

FirstSteps

A Guide to Your Child's Development



Florida
Developmental
Disabilities
Council

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Phone (850) 488-4180 / (800) 580-7801

Fax: (850) 922-6702

TDD: (850) 488-0956 / (888) 488-8633

www.fddc.org

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FOREWORD

Do you remember how you were first told that your child had a disability? You probably remember where you were standing and what day it was. You probably remember this event with great clarity.

Upon hearing of a developmental disability or delay, you likely experienced many diverse and overlapping emotions, thoughts and reactions. It's also likely that all of the mixed feelings you experienced have been felt by the generations of parents who have come before you in your community and around the world.

Although you felt the same emotions as millions of other parents, you also had your own unique reactions. Your feelings, then and now, are as distinct as your personality, your relationships and your daily life routines. In addition, you probably experienced many competing and conflicting emotions. At one moment, this new diagnosis may have confirmed your suspicions, leading to some sense of relief. In the next moment, it may have confirmed your worst fears, leading to a sense of sadness and despair. A diagnosis of a disability may cause one parent to rise to immediate action and another to withdraw and shut down for a time. No matter what your reactions, however, the one thing you have in common with all parents is the need for information, guidance and support.

Accurate, concise and accessible information is essential at this time. Many new parents have had no previous personal experience with the world of disabilities, and the amount of information available is enormous. Along with volumes of printed and electronic materials, you will suddenly be exposed to the advice, experiences, opinions and sometimes "horror stories" of your friends, relatives and co-workers. Most will be well-meaning, but many will be misguided in their understanding of your unique situation.

The First Steps publication serves as a reliable source of information for parents who are at the beginning of this new journey. Along the way, you may discover new depths of sadness, but also new heights of joy and appreciation. You will learn a new vocabulary, discover advocacy skills you never knew you had and meet new people who will become important in your life as friends, teachers, doctors, therapists and caregivers. First Steps is a valuable tool to help guide you in the initial steps of your journey, as well as a resource you can visit again and again as you, your child and your family grow through the coming years together.

To get through the hardest journey we need take only one step at a time, but we must keep on stepping.

– Chinese Proverb

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Complex Systems Innovations
Gary Walby, Ph.D., M.S.P.H., M.S.
Project Director

Lynn Marie Firehammer
Consultant

Samantha Marcus, MSW
Research Associate

Madison Media
Michael Curtis, M.B.A.
Art Director

**Florida Developmental
Disabilities Council**
Donna Phillips, Ed.D.
Project Manager

Rick Lockenbach, Esq.
Project Manager

First Steps Advisory Committee
Lynne Daw
*Northwest Regional Operations
Manager, Agency for Persons
with Disabilities*

Mimi Graham, Director
*FSU - Center for Prevention and Early
Intervention Policy (FSU-CPEIP)*

Donna Hagan, Executive Director
*Healthy Start Coalition Jefferson,
Madison and Taylor Counties*

Janie Register
*Program Specialist for Pre-K Children
with Disabilities, Florida Department
of Education (FDOE)*

Laura Rumph
*Early Steps Section Administrator,
Florida Department of Health*

Gail Vail, Program Director
*Children's Medical Services Network,
Florida KidCare*

Parent Review Committee
Alex DeMolina
*Bay Area Early Steps, Family
Resource Specialist*

Rose Mary Lumm, M.Ed.
*Central Florida Early Steps, Family
Resource Specialist*

Doris Tellado
*North Central Early Steps, Family
Resource Specialist*

Sandra E. Angulo-Duncan
*North Dade Early Steps, Family
Resource Specialist*

Paula Keyser
*West Central Early Steps, Family
Resource Specialist*



Chapter 1:

• *Child Development*



When babies arrive in the world, they are tiny, helpless, yet very individual people that are entirely dependent on their parents or other caregivers to take care of all their needs and wants. Somehow, and it is still a bit of a mystery, with the proper nurturing and care, they grow to become independent adults that can take care of themselves and others. The journey from birth to the beginning of adulthood is when children soak up everything in the world around them. They mix experiences with the qualities they are born with in order to mature little by little in many ways. For some, development changes course because of an injury, neglect, a shortage of needs such as food or medical care or changes in family life or resources (through death, loss of job, divorce or other means). For others, it is through an intellectual or developmental disability that is no one's fault; it is just there and will require changes in how parents and families interact.

Understanding typical child development can help you better understand developmental challenges. Here we briefly cover child development through discussions of major developmental milestones and areas, including physical, mental, emotional, social and sexual developments. Developmental stages are defined for the purpose of this guidebook to be the following four stages:

1. Infancy (covering birth to age 2)
2. Early Childhood (covering ages 2 to 7)
3. Middle Childhood (covering ages 7 to 11)
4. Adolescence (covering ages 11 to 22)

It's important to remember that the information on these stages are general statements about when development occurs in a child's life. Each child develops at his or her own speed, and within a given child certain areas may even progress faster than others. For example, a twelve-year-old may have the physical growth and change of an adolescent but mentally still be in the concrete operational stage of thinking (which will be addressed later in the chapter). It is normal that one aspect of a child's being will mature faster than another. For most children, given the right nurturing and stimuli, everything will catch up in the end. These ages are just averages and should be looked at as a general guide rather than a rule.

Broadly speaking, the stages of development can be summarized like this: when babies are in infancy, they are changing from being totally dependent on caregivers to learning to walk, talk and play alongside others. They are realizing they are individuals. When children enter early childhood, they continue to improve their ability to move with increasing balance and

grace (large and small motor skills). They also grow mentally and socially as they enter school and other places where they interact with children. During middle childhood, children continue to grow and improve physically while also growing mentally as they attend school. They maintain friendships in groups, usually with those of the same sex, and begin forming ideas about how to act. During adolescence, a child's body matures as he or she goes through puberty. Teens attempt to assert their individual identities while still needing rules and limits to continue to help them make good life decisions. During later adolescence, young adults begin the tasks of finding a life calling, a job and possibly creating a family of their own.

Over the years, scientists have created theories to explain how children develop. While they realize that every child is special and grows in his or her own unique way, they also have recognized that there are general patterns children tend to follow as they grow up. Knowing a little about what to expect may help you realize when there are issues or when things are fine. We'll also list some of the milestones for different developmental areas or domains. The theories and milestones in this chapter have stood the test of time and will help you understand how children *typically* develop.

DEVELOPMENTAL CATEGORIES

There are four main areas in which children grow: physical, psychological and cognitive, social and emotional and sexuality and gender identity.

Physical

Out of all the areas, the physical is often the most obvious. When an infant is born and everyone congratulates the parents, asking how long the infant is or how much he or she weighs, it doesn't take long for those answers to become outdated. All children grow in height and weight with expected changes in physical skills happening as the child ages, e.g., crawling, walking, running, writing and/or throwing a ball.

Psychological and Cognitive

Children's minds and how they think change at different rates until any one child reaches a natural limit determined by genes and how much his or her environment supports learning. Children learn to talk, reason and see cause and effect, all while their brains absorb more information and they learn how to use that information. Children learn to process and organize all the information that comes to them from the world around them. They

must learn how to solve problems, to talk and to complete mental tasks such as remembering telephone numbers or using computers.

Social and Emotional

All children grow socially and emotionally. Peekaboo, laughing, eye contact, snuggling, crying and reaching out to touch and hold objects are all building blocks to understanding the emotions of both others and themselves. As children grow, they learn how to play as well as work and live with other people, such as family, friends and teachers. They learn how to understand both their own feelings and others' emotions. Children learn how to think about and handle strong emotions through talking and describing and not through hitting and yelling. Here we see that the physical, emotional and psychological areas all come together. When they all come together in healthy development, children develop a healthy and positive self-esteem as they go through the long process of figuring out who they are. Children also gain a sense of morality as they learn the difference between right and wrong.

Sexuality and Gender Identity

Finally, children have to develop sexually and form a gender identity. Like any experience that involves handling strong emotions, this area spans the physical, psychological and social areas. Children learn early how their bodies work, how they are different from other children and begin to think about the basic differences between boys and girls. As his or her body changes in puberty, he or she becomes more aware of emotions, feelings, attachments and thoughts about others. While confusing, it is also a time of learning to responsibly handle sexuality so as to balance sexual desires and appropriate behavior.

DEVELOPMENTAL STAGES

Development is fluid and continuous throughout most of a child's lifespan. Clusters of expected abilities at certain broad times, e.g., infancy and early childhood, are described in stages. Three examples of stages of development are described next.





Words to Follow

"Development is something that you take for granted. You just assume it is something that will happen like it is supposed to. Until it doesn't."

- Parent of an 8-year-old son diagnosed on the autism spectrum

"My child has always been happy. Our family and friends nicknamed her 'Smiley' in the first month and she never stopped. We began to notice though that she wasn't keeping up with other kids in what they were learning. We had an evaluation and found that her thinking, what they were calling her cognitive domain, was way behind. We cried and cried because we thought she'd never make her dreams. Then we realized that it was our dreams that weren't being met. It wasn't easy, but we changed our expectations. Throughout, she's always been 'smiley' and now we can't imagine it differently."

- Parent of 16-year-old daughter with an intellectual disability

A child's stage of development can be understood in part by his or her age, as most children develop similarly. Doctors, teachers and other professionals can determine a delay in development by comparing what a child is able to do with what children of the same age are capable of. However, a child's age only provides a clue as to his or her stage; it does not determine it. It is the tasks and skills children master that truly identify what stage they are in. Because of this, different children of the same age can be expected to be at different developmental stages, and it is only when a delay is bad enough that it may be a problem in need of help.

The most important thing to remember is that children develop at different rates. The second most important thing is that earlier stages are needed as building blocks for later stages. As a parent, you should keep this in mind when you read the following information on stages and milestones. Remember that these are generalized; average ages that research has found are where children typically develop these skills. In reality, children reach milestones across a wide range of ages. Sometimes children will even appear to skip an entire developmental stage as they advance quickly in a short amount of time.

DEVELOPMENTAL THEORIES

Psychosocial Theory (Erik Erikson)

Erikson states that the development of identity and the ability to be social with others is critical for a happy and productive life. This is what Erickson calls psychosocial development. All parents would likely agree that children need to be with others in order to develop but may not know how this typically happens. Although his theory goes all the way to old age, we'll focus only on the first five stages that take a child through adolescence.

