, for example, where is the best place to start?
- 6. Finally, consider ways to ask your question to get the information you need. What is the most effective approach?

My goal for my family ..



Reflection

Other perspectives ...

Next steps ...



Positive self-talk

Asking for more information can be intimidating. Sometimes the people you need to talk to might be busy or in a rush. Be patient and persistent: You might need to ask in a few different ways or talk to several people. Your questions are important and deserve to be answered, because you are the best advocate for your child and your family.

Getting started

Using the "burning question" sticky notes as a starting point, make a list before each call or appointment. Consider the best way to ask your questions. If you don't get to them all, find out how you can follow up. For example, maybe the provider will give you an e-mail address.





PROFESSIONAL RESOURCE

Play is the most important learning activity for young children of all abilities. Parents often learn about the many things their child can do when they join her in play that's adapted to her temperament, interests, skills, abilities, and approaches to learning.

When parents interact in nurturing and loving ways with their child, it builds secure attachment that later helps her grow in selfesteem and self-confidence. In turn, children give adults reasons to be playful, spontaneous, and experimental - to rediscover a sense of wonder.

Some children don't instinctively play, even though it's serious business for them! Children with disabilities or chronic illnesses often need the adults around them to encourage their play. Many adults don't know how to play either, or they have forgotten what they used to enjoy. Yet parents who learn to play again find it easier to enter their child's world.

When parents learn to identify and observe how play relates to their child's growth and development, they are better able to assess her capacity for play and provide opportunities that fit her abilities. In addition, tuning in to their child's play helps parents discover ways to make or adapt toys and activities that will both broaden their child's opportunities and challenge her.

What is play?

Play is a complex mix of behaviors that's sometimes hard to recognize when you see it. Some characteristics of play include enjoyment, active engagement, intrinsic motivation, freedom to modify external rules, attention to process rather than product, and nonliteral experiences (Klein, Wirth, & Linas, 2003).

Professionals have long recognized the value of play in all areas of a child's development: social-emotional, cognitive, language, and

Parent handouts

Silly Me!

Playful Obstruction

Tips for Play Partners

Developmental Stages of Block Play

Sensory Learning and Play

Water Play

Music Can Help Your Child

Activity pages

Action Verses

Block Play

Blowing Bonanza

Cozy Tent

Craft Stick Puzzles

Floor Time

Kitchen Play

Me Then You

Peek and Find

Together Time

Reality Check



motor. Out of the laughter, hugs, and surprises of rough and tumble and simple playtimes, children learn to trust, feel secure, and begin to join society. Play is the way children find out who they are, what they can do, the difference between inner and outer reality, and how to get along with other people (LeComer, 2006). Experts have found that:

- Play helps children achieve mastery and control over their environments.
- Play helps children integrate and assimilate new experiences and new behaviors.
- Play creates a noncompetitive environment for children to experiment and provides opportunities for learning through trial and error.
- Playing with materials helps children learn problem-solving skills.
- Imaginative play relates to longer attention spans, more self-control, improved selfknowledge, and increased ability to interact and communicate with others.
- Dramatic play helps children develop problem-solving skills as they work together to develop a dramatic play situation.
- Play serves as a way for children to work out their fears and anxieties.
- Play allows children to cope with normal conflicts, such as separation and sibling rivalry.
- Play helps children to cope with stressful events, such as illnesses and hospitalization. For example, re-enacting painful or unpleasant events helps children develop imaginative solutions that give them a sense of control.
- Play lets children become more aware of themselves, other people, and their surroundings.

Although it encourages relaxation, play can be intense and vivid, too. Play involves

experimenting and taking risks with what is otherwise unfamiliar (Widerstrom, 2005). Play places children children in control of making choices and decisions. This enhances their sense of mastery and independence, which is especially important for children with disabilities who may be more dependent on adults than their peers (Widerstrom, 2005). Play also teaches us trust, cooperation, respect for others, sharing, mastery, and many of life's other lessons (Burghardt, 2005). Play is a fundamental need.

The two preeminent 20th-century theorists of cognitive development, Jean Piaget and Lev Vygotsky, both emphasized the essential role of play in cognitive development. Jean Piaget was a Swiss psychologist who wrote on cognitive development for more than 50 years, beginning in the 1920s. He argued that all knowledge comes from action, and that children actively acquire knowledge through interacting with the physical environment. Play provides children with many opportunities to interact with materials in the environment and construct their own knowledge about the world.