1. **Birth to Age 1.** If infants are consistently provided with all their basic needs, such as food, clean diapers, warmth, loving affection and soothing from caregivers, they will learn that they can trust other people in their lives to love them and to take care of them.
2. **Age 1 to 3.** Young children become independent and gain confidence when caregivers are supportive and give children safe space to make their own decisions and to experiment with problem-solving skills without shaming or mocking the child.
3. **Age 3 to 6.** Children continue to develop their identity and begin wanting to try to learn new things while being taught to be responsible for their actions.
4. **Age 6 to 11.** Children become capable of more and more difficult tasks and learn in structured settings. Children who do well in

school are more likely to develop a sense of confidence. They feel good about themselves and their ability to succeed.

5. **Adolescence.** During this stage, adolescents explore their independence and develop a sense of self. Teens who receive the right encouragement and reinforcement as they safely explore the world will develop a strong sense of self and a feeling of control.

Cognitive Development Theory (Jean Piaget)

Piaget uniquely studied how children learn to think. His studies of cognitive development resulted in four stages.

1. **Birth to Age 2.** The infant uses his or her senses and motor abilities to understand the world through figuring out how to make use of his or her body. He or she does this by experiencing everything with his or her five senses (sensory) and by learning to crawl, walk, point and grasp (motor).
2. **Age 2 to 7.** Children learn from looking at others and experiment with making decisions. They start to use more sophisticated language and pretend play. Children pretend dolls or other toys are people and teach them school, pretend they are a parent or pretend to be other people they regularly see in their world.
3. **Age 7 to 11.** The child learns to use logic, problem-solving and to organize information he or she learns.
4. **Age 12 and Up.** Adolescents learn to think more abstractly and to solve problems using advanced processes such as algebra.

Moral Development (Lawrence Kohlberg)

Kohlberg found that there are three stages of moral development when we learn right from wrong, acceptable from unacceptable and change our views over time as our ability to think becomes more sophisticated. Imagine as you read the stages how moral beliefs might change as a child grows emotionally and mentally.

1. **Most 9-year-olds and younger.** Children's understanding of morality is essentially only driven by consequences. They believe that what is wrong is what they will be punished for.
2. **Most adolescents and adults.** People act in moral ways, because they believe that following the rules is the best way to make and keep good relationships and a healthy community. Thus, they would not steal only because of fear of punishment, but also because it hurts others.
3. **Some adults.** In this stage, people determine what is moral based

on a set of values or beliefs they think are right all the time, which may not be in agreement with the law. Thus, they may break a law or rule to serve what they believe is a greater good.

Now that we have presented some theories of child development, we will next look at milestones. Here we list examples of milestones for specific ages regarding four different domains of development. Milestones are the things parents and others can look for and observe to help get a sense of their child's development. These are not, of course, all possible milestones but were selected to give a good sample across ages and domains.

Milestones Across Domains				
Age	Social Emotional	Language and Communication	Cognitive	Motor or Movement
2 months	<ul style="list-style-type: none"> • Briefly calms himself or herself, e.g., brings hand to mouth • Begins to smile at people • Tries to look at parent 	<ul style="list-style-type: none"> • Makes coos and gurgling sounds • Turns head towards sounds 	<ul style="list-style-type: none"> • Pays attention to faces • Begins to follow with eyes and recognize people at a distance • Begins to act bored (cries, is fussy) when activity doesn't change 	<ul style="list-style-type: none"> • Can hold head up and begin to push up when lying on tummy • Makes smoother movements with arms and legs
4 months	<ul style="list-style-type: none"> • Smiles suddenly, especially at people • Copies some movements and facial expressions • Likes to play with people and may cry when playing stops 	<ul style="list-style-type: none"> • Babbles with expression and copies sounds he or she hears • Cries in different ways to show hunger, pain or tiredness 	<ul style="list-style-type: none"> • Responds to affection • Uses hands and eyes together, such as seeing a toy and reaching for it • Follows moving things with eyes 	<ul style="list-style-type: none"> • Holds head steady, unsupported • Pushes down with legs when feet are on a hard surface • May be able to roll over from tummy to back • Brings hand to mouth • Holds toy and shakes it
6 months	<ul style="list-style-type: none"> • Knows familiar faces and begins to know if someone is a stranger • Likes to look at self in mirror • Likes to play with others, especially parents 	<ul style="list-style-type: none"> • Responds to sounds by making sounds • Strings vowels together when babbling and takes turns with parents making sounds • Responds to his or her name • Begins to jabber with consonants 	<ul style="list-style-type: none"> • Looks around at things nearby • Shows curiosity and tries to get things that are out of reach • Brings things to mouth to study them • Begins to pass things from one hand to the other 	<ul style="list-style-type: none"> • Rolls over in both directions • Supports weight on legs and may bounce when standing • Begins to sit without support • Rocks back and forth, sometimes crawling backwards before forwards

Milestones Across Domains				
Age	Social Emotional	Language and Communication	Cognitive	Motor or Movement
9 months	<ul style="list-style-type: none"> • May be afraid of strangers • May be clingy with familiar adults • Has favorite toys 	<ul style="list-style-type: none"> • Understands “no” • Copies sounds and gestures of others • Makes a lot of different sounds • Uses his or her finger to point at specific things 	<ul style="list-style-type: none"> • Looks for things he or she sees you hide • Plays peekaboo • Picks up things between thumb and forefinger 	<ul style="list-style-type: none"> • Stands with some support • Sits without support • Crawls • Can get into sitting position • Pulls to stand • Reaches and raises arms
1 year	<ul style="list-style-type: none"> • Cries when parent leaves • Has favorite things and people • Hands book for a story • Shows fear in some situations • Puts arm and leg out to help with dressing 	<ul style="list-style-type: none"> • Responds to simple spoken requests • Uses simple gestures with specific meanings, such as waving “bye-bye” • Makes sounds with changes in tone • Makes exclamations like “uh-oh” and mama/dada 	<ul style="list-style-type: none"> • Expresses by shaking, banging or throwing • Finds hidden things easily • Copies gestures • Puts things in and out of containers • Pokes with index finger • Bangs two things together 	<ul style="list-style-type: none"> • Gets to sitting position without help • Pulls up to stand; walks holding furniture • May stand unsupported • May take a few steps without support
18 months	<ul style="list-style-type: none"> • May have temper tantrums • Shows affection to familiar people • Plays simple pretend, like feeding a doll • May cling to caregivers in new situations • Explores alone but with a caregiver nearby 	<ul style="list-style-type: none"> • Says several single words • Says and shakes head for “no” • Points to show someone what he or she wants 	<ul style="list-style-type: none"> • Knows ordinary things like phones, brushes and spoons • Shows interest in dolls and/or similar toys • Points to get attention • Scribbles by himself or herself • Follows one-step verbal commands, like “sit down” 	<ul style="list-style-type: none"> • Walks alone • May walk up steps and run • Pulls toys while walking • Can help undress self • Drinks from cup • Eats with spoon
2 years	<ul style="list-style-type: none"> • Copies adults and older children • Gets excited with other children • Shows increasing independence • Shows defiant behavior 	<ul style="list-style-type: none"> • Points to things when named • Knows names of familiar people and body parts • Says sentences with 2-4 words • Follows simple instructions 	<ul style="list-style-type: none"> • Begins to sort shapes and colors • Completes sentences and rhymes in familiar books • Plays simple make-believe games • Follows 2-step instructions 	<ul style="list-style-type: none"> • Builds towers of 4 or more blocks • Stands on tiptoes • Kicks a ball • Climbs up and down furniture without help • Throws ball overhand
3 years	<ul style="list-style-type: none"> • Copies adults and friends • Shows affection for friends without prompting • Takes turns in games • Shows concern for a crying friend 	<ul style="list-style-type: none"> • Names most familiar things • Understands words like “in,” “on” and “under” • Says first name, age and sex • Names a friend 	<ul style="list-style-type: none"> • Works with toys, buttons and levers • Plays make believe with many items • Understands what “two” means • Copies a circle with crayon 	<ul style="list-style-type: none"> • Climbs well • Runs easily • Pedals a tricycle • Walks up and down stairs one foot at a time

Milestones Across Domains				
Age	Social Emotional	Language and Communication	Cognitive	Motor or Movement
4 years	<ul style="list-style-type: none"> • Enjoys doing new things • Shows increased creativity in make believe play • Cooperates with other children • Prefers to play with others rather than alone • Plays “mom” or “dad” 	<ul style="list-style-type: none"> • Tells stories • Sings a song or says a poem from memory, e.g., “Itsy Bitsy Spider” • Knows some basic rules of grammar, like “he” or “she” • Says first and last name 	<ul style="list-style-type: none"> • Names some colors and numbers • Understands the idea of counting • Starts to understand time • Uses scissors • Plays board or card games • Starts to copy some capital letters 	<ul style="list-style-type: none"> • Hops and stands on one foot for two seconds • Pours, cuts with supervision and mashes own food • Catches a bounced ball most of the time
5 years	<ul style="list-style-type: none"> • Wants to please friends • Wants to be like friends • Is more likely to agree with rules • Likes to sing, dance and act • Is aware of gender 	<ul style="list-style-type: none"> • Speaks very clearly • Tells a simple story using full sentences • Uses future tense, e.g., “grandma will be here” • Says name and address 	<ul style="list-style-type: none"> • Counts 10 things or more • Draws a person with at least six body parts • Knows about things used every day, like food and money 	<ul style="list-style-type: none"> • Hops; may be able to skip • Can do a somersault • Uses fork and spoon • Uses the toilet on own • Swings and climbs
Adapted from Milestone Moments from the Centers for Disease Control and Prevention				

Child development is not, however, all stages, domains and milestones. There are many other areas of development that are important for professionals to assess if there appears to be a delay. For instance:

- Transitions between activities, e.g., how does a child move from one activity to another? Do they need help to move to something new? Do they seem stuck?
- Interactions with friends, e.g., does a child initiate play? Can they share? Do they say yes, no or disagree without losing control?
- Use of classroom materials, e.g., do they appropriately use writing tools, books, computers or other classroom items as intended? Do they use items with creativity when needed?
- Participation in routines and activities, e.g., does the child interact in circle time, outdoor play, meal times and bedtime?

We’ll talk more about these in the next several chapters. Now that we have hopefully given you some idea of typical development, we will turn to describing developmental delays and disorders with some practical suggestions.



Chapter 2:

What are Developmental Disabilities?



Under state law (393.063(10), *Florida Statutes*, to be exact), a “developmental disability” means “a disorder or syndrome that is attributable to intellectual disability, cerebral palsy, autism, spina bifida, Down syndrome, Phelan-McDermid syndrome or Prader-Willi syndrome; that manifests before the age of 18; and that constitutes a substantial handicap that can reasonably be expected to continue indefinitely.” While the state law lists specific disabilities, these are not all of the possible developmental disabilities that a child may have. However, those listed in the law do make up the majority of developmental disabilities that children are diagnosed with. The ones listed and some others are briefly described in Chapter 4.

Understanding the disability of your child is very important. Having an understanding of disabilities in general will help you grasp the challenges you, your child, your family and others with disabilities face each day. At the same time, you’ll find lots of joy in having an exceptional person in your family.

THE PURPOSE OF LEGAL DEFINITIONS

In order to make consistent decisions on behalf of persons with disabilities, it is necessary to have definitions of categories to be used for identifying disabilities. This helps parents, professionals and others to be on the same page and to use similar language. It also helps parents to understand their rights and the rights of their child.

Although many people do not like to the idea of “labeling” individuals on the basis of a disability, it is easy to see that using categories is really not that much different than making rules about the age of the elderly for purposes of receiving Medicare. A similar example would be the categories for making rules about the annual income amount needed to qualify for some government programs. In other words, there must be “decision rules” in place to determine whether a person should be included in or not included in any particular category. Without rules, there would be chaos, and the system could not operate.

The term “developmental disability” means the presence of a lifelong disability that happens before the child is 18 years old. The term “developmental delay,” on the other hand, is used to refer to children who are not reaching developmental milestones at the expected times. Finding a developmental delay recognizes that a child has a significant delay in some area of development, but it does not mean that this delay will necessarily be lifelong or will lead to a disability. These children may “make up ground”

compared to peers. However, it is also possible for children to have a lifelong delay that does not meet the criteria of a specific developmental disability.

Very young children develop and change constantly. This makes it difficult to measure when something goes wrong. The good news is that developmental delays are often treatable. For example, an infant from a home that is underfed and under-stimulated may show signs of significant developmental *delay* at 12 months, but the proper early intervention may erase the signs of delay by the time he or she enters kindergarten at age 5. Therefore, it would be improper to diagnose him or her as having a developmental disability.

Other children may have recognizable conditions at birth that are so severe they leave little doubt of a lifelong disability. Still, care should be taken by medical professionals, education staff and family members to not make any predictions about a child's potential for progress. Even if a child has a diagnosed disability, no one, including doctors and other professionals, can know exactly how that child will develop and what they will or will not be able to do. We probably all know children who were never supposed to walk, talk, read or even live, and when they do these things, it is said to be a miracle. Belief in miracles aside, their progress is more likely due to our inability to see the future and to the people who believed in them and gave them the care and tools they needed to thrive.

STATE OF FLORIDA DEFINITION OF DEVELOPMENTAL DISABILITIES AND ESTABLISHED CONDITIONS

In Florida, Chapter 393 of the *Florida Statutes* (F.S.) defines “developmental disabilities” in terms of the conditions that may be categorized as developmental disabilities. Please note that the age of onset differs in the federal and state definitions (as you will see below). This is because states are given a lot of freedom to decide what is best for the children and families in that state.

The Florida Statute provides a definition for each of the conditions referenced in chapter 393.063(10) F.S. Specific conditions are further described in Chapter 4. Some of the language in the statute has been made simpler to understand in the following:

Spina Bifida means a person has a “divided spine” or backbone. It is a birth defect resulting from the incorrect development of the spinal column that

can leave the spinal cord exposed and may result in partial or complete paralysis of the lower body.

Autism is a condition involved with problems in social relations, communication abilities and a restricted range of play and interests. Autism results in social isolation and different degrees of unusual behaviors. Because of the apparent sharp rise in the number of cases of autism in the last 20 years, autism (now more commonly referred to as autism spectrum disorder) is the topic of Chapter 5.

Down syndrome is a disorder caused by the presence of an extra chromosome 21.

Intellectual Disability refers to mild to profound limitations in problem solving, thinking and decision-making related to below-average intelligence. People who have intellectual disabilities learn more slowly than others and may need assistance in areas like communication, self-care, self-direction, health and safety, leisure, work and academics.

Cerebral Palsy refers to a group of conditions resulting from damage to the developing brain that may occur before, during or after birth. This damage causes the loss or weakening of control over the voluntary muscles. Despite their motor impairment, many people with cerebral palsy have normal intelligence.

Phelan-McDermid syndrome is a disorder caused by the loss of the terminal segment of the long arm of chromosome 22, which occurs near the end of the chromosome at a location designated q13.3, typically leading to developmental delay, intellectual disability, dolicocephaly, hypotonia, or absent or delayed speech. (Dolicocephaly is a condition where the head is longer than would be expected, compared to its width, and hypotonia is low muscle tone that often involves reduced muscle strength.)

Prader-Willi syndrome is an inherited condition. A lack of muscle tone and a failure to thrive are present in early infancy. Later, an excessive drive to eat usually leads to significant weight problems. Obsessive-compulsive behaviors and difficulty with social interactions are often present alongside mild intellectual disabilities.



STATE OF FLORIDA DEFINITIONS FOR CHILDREN BIRTH TO THREE YEARS OF AGE

In Florida, infants and toddlers from birth to 36 months (three years) who meet the definition of “established conditions” and/or developmental delays under the federal Individuals with Disabilities Education Act (IDEA) may be served through Early Steps. Early Steps is directed by Children’s Medical Services of the Florida Department of Health in compliance with Part C of the IDEA and is described in greater detail in Chapters 3 and 15. An explanation of the definitions found in the IDEA can be found in Appendix A.

STATE OF FLORIDA DEFINITIONS FOR CHILDREN THREE TO FIVE YEARS OF AGE

In Florida, children from three to five years old can receive special education services under Part B of the IDEA according to different categories of disabilities, including a category of developmental delay. Services for children of three to five years of age with disabilities, as well as services for those through age 21, are administered by the Florida Department of Education and are described in greater detail in Chapter 15.

The federal definition makes a slight difference between children from birth to five years and children five years and older. Children from birth to five years are often given a diagnosis of “developmental delay” in place of “developmental disability.” This recognizes the resilience in children and the success of early intervention. The federal government has endorsed a series of legislative definitions of developmental disabilities which have changed over time. The current federal definition can be found in Public Law 106-402, known as the Developmental Disabilities Assistance and Bill of Rights Act Amendments of 2000, or abbreviated as the Developmental Disabilities Act, section 102(8):

FEDERAL DEFINITION OF DEVELOPMENTAL DISABILITIES
<p>The term <i>developmental disability</i> means a severe, chronic disability of an individual 5 years of age or older that:</p> <ol style="list-style-type: none">1. Is attributable to a mental or physical impairment or combination of mental and physical impairments;2. Is manifested before the individual attains age 22;3. Is likely to continue indefinitely; and

FEDERAL DEFINITION OF DEVELOPMENTAL DISABILITIES

4. Results in substantial functional limitations in three or more of the following areas of major life activity:

- (i) Self-care;
- (ii) Receptive and expressive language;
- (iii) Learning;
- (iv) Mobility;
- (v) Self-direction;
- (vi) Capacity for independent living; and
- (vii) Economic self-sufficiency.

5. Reflects the individual's need for a combination and sequence of special interdisciplinary or generic services, supports or other assistance that is of lifelong or extended duration and is individually planned and coordinated, except that such term, when applied to infants and young children means individuals from birth to age 5, inclusive, who have substantial developmental delay or specific congenital or acquired conditions with a high probability of resulting in developmental disabilities if services are not provided.

DEVELOPMENTAL DOMAINS

There are a number of different ways you may hear your child's development described as you learn more about his or her abilities and needs. One common way may be "domains" of development, with domains being a term that refers to specific areas of growth and change. The following are common definitions of domains of development:



The **Motor Domain**, or motor skills, is the child's ability to move on purpose, which includes learning about his or her own body (how fascinating toes can be to an infant!) and the environment. It is through the motor domain that a child develops large (gross) movements, like walking. Through this domain they also develop fine controls, including balance and hand-eye coordination. Motor development depends in part on a child's growth in weight and height, as well as physical health. Poor nutrition and frequent illnesses can affect the physical development of a child.

The **Communication Domain**, or language development, is actually made up of several parts. Language development is very dependent on other developmental domains. For instance, communication includes a wide range of social behaviors and skills. Effective verbal ability is dependent on:

- Articulating or speaking words correctly
- Using the right words at the right time
- Using proper grammar when speaking and writing
- Linking thoughts for conversations to make sense to others
- Using the right tone, gestures and body language for a given situation

The **Cognitive Domain** focuses on how children learn and understand information. It is the development of the thinking and the organizing of the mind. It involves reasoning, problem solving and the memory.

The **Adaptive Domain** refers to the skills used for daily living, such as dressing, eating, toileting and washing. During early childhood, your child learns to dress and undress without assistance, to use utensils for eating and to pour drinks for himself or herself. A child also becomes able to use buttons, zippers and snaps, using fine motor skills for daily living.

The **Social and Emotional Domain** deals with children's ability to understand their own emotions and the emotions of others, to form attachments, to play with others and to handle peer pressure, among other things. This is an important and often hard to understand domain for parents. Whether there is a **Behavioral Domain** is open to debate. Behavior is part of any person, and problems with behavior are possible in all children. We cover the social-emotional domain and behavior in Chapter 8.

The **Sensory Domain**, like behavior, is not always considered a domain of its own but is related to all other domains. Sensory processing is a complex set of actions that enables the brain to understand what is going on both

inside the body and in the world around us. This is covered in Chapter 6.

Florida CHAPTER 393.063 F.S. Definition of HIGH RISK:

“(19) A ‘high-risk child’ means, for the purposes of this chapter, a child from 3 to 5 years of age with one or more of the following characteristics:

(a) A developmental delay in cognition, language or physical development.