Lev Vygotsky was a Russian psychologist and a contemporary of Piaget. Vygotsky theorized that play serves as the primary context for cognitive development. In play, the child interacts with and learns from others parents, more skilled peers, teachers. Further, when children use objects to represent other objects in play (for example, using a block as a telephone), they set the stage for abstract thought. Once the child has developed representational abilities through play, she is able to use these abilities to develop reading and writing.

The professional resource Learning and Play Within Everyday Routines includes more about the stages of play children typically go through as they grow and develop.



Types of play

Children with disabilities or chronic illnesses often need adult encouragement to play. When parents can identify the different types of play, they are better able to determine how their child thinks about play, what materials could be used, how to structure play spaces, and what opportunities best support her interests (Hurwitz, 2002/2003; Piaget, 1962, as cited in Zigler et al., 2004).

Young children's play can be broken down into different types that work together for a comprehensive learning experience (Hamlin & Wisneski, 2012):

- 1. Functional play: Using real materials and objects as they are meant to be used, for example using a cup to feed a doll. Children are exploring and using their senses to learn about objects in their environment. A child who is just learning to play pretend needs to have realistic props because she is not yet able to think abstractly.
- 2. Relational play: Using real objects in real life, like a bowl with a spoon (and sometimes in ways that don't go together). This type of play is a prerequisite for constructive and dramatic play.
- 3. Symbolic play: Using objects and language to represent ideas. This type of play typically begins around 18 months and is the beginning of representational thought. Children gradually move from single-event play to pretending around a single theme, then pretending a complex sequence of events. In this stage, a child will take on familiar roles and substitute words for actions or objects. Around age 3 or 4, children begin to use dramatic play to express their emotions. Around age 4, they start to include peers in their dramatic play.
- 4. Constructive play: Using materials such as play dough, blocks, or paper to build, create,

- or construct something new. This type of play usually beings around 2 years of age. Pretend play often overlaps constructive play; for example, a child may pretend to be a construction worker building a road.
- Rough-and-tumble play: Laughter and physical activity are hallmarks of this type of play. It usually involved good-natured running, chasing, fleeing, wrestling, and open-hand hitting. More common in boys than girls, it is characterized by children alternating roles and should not be aggressive or designed to hurt another (Linder, 2008).
- 6. Dramatic play: Taking on the role of another person or object or pretending to do something (like drink juice from an empty cup) usually appears when children transition from sensorimotor play around 18 months.
- 7. Games with rules: This type of more structured and planned play often involves rules or limits that children impose on themselves. Following detailed rules should not be expected of children until they are able to understand the concepts of taking turns and cooperating, usually starting around 2½ years. This type of play is more fun for toddlers when everyone participates all the time (as in circle games like Ring Around the Rosy, where the "rules" are that everyone holds hands and everyone falls down).

A child's readiness or interest in play at any level depends on her cognitive development, social-emotional maturity, and motor skills. Adaptations and supports from adults and peers enable her to progress and be successful in her play.

Influences on play

Play styles are not universal. Studies of play from around the world suggest that play styles are highly influenced by culture. For example, not all children have been socialized to engage



in symbolic or object play. In Western society, where symbolic play is the norm, objects such as blocks and stuffed animals are often integral to children's activities.

Other cultures, such as African and Chinese, may be much more oriented to feelings and people, and include more proficiency at nonverbal communication. As a result, children from these cultures may be less object-oriented and less interested in manipulating and exploring objects.

For example, researchers from Northwestern University studied 24-month-olds from the United States and China. The children watched a series of repeated scenes. In the first, a girl was petting a dog. The scene then changed the object or the action – a girl petting a pillow (switching the object); a girl kissing a dog (switching the action). The children from China preferred the scene with a new action, while the children from the United States preferred the scene with a new object. This is experiment offers the earliest evidence that children's "attention may already be shaped subtly by the attentional patterns characteristic of adults in their cultural communities" by 24 months of age (Science Daily, 2016, para. 7).

How a child plays is often influenced by her style of learning as she matures. Some children learn by listening, some by looking, and some by moving their bodies. Very young children typically employ all learning styles before developing a primary learning style. Therefore, parents should provide a variety of play opportunities to appeal to all the styles.

Research has shown that men and women have distinct differences in play styles. Fathers engage in significantly more physically stimulating games such as bouncing and lifting. Mothers tend to play more verbal games such as Pat-a-cake and Peek-a-boo, or they play more conventional games involving a toy.