(b) A child surviving a catastrophic infection or traumatic illness known to be associated with developmental delay, when funds are specifically appropriated.

(c) A child with a parent or guardian with developmental disabilities who requires assistance in meeting the child’s developmental needs.

(d) A child who has a physical or genetic anomaly associated with developmental delay.”

Federal IDEA Part C, Section 632 definition:

“(1) An at-risk infant or toddler. The term ‘at-risk infant or toddler’ means an individual under 3 years of age who would be at risk of experiencing a substantial developmental delay if early intervention services were not provided to the individual.”

DEFINING HIGH RISK

Florida Statutes, like the federal law, also make a special provision for children under the category of a “high-risk child.” Children determined to be at “high-risk” may be eligible for certain services through Early Steps, through the Florida Agency for Persons with Disabilities and through the school readiness services of the Florida Department of Education Office of Early Learning. Thus, while high risk has a legal meaning, it also has a practical meaning. Children with disabilities are often less able to exercise caution and self-care and should be considered “at risk” and in need of ongoing monitoring until it is consistently proved that they can be trusted to perform self-care routinely. Such individuals might then be considered “lower risk.”





When The Trees Sing

A Poem By Mattie Stapanek

When the trees sing,
It doesn't really matter
If you know the song, Or if you know the words,
Or even if you know the tune. What really matters
is knowing, That the trees are singing at all.

By Mattie J.T. Stapanek. Reprinted with permission from Journey Through
Heartsongs (Hyperion/VSP, 2002).

Words to Follow

"In the long run, men hit only what they aim at. Therefore, they had better aim at something high." - Henry David Thoreau

"What would happen if they simply went on assuming their children would do everything? Perhaps not quickly. Perhaps not by the book. But what if they simply erased those growth and development charts? What if they kept their expectations but erased the timeline? What harm could it do? Why not try?" - Adapted from Kim Edwards,
The Memory Keeper's Daughter

"A true friend knows your weaknesses but shows you your strengths; feels your fears but fortifies your faith; sees your anxieties but frees your spirit; recognizes your disabilities but emphasizes your possibilities."
-William Arthur Ward

"There are only two ways to live your life. One is as though nothing is a miracle. The other is as though everything is a miracle."
- Albert Einstein

WHAT CAN YOU EXPECT YOUR CHILD TO BE FEELING AND EXPERIENCING?

We wish there was a simple answer for this. Children with disabilities will experience needs and feelings to the degree that they can, just like anyone. Children with complex medical needs and intellectual disabilities will still experience happiness, pleasure, anxiety, pain and more, but they may not be able to share them in the same ways other children do. You will learn the language of your child better than anyone. It will be important for you to maintain hope, learn how your child shares his or her feelings and be ready to teach others as well.

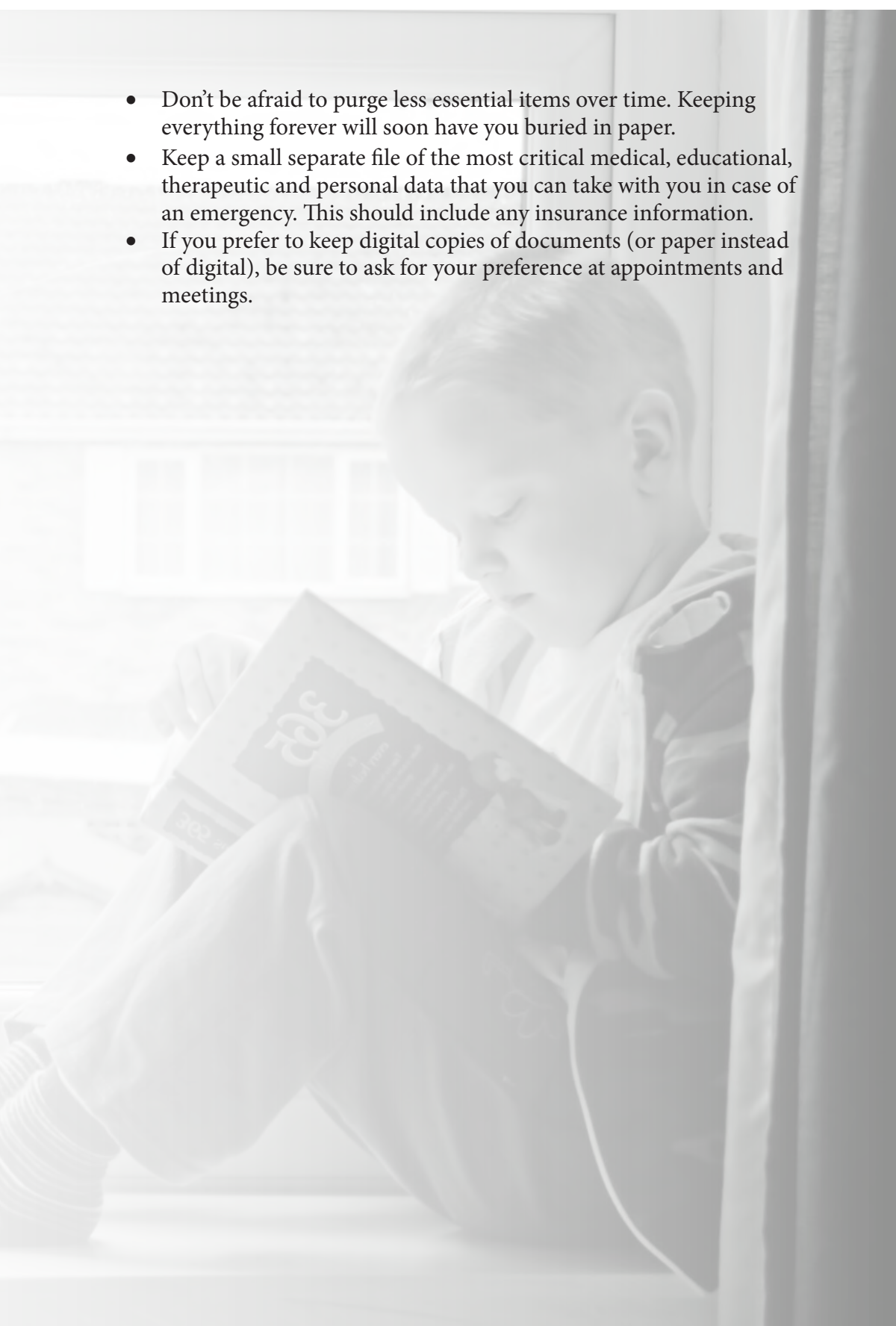
Children that have physical disabilities may be aware quite early of their differences and will need your support in understanding and coping with these differences. We cannot stress enough that all children have strengths and abilities. It may be quite difficult at times, but remaining positive and helping your child to express, learn from and control his or her emotions is very important.

ORGANIZATIONAL SKILLS FOR THE MOUNTAINS OF PAPERWORK

As you begin your journey, you will start to get many papers, documents, reports, flyers, brochures and other information. Maybe this part of your journey has already started. You need to be as systematic as possible in organizing and keeping information. Some information will be important to bring to professionals, some to schools and some to help others better understand your child in daycare or similar places. The following are some suggestions from other parents of children with disabilities:

- Find a place where you can keep all the documents you receive in an organized system. Make sure nothing else takes over that space. This can be folders, binders, a drawer in a desk or a section in a file cabinet.
- As you receive new papers, make sure you file them as soon as possible. When you get behind, you may end up getting frustrated and throwing away papers that you wanted to keep.
- File according to a system that makes sense to you. Some parents keep items by topic and then from most to least recent. You'll need to decide what is right for you.
- Always leave an appointment or a meeting with some type of paper that summarizes or otherwise informs you. These are good memory helpers for when you try to remember what went on.

- Don't be afraid to purge less essential items over time. Keeping everything forever will soon have you buried in paper.
- Keep a small separate file of the most critical medical, educational, therapeutic and personal data that you can take with you in case of an emergency. This should include any insurance information.
- If you prefer to keep digital copies of documents (or paper instead of digital), be sure to ask for your preference at appointments and meetings.



Chapter 3:

Getting a Diagnosis



The experience of receiving a diagnosis of a disability for your child is shared by many parents. The feelings, thoughts and reactions you have are easily understood by other parents who have gone before you. This can be comforting, as there are often other parents to talk to and learn from. Yet the type and cause of the disability, the age of your child when the diagnosis is made and the circumstances surrounding the diagnosis can make a difference in the type of impact it has on you and your family.

The reality of a child's disability can become apparent at many different times:

- Before birth (prenatal)
- At birth (perinatal)
- As an infant or toddler (birth-two years)
- As a preschool-aged child (three-four years)
- When a child is school age (five years or older)
- As a result of illness or injury at any age
- Upon adoption or foster placement

Identifying a disability at these times will have many things in common, but some things will differ. Nevertheless, the realization of a special need for a child at any age will have a profound emotional effect for all parents and other family members. Although the timing may differ, receiving the diagnosis is never easy.

DIAGNOSIS DURING PREGNANCY

One of the most common concerns of expectant parents is that something will be “wrong” with their baby. For most parents, this means that they are worried about the possibility of a birth defect. Although this term sounds harsh, it is still a commonly used term in the medical field for physical defects that develop before birth and are therefore present at birth. The term “congenital disability” is also used.

The diagnosis of birth defects has been revolutionized by the widespread use of ultrasound scanning and genetic testing either before or during pregnancy. Used properly, ultrasounds can detect many physical problems of the fetus, such as Spina Bifida, before birth. Ultrasounds can also accurately detect major abnormalities of the limbs and internal organs.

There are three common ways to detect prenatal defects: by examining cells in the amniotic fluid that surrounds the developing fetus, by examining cells from the placenta or by simply testing the mother's blood. You might

have experienced or heard of amniocentesis, chorionic villus sampling (CVS) or non-invasive prenatal testing (NIPT). Many chromosomal anomalies, such as Down syndrome, can be detected in this way. Below, the three procedures are explained in more detail.

Amniocentesis

The doctor inserts a thin needle through the pregnant woman's abdominal wall into the uterus. A small sample of amniotic fluid is taken from the sac surrounding the fetus. The fluid is analyzed for serious genetic and chromosomal disorders, such as Down syndrome. Amniocentesis is usually performed during the second trimester, between the fifteenth and twentieth weeks of pregnancy, although it may be done later, typically after the thirty-sixth week, to test whether the baby's lungs are developed enough for birth. Results of most amniocentesis tests are available within about two weeks.

Chorionic Villus Sampling (CVS)

With CVS, a long, slender needle is inserted through the abdomen to remove a small sample of cells (called chorionic villi) from the placenta. A second method is when a catheter (a thin plastic tube) is placed into the vagina and then inserted through the cervix to take cells from the placenta. CVS is usually performed earlier during the pregnancy than amniocentesis, most often between the tenth and twelfth week of pregnancy. With CVS, there is a rare chance of a false-positive test — when the test is positive, but no disease exists. CVS can't identify all birth defects, including Spina Bifida or other neural tube defects. The test results are available within one to two weeks.

Non-Invasive Prenatal Testing (NIPT)

NIPT is a screening test. This means that an amniocentesis or CVS may be offered to confirm results. During pregnancy, some of the baby's genetic information (DNA) crosses into the mother's bloodstream. NIPT analyzes this DNA to check if the baby has a higher chance of having certain chromosomal disorders. A blood sample is taken from the mother (not from the baby), usually after the tenth week of pregnancy. Because NIPT only involves a blood draw from the mother, the pregnancy is not at risk for miscarriage or other complications. The test results are available within one to two weeks.

More accurate and less invasive tests are being developed that will help

women in the future. One such diagnostic procedure to discover Down syndrome, called MaterniT21, has been developed and is being tested now. Early results indicate that it may be 99.1% accurate, with no risk for the fetus. This and other tests may largely replace amniocentesis in the future.

Parents who are concerned about possible genetic conditions that run in their families can seek genetic counseling before making the decision to become pregnant. The diagnosis of a disability during pregnancy leads to the need for difficult decisions as well as a sense of stress and urgency. Although this may lead to moral and ethical questions as well, it also opens several courses of action that can be taken after careful consideration of all the options.

Some medical issues in the fetus can be treated before birth. Because it carries high risks, fetal surgery is generally only used in the most serious situations but is now performed successfully in many cases. Fetal surgery allows doctors to treat certain problems of the fetus that might otherwise be fatal or cause serious problems if permitted to progress. Fetal surgical techniques offer early intervention in order to treat such defects before they become more serious.

Even in cases when treatment is not given to the baby before birth, advanced detection of the abnormality can lead to better preparation at the time of birth. As a parent, you might be able to become more emotionally prepared and informed, and the medical team can be ready to carry out emergency procedures if necessary.

If you have experienced the diagnosis of a birth defect during your pregnancy, you already understand the urgent need to make decisions that go along with this discovery. You are also aware of the moral decisions you faced. If you were given the option of terminating your pregnancy, you experienced the distinct dilemma involved in making that decision.

Some parents prefer not to seek out information about their unborn baby. Perhaps you felt that you would not do anything differently if you knew, for example, that your baby would be born with Down syndrome. As a result, you may have decided that you did not want to screen for this condition before the baby's birth. Or you may have decided that knowing about a disability for several months during pregnancy would cause you too much anxiety. For many reasons, parents often make the decision not to have ultrasound scanning or other medical procedures. There is no right or wrong decision. Parents should talk openly with partners, family, trusted friends





Facing the Future

A Poem By Mattie Stapanek

Every journey begins
With but a small step.
And every day is a chance For a new, small step
In the right direction.
Just follow your Heartsong.

Although he lived with a rare form of muscular dystrophy, in his brief 13 years, Mattie Stapanek wrote hundreds of poems he called Heartsongs. His book of poems, titled Heartsongs, has become a national bestseller.

By Mattie J.T. Stapanek. Reprinted with permission from *Journey Through Heartsongs* (Hyperion/VSP, 2002).

Words to Follow

"If I know what love is, it is because of you." - Hermann Hesse

"There is sacredness in tears. They are not the mark of weakness, but of power. They speak more eloquently than ten thousand tongues. They are messengers of overwhelming grief... and unspeakable love."

- Washington Irving

"All about me may be silence and darkness, yet within me, in the spirit, is music and brightness; and color flashes through all my thoughts."

Helen Keller

and doctors when making important prenatal decisions.

Resources

For more information on maternal blood testing and other screenings with additional details on which proteins are tested and why, visit <http://library.med.utah.edu/WebPath/TUTORIAL/PRENATAL/PRENATAL.html>

DIAGNOSIS AT BIRTH

Many events can occur during the birth of a baby that cannot be predicted during pregnancy. Whether it is the discovery of an undetected birth defect or as a result of the delivery itself, the news of a problem in the newborn baby is difficult for everyone involved. When life-threatening difficulties are present at birth, such as when the baby is born prematurely, a cycle of events can be set into motion that can be traumatic for the parents. If you have had a premature infant, or “preemie,” you may already know the feeling of loss of control that many parents experience.

Premature infants may have many special needs that make their early care different from that of full-term babies, which is why they often begin their lives in a Neonatal Intensive Care Unit (NICU). The NICU is designed to meet the unique needs of the premature infant. Full-term infants with special medical needs may also be given care in the NICU. Make sure to ask questions and do not settle for answers that you do not understand. Also, keep in mind that sometimes professionals give vague responses, because they just don’t yet know and are themselves waiting for answers from tests and consultations. While this is a time when many parents report feeling out of control, this is an expected feeling, and you should take control of what you can. This includes asking questions, deciding on visitation schedules and reaching out to others for support.

Parents who spend time with their newborn babies in the NICU experience many feelings of loss and fear, even though they know that their child is receiving the best care possible. You may have to make quick decisions about the need for one surgery or many surgeries. At times, you may feel like an outsider in your baby’s life. You may have wanted to breastfeed your baby and now find out that you can only do so by pumping your milk for tube feedings. You may have pictured yourself holding and cuddling your new baby, only to be told that your baby is too fragile to be picked up at first. If you can, try to be involved in your baby’s care as much as possible, and allow yourself to lean on the understanding and expertise of the medical personnel in the NICU. Remember that you are a *critical member* of the

team that is helping your child, and do not hesitate to remind others that you are a team member.

When lengthy medical interventions are needed early in your infant's life, you may experience difficulty feeling close to your baby. It may be difficult to connect with your baby because he or she is in an incubator in the NICU, or you may be afraid to let yourself get too close to him or her because you are afraid your child may not be with you for long. We talk about attachment, the relationship with your child, in Chapter 7. It is important to remember that you can express attachment for your child through concern, questions and spending time, even if only through a glass at first. This is your child, and your strength and love is critical support for him or her.

You may experience difficulties managing all the other aspects of your life including your job, your responsibilities at home and your other children. You will likely feel you need to be at the hospital with your infant at all times. Remember that your baby will need a strong and well-functioning home when they leave the hospital. Taking care of yourself, your family, your partner, your children, your job and your home is also building the nest for your new infant. Maintaining a routine as much as you can will also help you feel more in control. We talk about routines in Chapter 9.

Today, medical staff are generally very aware of the importance of the relationship between a newborn and his or her parents and will help you work through the difficulties you are experiencing. There are also a number of other personnel at the hospital that will be there to help you aside from the medical staff. Social workers, case managers and others will be available to help you understand what is happening. Remember to allow the people closest to you to support you and hold you up during this difficult time.

NEWBORN SCREENINGS

It is very important to understand that routine newborn screenings are an important part of early detection but are NOT the same as receiving a formal evaluation to find out if there is a developmental disability or delay. When babies are born in medical facilities, they receive several "newborn screening tests" before they are discharged. One of these tests, for example, checks for the presence of phenylketonuria (PKU) in the baby's blood. PKU is an inherited disorder of body chemistry that, if untreated, causes moderate to severe intellectual disability. Fortunately, through routine newborn screening, almost all affected newborns are now diagnosed and treated early, allowing them to grow up with normal intelligence.

Another newborn screening test that is considered “universal” (meaning it is performed on all newborns) is an infant hearing screening. Up to four in 1,000 newborns in the U.S. have significant hearing impairment. Without testing, most babies with hearing loss are not diagnosed until two or three years of age. By this time, they often have delayed language development that will affect future social and academic skills. Detection of hearing loss in the days following birth allows the baby to be fitted with hearing aids before six months of age and also receive an evaluation to determine if he or she may be a candidate for cochlear implants.

The pulse oximetry test is performed on each newborn to detect for Critical Congenital Heart Disease (CCHD). A sensor attached to the baby’s foot or finger shows the amount of oxygen in the infant’s blood. Other common screenings conducted on newborn babies include tests for sickle cell anemia and a number of disorders of the metabolism.

The March of Dimes has taken the lead in advocating newborn screening for all babies in all states. The March of Dimes would like to see every newborn screened for 32 specific disorders, most of which have effective treatments available. At this time, each state sets its own standards for newborn screening tests. Florida screens for 31 disorders that are recommended by the United States Department of Health and Human Services and an additional 22 secondary disorders, unless a parent objects in writing.



DIAGNOSIS AS AN INFANT OR TODDLER (BIRTH-2 YEARS)

The majority of infants in the United States are born without significant incidents and go home shortly after birth. Even most infants with the most serious medical conditions eventually leave the NICU. Sometimes parents take their babies home with the knowledge that their child will have developmental delays or special health care needs, or they may know that their child is “at-risk” for a developmental delay or disability.

Other parents, however, leave the hospital without any knowledge that their child will experience a developmental delay or disability. Your baby may seem to show typical development for a period of time before you notice that that he or she doesn't seem to hear your voice or perhaps doesn't seem to look for your face. Maybe your child was babbling and using words, and now, at 20 months, he or she stops talking.

All parents observe their children and delight in the new skills they demonstrate. When skills don't emerge at the time you expect them, though, you may become worried or suspicious. Typically, you become aware your child has a behavior or an inability that doesn't seem quite right. *Shouldn't my child be sitting up by now? Why isn't my child talking yet?* Given that all parents have worries about their children, how are you to know when you should really be concerned?

The best advice is to trust your intuition and your insights about your child's development. No one knows your child as well as you do. **If you believe that something is wrong, it's time to take action.** Most importantly, don't let anyone talk you out of getting your child evaluated to see if there is a delay or disability. Below, we describe the process for getting an evaluation for your infant from Early Steps. This organization does comprehensive evaluations for over 40,000 infants a year for developmental disabilities or delays and serves every county in Florida.