The special way fathers play with their children is important. When infants vocalize, fathers are more likely to vocalize back to them, while mothers are more likely to hold, touch, or pick them up. Dr. T. Berry Brazelton noted that the difference in parents' play styles helps children learn to expect the reactions that characterize each parent (2003). Discriminating and responding appropriately to each parent prepares children for relationships with others. Children learn to develop expectations about the kinds of experiences associated with certain individuals.

Fathers' play has been linked to emotional regulation as well as shown to play a significant role in cognitive and language development (Roggman, Boyce, Cook, Christiansen, & Jones, 2004). One researcher suggested that fathers probably make their primary contribution to their child's development through play (Meyer, Vadasy, Fewell, & Schell, 1984). Father play tends to be more physical. Fathers use their bodies more than toys when they interact with their children, challenging their motor and problem-solving skills. Fathers tend to encourage their children to explore the world and seek novel experiences (Pruett, 2000).

Children do not seem to be bothered by the differences in play styles between mothers and fathers. They most likely come to accept and enjoy the differences. Sometimes one parent prefers active play and the other parent prefers quiet play. However, it is a good idea if both parents use both kinds of play at various times with their child. Single parents may want to seek out adults of the opposite gender to be play partners with their child.

Finally, there is obviously great variability in what children with different conditions, disorders, and delays can and cannot do. Children's unique characteristics may limit their ability to initiate or respond to play, or they may seem to lack the desire to play. Developmental delays and other conditions may interfere



Learning styles and corresponding activities

	If the child prefers	Try	For example
	Auditory learning	Listening activities	 Toys with music Wind-up toys Toys that can be moved to make a sound Hide-and-seek with sound-producing toys
	Visual learning	Looking activities	 Mobiles with intense colors and interesting shapes Unbreakable mirrors Bright pictures and posters Fish bowls or aquariums A game of peek-a-boo Bubbles
	Tactile learning	Touching activities	 Patchwork quilts with different textures Balls made of different materials A board with textured materials like sandpaper, foam rubber, or foil Play dough or finger paint
	Oral learning	Touching activities	 Safe items with different textures such as rattles and teethers (Always make sure the items are not choking hazards.)
	Kinesthetic learning	Movement activities	 Rocking Gently swinging in a blanket "hammock" Running Climbing Peddling bikes Gymnastic activities



with or inhibit early play interactions between parents and their child.

Examples of challenging influences within play might include:

- Inhibition of skills that may come naturally for many children.
- Playing at one level of development for a longer time than other children.
- Spending more time at one stage of play before moving on to more complex play activities.
- Parents' feeling less confident about initiating activities.
- Decreases in the kinds of responses a child can give.
- Limits to certain levels of ability.
- Physical barriers to toys or activities without adaptations.
- Pent-up frustration in both parents and their child.

Even with these difficulties, children with special needs can learn within their play. They can often do everything a typically developing child can do if their abilities are taken into account.

Considerations for adapting play

When planning play activities with their child, parents should consider her temperament, interests, skills, abilities, and approaches to learning. Her environment is another important factor. They will want to take into account the the level of sensory stimulation, the amount of time an activity will take, the time of day, the accessibility and safety of the space, and the child's familiarity and comfort level with her surroundings.

Parents also need to remember to tune in to their child's mood and feelings during playtime and change or stop play when it's no longer fun.



Additional resources

- National Institute for Play www.nifplay.org
- Let's Play! Project from the University of Buffalo http://letsplay.buffalo.edu
- The National Lekotek Center (Videos about adapting play for children with specific disabilities) www.lekotek.org
- **Able Play**
 - (Research, ratings, and reviews of tovs)
 - www.ableplay.org
- Toys "R" Us ("Toy Guide for Differently Abled Kids") www.toysrus.com
- Fat Brain Toys (Recommendations from expert advisory panel) www.fatbraintovs.com

There are many ways parents can adapt toys and activities to broaden their child's play opportunities. If therapists work with the child, they can make recommendations. Other parents of children with similar abilities can be great resources, as can toy lending libraries and internet sites and like The National Lekotek Center (<u>www.lekotek.org</u>) and Able Play (www.ableplay.org).

Many adaptations to toys are simple and inexpensive. When parents pay attention to their child at play, they will begin to recognize her efforts and will be better able to support her with adaptations. All children need to socialize, regardless of their abilities, because



they learn ways to play from others. Integrated play programs give children with special needs an opportunity to associate with their typically developing peers, which gives them the opportunity to learn play skills and behaviors.

Accessible playgrounds, neighborhood parks, museums, library story times, and music groups are some environments where children have opportunities to interact. Parents might also try taking part in existing community programs or classes. Children with special needs often demonstrate increased responsiveness when they play with other children.