You may want to start by sharing your concerns with your spouse or other family members. If they try to brush off your questions, you may start to doubt yourself. If you feel strongly that there is something unusual about your child's development, trust your judgment and contact your child's clinic or pediatrician. If the doctor who sees your child also brushes off your concerns, but you still have them, take the next step and seek an evaluation for your child. **Trust yourself!** If it turns out that your child is progressing normally, then nothing has been lost. If a developmental delay

is found, however, then you have not wasted precious time, and early intervention services can be started.

It is not easy to admit to yourself or to others that you suspect your child has a developmental delay. It may make you feel anxious or isolated. Try to overcome those feelings by focusing on the importance of early detection and taking the first step.

Remember that it may not be you who first sees the signs of a developmental delay in your child. Your friend or family member, your pediatrician or your child care provider may be the one who brings it to your attention. In this case, you might resist what they are telling you. You may want to deny that anything is wrong, and you may try to avoid the people who shared their concerns with you. Try to evaluate the information as objectively as you can, and if you believe their concerns are valid, seek an evaluation for your child. Remember, there is nothing to lose and everything to gain. If the evaluation is negative, you no longer need to feel anxious. If positive, you have gained valuable time in starting early intervention services.

Sometimes, when you are finally with a physician or an early childhood specialist, they will tell you that “every child is different.” They will say that even though your child has a mild delay, he or she will probably “grow out of it” and “maybe we should wait and see.” Often, this advice is comforting because it is what you really want to hear. Or for other parents, it may make you furious, because you feel you are not being taken seriously. Again, trust your judgment and err on the side of being over-concerned. This way, intervention can begin earlier if a problem is found.

The Early Steps Evaluation

An Early Steps evaluation is meant to determine if there is a developmental delay or the extent of delay in a known developmental disability. It also determines whether or not the delay makes your child eligible for services through Early Steps. Parents should realize that a diagnosis is a beginning point. While finding and planning for problems is truly important, the Early Steps evaluation is especially valuable, because it also focuses on finding the infant’s and family’s strengths. An Early Steps evaluation starts with a referral. You can refer yourself or you may be referred by a pediatrician or other person or office. Once you are referred, a service coordinator will contact you, and you will be asked to answer questions that will be helpful for the evaluation. They also help you to understand the process better. This is a very family-friendly process, and you will have time to ask all the

questions you want.

The service coordinator then sets a time for an evaluation, which may be at a clinic or at your home. The evaluation will take place with at least two professionals that have the special knowledge to help evaluate your child based on your talk with the service coordinator. The types of professionals that may be part of the evaluation team are an Infant and Toddler Developmental Specialist (ITDS), a physical therapist, a speech therapist, an occupational therapist or others.

The evaluation will assess the child on the domains outlined in Chapter 2 (communication, motor, adaptive, social-emotional and cognitive). The evaluators will determine how your infant or toddler compares to typically developing children of the same age to determine if and how much a delay is present. They will also assess for the red flags of autism, sensory challenges and behavioral issues. You will be part of this process and an active team member.

If your child is found eligible for services through Early Steps, you will work with the evaluation team and service coordinator to create an Individual Family Service Plan (IFSP). This plan sets initial goals, honors your priorities and begins the process of helping you to become the “coach” of your child. It is very important for you, the most important thing in your child’s life, to accept that you are the best help for your child. You must keep this in mind as you are taught how to use the basic routines of everyday life to improve your child’s development.

Resources:

Below is the website link for the Early Steps program. At the bottom of the home page is the Early Steps Directory which provides information and referral services to families of children with disabilities and special health-care needs. There is also a link for information to each local Early Steps site in the state, so you can find the office nearest to you.

- Early Steps: http://www.floridahealth.gov/AlternateSites/CMS-Kids/families/early_steps/early_steps.html
- Contact information for each Local Early Steps (LES) office: <http://www.floridahealth.gov/AlternateSites/CMS-Kids/home/contact/earlysteps.pdf>

DIAGNOSIS BETWEEN AGES THREE AND FIVE YEARS

Most severe disabilities and special health-care needs will be diagnosed before your child reaches age three; therefore, problems that are identified between the ages of three and five will tend to be issues not connected to obvious conditions like Down syndrome. During the preschool years, referrals are generally made on the basis of cognitive delays or difficulties, learning disabilities, behavioral issues or speech and language problems.

You may suspect delays in your three-to-five-year-old in the same way that some parents suspect difficulties in their infants or toddlers. You may have thought that your child was developing typically up to age three or four, but you now notice that he or she seems to be having difficulties in some specific areas. A child care provider or preschool teacher may tell you that your child is not showing age-appropriate skills or behaviors at school.

Again, you may feel anxiety or dread in this situation, or you may feel relieved that someone agrees with your suspicions. In either case, it is important to seek out and cooperate with the procedures and assessments that will yield information about your child's development.

Some disabilities do not become apparent until children enter kindergarten. During the kindergarten year, children are exposed to increasingly structured academic activities, and some specific learning disabilities or problems with paying attention may make their appearance at this time. Referrals may also be made later in the elementary school years.

Florida children are assessed on how ready they are for kindergarten via the Florida Kindergarten Readiness Screener (FLKRS). This is done through the Office of Early Learning in the Florida Department of Education. The Florida Diagnostic and Learning Resources System (FDLRS) helps to provide evaluations for persons with developmental disabilities and other challenges for ages three-22.

Resources

FLKRS Screening: http://www.floridaearlylearning.com/providers/provider_resources/florida_kindergarten_readiness_screener.aspx

FDLRS Website: <http://www.fdlrs.org/>



DIAGNOSIS WHEN THE CHILD IS SCHOOL AGE

Diagnosis when a child is in elementary school is most likely, but not exclusively, going to be due to issues of intellectual disability, behavior or a combination of both. While a behavioral disorder is not exactly a developmental disorder, many behavior-related issues can persist for years without help. Youth with intellectual disabilities may also have specific learning disabilities that make it harder for them to read, write, do math or remember facts. This will make it even harder for them to do well in school.

If you suspect that your child is struggling in school, ask the school to test your child for intellectual and learning disabilities/issues. Do not assume that this is something that will get better by itself. You also should not assume that the school system will take care of this without your input. Children can become frustrated and begin to have behavioral problems if they have a hard time understanding school work. Youth can easily turn off from school if they are unsuccessful over and over. Educate yourself on what schools require to be eligible for testing. Do not be afraid to talk to teachers, school administrators and district school staff to make yourself heard.

DIAGNOSIS AS A RESULT OF ILLNESS OR INJURY

Nothing in life prepares a parent for a serious illness or injury to a child. When these events occur, parents generally report that “time stops,” and life as they knew it ends for a period. Extended hospital stays and medical appointments can take priority over all other life activities and can place a severe strain on family functioning and finances.

When a young child develops a disability as a result of a severe illness or an accident, the sense of loss is compounded by the random nature of what has happened. With all that is going on, parents sometimes struggle to make sense of it all. A parent may isolate himself or herself or cut off from normal supports. It is very important for parents to include the help of others when needed.

If, for example, your child contracted viral encephalitis, he or she may have spent extended time in the hospital, followed by ongoing healing at home. This could create some long-term consequences. You may believe that you are to blame for not properly protecting your child. At the same time, you may rejoice at his or her recovery but also mourn the developmental delays he or she is experiencing. While your family is adjusting to your new journey, you may find that your private insurance is capped out and your

out-of-pocket expenses are costly. As a result, your anxiety and exhaustion levels will likely be running high. Taking care of yourself and helping your family adjust are the subjects of Chapters 9 and 10.

A serious accident or injury to your child may also bring life-altering events to you and your family. You may experience bouts of guilt even when the accident could not have been prevented. When the immediate medical emergency is over, you will face the challenge of reconstructing your life and that of your child and family. Gradually, life will return to being normal, although it may be a “new normal.” Like other parents, you will encounter new joys, new sorrows and a new awareness of the important things in life. Seeking help through support groups and making new friends with parents and families having similar changes will help you adjust to the new normal. Other suggestions include searching for supports on the internet and asking pediatricians, friends and others for suggestions. You will find that your new relationships and experiences bring unexpected joy, new friends and new supports.

DIAGNOSIS UPON ADOPTION OR FOSTER PLACEMENT

Many parents who adopt children are aware if the child they are about to welcome will have a disability. In fact, many adoptive parents make a conscious decision to request a child with a disability or special medical needs, feeling confident they can welcome this child into their family. The same is true for many parents who provide foster families for young children. In fact, foster parents are generally taught to expect that the children they receive may have many unmet emotional needs and the possibility of developmental delays.

Other times, however, an adoptive parent may be completely unprepared for the diagnosis of his or her adopted child. Perhaps you had arranged to adopt a newborn as soon as he or she was born, or you have sought an international adoption in which you were matched with a child without first meeting him or her. When you meet that newborn or young child for the first time, you likely experience the same range of emotions that parents of biological children experience.

It is sometimes assumed that adoptive parents will not feel the same sense of loss and despair as biological parents, since it is not really “their child,” but this is not generally true. In the first place, this really is “your child.” You too may feel a sense of betrayal because “this is not what you signed up for.” Just as the biological parent must give up the expectations of the “text-

book” child-raising experience, so too must the adoptive parent. You are entitled to the same feelings and reactions as any parent facing the same change of plans. Fortunately, you will also feel the same joy and positive feelings when your child shows progress and achievements on his or her own schedule.

No matter if your child was injured, adopted, fostered or your child has a disability or delay that was known or unknown prior to birth, taking the best possible care of yourself must be a top priority. We talk about this extensively in Chapter 10.

WAITING FOR A DIAGNOSIS

Parents have often noted that they had suspected something was wrong, talked to pediatricians, specialists, clergy, teachers, friends and family and had many assessments completed. Through all this, they were not given a diagnosis or were told that their child is too young to have a diagnosis. Perhaps you or someone you know may have experienced the anxiety of a long assessment process. Waiting for results of genetic testing and other long diagnoses can be very stressful. Parents want a diagnosis to validate their thoughts and beliefs or to tell them that their fears have simply been misplaced. For some parents, it is a form of relief that they now know for sure and can concentrate on the delay. They no longer have to convince others or feel like they are all alone.

Other family members may see the diagnosis as confirming their worst fears. Parents may feel that hope is now gone. Either way, the reality is that even for typically developing children, there are times that include arguing, problems in school, problems at home and other normal, yet stressful, experiences. An official diagnosis may never be made, but that does not reduce the reality that your child will need your help and the help of others to strive.

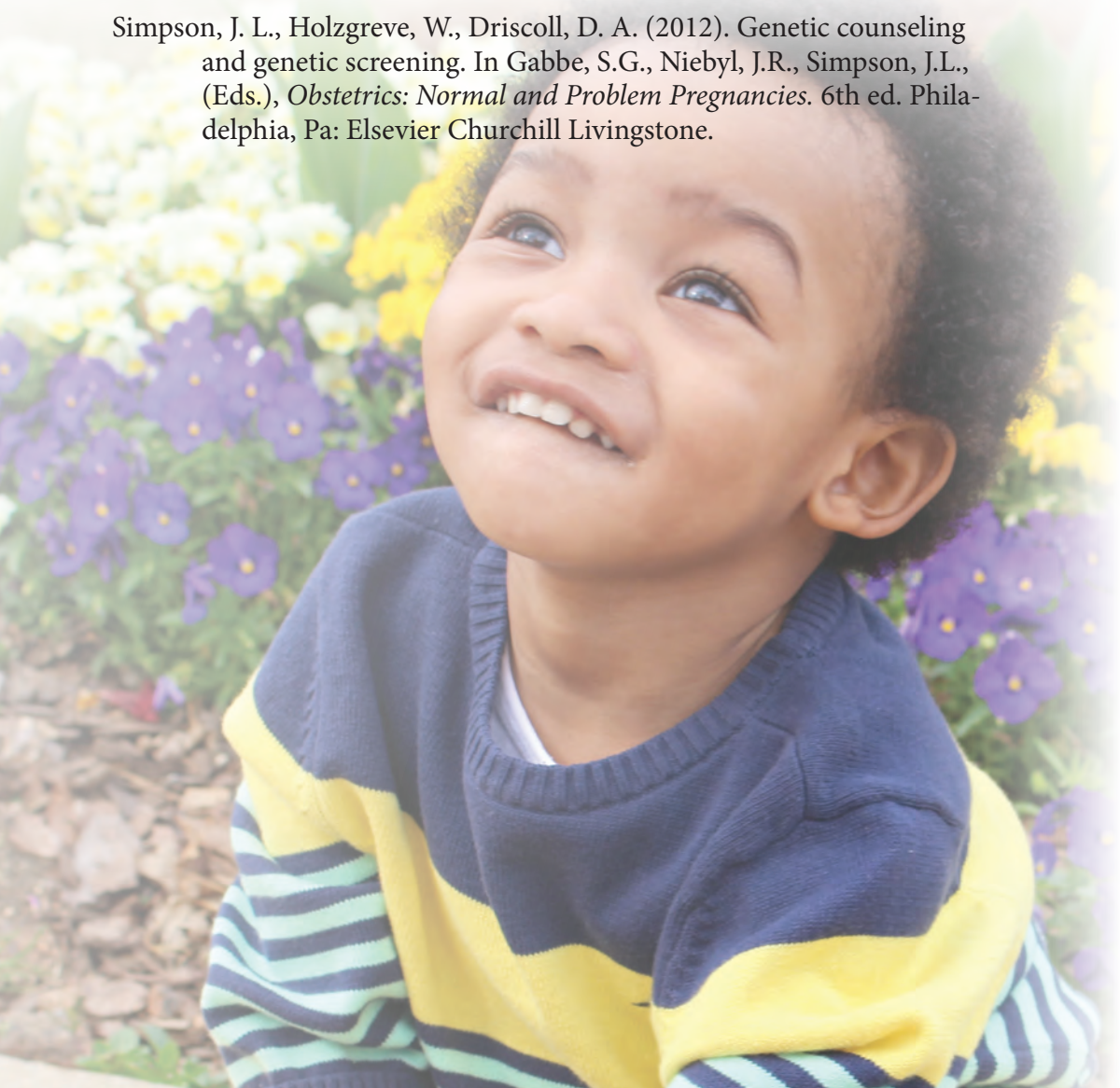
A realistic concern is that without a diagnosis, some insurances will not pay for the help your child may need. Be sure to take advantage of Early Steps, FDLRS and other services that are free to all families if their child’s delay or disabilities makes them eligible. These are NOT based on how much money your family makes. These services are very high quality. Be the squeaky wheel at the school to get the help you need. Not having an official diagnosis does not mean that you cannot be a strong advocate for your child.

As noted, we cover parental self-care in a future chapter. However, here are several things you can do to help reduce your stress:

- Talk with your partner, family and friends. Don't keep it all bottled up.
- Take care of your basic needs, like eating right and exercising.
- Join an activity that motivates you.
- Stick to a routine.
- Practice affirmations that focus on the good but prepare for the bad.
- Don't isolate yourself. Keep your support system strong but begin to look into support groups that may be more appropriate.

CITATIONS

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Chapter 4: Developmental Disabilities, Common and Uncommon

In this chapter, we describe some common and less common disabilities. As they say, knowledge is power, and the more you know, the better you and your family will adapt. These descriptions are by no means exhaustive, but they are a starting point for parents. We will cover the most common developmental disabilities. Appendix A gives brief descriptions of others, with links to specific websites found in Chapter 18. This chapter, really this entire guide, will not relieve all of your anxiety or all of your questions. Every child is unique, and thus you will learn about your child first and know more about him or her than anyone. As you review this chapter, you may be reading only to know more about your child with his or her specific disability. We suggest you take the time to read about other conditions here as well. Finding that you are part of a much larger family now, one that is powerful and knowledgeable, can offer some peace of mind.

IN GENERAL TERMS: A LAYMAN'S DEFINITION

Legal definitions serve the purpose of determining which people are eligible for services provided by federal, state and local governments. In common language, however, a “developmental disability” is a broad term referring to a variety of conditions that interfere with a person's ability to function in everyday life. These conditions can be physical, intellectual or behavioral in nature. This term “developmental disability” includes persons who are considered to have an intellectual disability. Some children have more than one area of disability.

Developmental delays and disabilities can have many different causes:

- Biological (such as Spina Bifida)
- Genetic (such as Down syndrome)
- Complications of pregnancy (such as prematurity or infections)
- Complications of delivery (such as oxygen deprivation)
- Environmental (such as injuries or lack of nutrition)

In many cases, however, the cause of a disability is unknown. This is frustrating for many parents in the early stages of their child's diagnosis. This is also discussed in Chapter 3. You may feel that it is very important to learn the cause of your child's problem so that you can better understand it. You may continue to seek a cause for many years. You may even move from specialist to specialist in search of new tests or new knowledge, believing

that someone may have the information you need. In some cases, you will find the cause, or at least a probable cause, that you have been seeking. In other cases, you will not find a cause, but you may finally realize that you have done everything possible, and you will allow yourself to stop.

In the end, many parents come to realize that it is not the cause, or even the diagnosis, that is most important. Rather, it is an understanding of your child's specific strengths and needs that is important. Most early childhood specialists will tell you they don't plan your child's activities based on a cause or a diagnosis, but instead they plan on your child's present skills and abilities. They also create a plan with what you have all agreed on, as a team, are the next skills to be learned. If your child needs to learn how to hold a spoon, it doesn't really matter why he or she isn't holding that spoon. What matters are the steps and adapted tools that will be needed to help him or her learn how to hold the spoon. Nevertheless, your need to know the cause of your child's disability will be strong, especially if you are planning to have another baby. No one has the right to tell you that you need to give up on finding the cause or getting a diagnosis.

It is also important to keep in mind that no two children with developmental disabilities are alike, even if they have the same type of disability. Even when the cause of a disability is known and a diagnosis is given, you will still have a truly individual child. The bottom line is that when it comes to being unique, disability doesn't matter. All children are unique.

DESCRIPTIONS OF THE MOST COMMON DEVELOPMENTAL DISABILITIES

As you begin to learn more about developmental disabilities, you will soon find that pinning down a specific definition for a specific purpose can be challenging. Different departments within the federal government may use different definitions under the laws that govern their operations. For example, the definition of a disability under the Americans with Disabilities Act of 1990 (U.S. Department of Justice) differs from the definition of a disability in use by the Social Security Administration. As a parent, you will become aware of these multiple definitions, which can be frustrating. We suggest you be sure to match the correct definition with the services you are seeking. This is not always an easy task, but it will help make your interactions with different agencies go more smoothly. You will also want to become familiar with the definitions used in different agencies in Florida, as well as in the county school district in which you live. Florida is one of the states that recognize the eligibility category of "developmental delay"

for children ages three to five. This is important, because your child may be eligible for services that would require a formal diagnosis in other states.

What is common for all the descriptions of developmental disabilities in this chapter is that you, as a parent, must become an advocate for your child, your family and yourself. While each of the disabilities discussed has its own set of challenges, parents can learn from and find incredible fulfillment, strength and joy in supporting their child with special needs. They can also learn from and support each other.

Autism

Autism and the autism spectrum are covered in more detail in Chapter 5. In brief, autism means a developmental disability that seriously affects communication (verbal and nonverbal), social interaction and educational performance. It generally starts before three years of age. Characteristics often linked with autism are engaging in repetitive activities and stereotyped movements (e.g., finger rolling or rocking), resisting change in routines or environment and responding unusually to sensory experiences. Onset before the age three is not set in stone. However, autism can sometimes be detected at 18 months or younger. By age two, an experienced professional's diagnosis can be considered reliable. However, many children do not receive a final diagnosis until they are much older.