Your role

Be sensitive to the difficulties faced by parents. They may feel overwhelmed by juggling everyday responsibilities with caring for their child and therapy sessions. It can be extremely

difficult for them to find time to play with their child or for leisure activities of their own.

Sometimes parents feel compelled to make every minute count toward developmental progress and they don't want to "waste time" playing (LeComer, 2006). They may need help seeing how to accomplish therapy goals or specialist recommendations through play - but it can be done! Children enjoy the freedom of play, so they may not mind repeating an activity that could be exactly what they need to strengthen a skill.

Parents may need to extend themselves repeatedly – and sometimes dramatically – in order to engage their child in play. They may need to adapt toys or activities to make play possible. They may need to watch for their child's signals and reactions, however small and subtle, so they are prepared to respond



Tips for encouraging participation in play

There are a variety of ways that parents can assist their child's play and extend her attention and interest when she becomes frustrated.

Encourage parents to ask the following questions when considering how to adapt an activity for their child:

- How can we change the environment?
- What equipment or positioning do we need?
- How can we adjust the schedule or time of day?
- How can we focus the activity more on my child's interests?
- How can we change the materials?
- How can we simplify the instructions?

Other things parents might consider include:

- How does your child respond to new things?
- How does your child react to different textures, smells, and tastes?
- Who can we invite to join us?

Prompts to help you learn more about a family's attitudes and perceptions about play:

- "How do you most enjoy playing with your child?"
- "How do you schedule play time for yourself?"

- "What's the most enjoyable activity you and your child do together?"
- "Are you looking for new ideas for playing with your child?"

- "Were you ever or are you still selfconscious about being silly with your child?"
- "How much do you value play in your own life?"

- "What types of play did you enjoy as a child?"
- "Have you enjoyed playing with your child or is it hard for you to find things that you both enjoy?"



Be aware that talking about play could trigger grief, anger, and frustration for some parents. Feelings about conditions, disorders, or delays may be expressed as negative feelings about play itself. This is especially common if the disability interferes with a child's ability to play the way her parents expect.



to her efforts to initiate play or communicate during play.

Children can become overstimulated in any sensory area during play. When a child is excessively or inappropriately stimulated, she may withdraw. She is taking "time out" to develop a strategy to deal with the source of stimulation. Parents should watch their child's reactions when they play together. Is she responding or withdrawing? Following their child's lead will help parents find play that is enjoyable to her.

When talking with parents about adapting play and activities, encourage them to:

- Consider their child's attention span when setting expectations. Some children won't play for very long - seconds or minutes rather than hours.
- Play along with their child, but try not to play for her. Whenever possible, parents should try to make themselves available if their child lets them know she wants them to join in her play.
- Facilitate, but don't direct, their child's play. The more parents know their child, the better they will be able to suggest ways to play that interest her and have materials around that fit her needs.
- Let the child work out her own problems. Don't rush in with quick solutions.
- Pay attention to and recognize the child's play. Simply saying, "I see you" or "I see what

- you are doing" confirms for the child that play is valuable and helps her develop inner standards of "good" work and fulfilling activity.
- Be aware that parents' own needs (for doing things the "right" way, for cleanliness, for organization) may not be what their child needs. Strive to find a workable compromise. One or several rooms may be considered "off limits;" however, it is most appropriate to allow toys and play in the rooms that the family uses most. Parents who live in apartments may have more limited space to work with.

It is important for parents to avoid imposing their own ideas on their child during play. Parents and caregivers should also tune in to their own reactions. Do they become discouraged when they reach out but their child is withdrawing? If play is not fun at that moment, they might try something else or postpone play until another time.

When parents play with their child, they often acquire a more positive perspective. They learn all of the things their child can do and enjoys doing. They realize that there are many things they enjoy doing with their child. And they often see the many ways their child is similar to other children. Through play, parents also receive rewards for the time and energy they spend with their child. Parents' self-esteem may improve when they see how much their child enjoys playing one of her favorite games with them!



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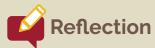
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Tips for encouraging participation in play

- 1. How can we change the environment?
- 2. What equipment or positioning do we need?
- 3. How can we adjust the schedule or time of day?
- 4. How can we focus it more on my child's interests?
- 5. How can we change the materials?
- 6. How can we simplify the instructions?



We are curious about ...





Reflection

My child's cues tell me ...

Today I learned my child ...

I could engage with my child a different way by

This time it worked to ...

While the activity is happening, we can build on it by ...

Next time we can ...

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