Cerebral Palsy

The Centers for Disease Control and Prevention estimates that approximately 8,000 to 10,000 babies will develop Cerebral Palsy (CP) each year. The parent of a child with CP is usually the first to notice these signs, and they tend to be the first to realize that the child is not developing normally. The signs of Cerebral Palsy typically develop before a child turns three. The cause of CP varies. Some include:

- Complications with birth, e.g., breech birth
- Problems with the mother's blood pressure, complicated by circulatory issues, while pregnant
- Issues with low birth weight in the infant (premature birth)
- Infections or exposure to toxins while pregnant

The signs of CP vary widely and can range from mild to severe. Some typical early symptoms include:

- A delay in the ability to learn to sit or walk
- An abnormal muscle tone, sometimes referred to as floppy, where



there is a general weakness in one or more body areas, e.g., limbs, neck or torso

- A choice of the child to be in an unusual body position or posture when at rest
- A difficulty in swallowing or a problem with drooling more than expected, though there are sensory issues that may account for this also (see Chapter 6)
- A difficulty in talking, unlike a communication disorder where there may be a difficulty in processing but instead due to issues using the muscles of the face and jaw to form words
- An uneven usage of limbs, e.g., dragging one foot or having one arm hang loosely
- An onset of tremors, though not usually continuous

If you are a parent of a child with CP, you will learn or may have already learned to be a planner and a predictor. We talk about planning to reduce stress and preparing for emergencies throughout this guide. We emphasize this more for children with CP, especially for those with more severe and complex CP due to the risk of medical complications. Some things that parents might consider keeping handy include:

- Doctors' phone numbers
- Medical records
- School contact information
- Emergency contacts
- Babysitters' phone numbers
- Imaging and lab test results
- Medications

Plan to maximize your child's potential by enrolling him or her in activities and services. Children with CP have the same range of intelligence as that of typically developing peers. Preparing for your child's independence within his or her abilities, helping your child to socialize, looking for ways to improve his or her quality of life and encouraging your child in his or her pursuits are all things you can do as a parent. That sounds just like any other child, right? What is different for a child with CP is that you must make sure to create a concrete plan. Rehearse the steps you would take in an emergency, even if your rehearsing only consists of repeated discussion. Planning for education, service delivery and preventive medical care are all very important. This is also what you do with typically developing children, but it is even more true for a child with CP.

When considering a financial plan, as many parents do, you will likely

have to plan for some additional expenses that most parents do not have to plan for. Before you despair, remember that there are many community resources (some listed at the end of this section) that can help you plan and obtain needed “durable goods” (e.g., a wheelchair), consumable goods (e.g., diapers) and services. Here are some things that you will want to plan for:

- Additional medical care
- Equipment
- Vehicle modifications
- Assistive devices
- Specialized education
- Physical therapy
- Medications
- Caregivers

Cerebral Palsy has had, and continues to have, a great deal of research revolved around it. Keeping current is difficult, but fortunately there are many great organizations that do that for you. One that we suggest parents keep handy is United Cerebral Palsy or UCP. UCP offers many resources and links to supports. It is highly recommended that you join a support group in your area.

Resources

United Cerebral Palsy: <http://ucp.org/>

My Child at Cerebral Palsy: <http://www.cerebralpalsy.org/>

CP Family Network: <http://cpfamilynetwork.org/>

The Friendship Circle - Resources to Know About: <http://www.friendship-circle.org/blog/2013/11/06/20-cerebral-palsy-resources-you-should-know-about/>

Intellectual Disability

There are many possible causes for a child to have an intellectual disability: chromosomal or genetic issues, environmental toxins, alcohol or drug use by the mother, preeclampsia, malnourishment, illness, injury and more. No matter the cause, there will be limitations in:

- **Adaptive behaviors.** First described in Chapter 2, problems with adaptive behavior are often the most stressful for parents. Adaptive skills are those that get us through day-to-day life, such as being able to take care of oneself (getting dressed, keeping clean), being able to properly communicate with others and not becoming overwhelmed by changes.
- **Intellectual functioning.** This is related to the intelligence quotient,

or I.Q., of the child. There will be limits to solving problems, communicating, making decisions and using memory. It also affects a child's general learning ability.

There are many signs of an intellectual disability in a child. For example, below is a simple list from the Centers for Disease Control and Prevention (CDC) of the most common signs of mild and moderate levels of intellectual disability. For children with very severe levels, there are often medical complications and other issues for parents to adjust to. Children with severe levels of intellectual disability may require a great deal of physical care for most of their lives.

Common Signs of Intellectual Disability (Adapted from the Centers for Disease Control and Prevention)

- Rolling over, sitting up, crawling or walking late
- Talking late or having trouble with talking
- Being slow to master things like toileting, dressing and feeding himself or herself
- Finding it hard to remember things
- Having trouble seeing the results of his or her actions
- Having trouble understanding social rules
- Developing behavioral problems such as explosive tantrums
- Having difficulty with problem-solving or logical thinking

The keys to parenting a child with an intellectual disability include patience, repetition, translation and rejoicing when it comes to small victories. Let's address these one at a time:



- **Patience:** Stated earlier, your child may take longer to learn some adaptive (everyday) behaviors or school-based tasks. He or she may seem to forget, but it actually just takes longer for information to enter his or her “long-term memory.” Try to keep your frustration low by realizing that this is not on purpose. Remember that your child may be frustrated as well.
- **Repetition:** Going hand in hand with patience, you can expect to give the same lesson or instruction time and time again. While at times frustrating, you can help your child to retain what he or she learns and make decisions to his or her ability by calmly repeating lessons.
- **Translation:** This means that you will learn to translate the world into messages that your child can understand. In fact, you will be your child’s best translator. In reverse, you will help the world understand your child, as you will know his or her thoughts and needs better than anyone.
- **Rejoicing:** The joys of seeing your child learn something, retain it and proudly show you are amazing. Stay focused on the positives and celebrate with your child. You both deserve it.

Resources

American Association on Intellectual and Developmental Disabilities:

<http://aaidd.org/>

The Arc: <http://www.thearc.org/>

Center for Parent Information and Resources: <http://www.friendshipcircle.org/blog/2013/11/06/20-cerebral-palsy-resources-you-should-know-about/>

South Florida Resource Center: <http://www.sfptic.org/>

The Arc of Florida: <http://www.arcflorida.org>

Down Syndrome

Down syndrome is a genetic condition that causes delays in physical and intellectual development. It occurs in approximately one in every 800 live births. Individuals with Down syndrome have 47 chromosomes instead of the usual 46.

Children with Down syndrome are usually smaller, and their physical and mental developments are slower compared to children who are unaffected. The majority of children with Down syndrome have mild to moderate intellectual disability. While some show no sign of having an intellectual disability, others may have severe intellectual disability.

Down syndrome is usually identified at birth or shortly after birth. Initially, the diagnosis is based on physical characteristics that are commonly seen in babies with this genetic disorder. These include low muscle tone, a single crease across the palm of the hand, a slightly flattened facial profile and an upward slant of the eyes. This diagnosis must be confirmed by a karyotype chromosome study which provides a visual display of the chromosomes grouped by size, number and shape. This study is done by examining blood or tissue cells. As indicated earlier, the diagnosis can also be made based on tests done during pregnancy.

Resources

The Arc: <http://www.thearc.org/learn-about/down-syndrome>

National Association for Down Syndrome: <http://www.nads.org/resources/facts-about-down-syndrome>

Prader-Willi Syndrome

Prader-Willi Syndrome (PWS) affects approximately one out of every 12,000 to 15,000 people from both sexes and all races. While the cause of PWS is complex, the disorder is known to cause life-threatening obesity in children. Those with PWS may have low muscle tone, incomplete sexual development and short stature. Mild to moderate intellectual disabilities are common, and even if the intellectual ability is average, there are almost always learning issues present. Parents will find that a chronic sense of hunger, coupled with a metabolism that utilizes far fewer calories than is common, may lead to excessive and compulsive eating. People with PWS also may have motor and social issues.

Raising a child with PWS will have some unique challenges compared to raising a typically developing child and adolescent. Sure, most teens will say they have an insatiable appetite, but your child with PWS will likely have food on his or her mind all the time. It is a genetically driven obsession, and you should not underestimate its power. Remember that it is a biological drive; your child will rarely feel full, and then never for long. After your child has eaten, he or she will want to eat again, often within minutes. You can expect to regularly hear “Can I eat yet?”, “I’m hungry!” and “Is it time yet?” It can be frustrating, but try to remember how your child must feel and how much stress and anxiety these food questions cause him or her all day.

To reduce the risk of obesity, it is important for children with PWS to be taught the importance of a healthy lifestyle early in life. Managing and

preventing obesity is dependent on having a sensible diet, modifying eating behaviors and using an exercise plan. However, children with PWS may not want to exercise. Keeping your child active through fun activities that burn calories is important. Also, it is critical to make sure that the diet is low in saturated and other “bad” fats. But be careful! Not all “low fat foods” are actually low in fat, and there are many substitute simple sugars that become stored as fat.

We know that keeping any child interested in exercise can be tough. Here are some suggestions for helping children with PWS to exercise happily:

- Visit different playgrounds for different experiences.
- Use swings to help them with their sense of balance.
- Use climbing frames (jungle gyms) to assist them with their concentration, coordination, balance and problem-solving skills.
- Use slides and water slides, as they are not only fun, but they also require a lot of stair-climbing to reach the top!
- Use monkey bars to help build their upper body strength.
- Join a play gym or Gymboree club to increase opportunities for social interaction.

Children with PWS will often try to sneak or hoard food. Your child may argue and become resistant or aggressive. Staying firm, while knowing you are keeping your child healthy, is vital. It is also important to support your partner and other family members to stick with the plan. Using locked cabinets and other features to keep food out of reach will also help. Be sure to praise, hug and reward your child when he or she eats right and exercises. Starting early in life can build long-term positive habits.

Resources

Prader-Willi Syndrome Association: <http://www.pwsausa.org/>

International Prader-Willi Syndrome Organization: <http://www.ipwso.org/>

Spina Bifida

Spina Bifida occurs when the spine of a baby fails to close during the first month of pregnancy, leaving a permanent opening in the spinal column. This is called a neural tube deficit (NTD). About 1,500 babies are born with Myelomeningocele Spina Bifida, the most serious form, each year. The exact cause of Spina Bifida remains a mystery. No one knows what causes incomplete closure of the neural tube.

Scientists suspect that many factors may cause Spina Bifida, e.g., genetic,

nutritional and environmental. It is known that an insufficient intake of folic acid—a common B vitamin—in the mother’s diet is a key factor in causing Spina Bifida and similar problems. Prenatal vitamins typically contain folic acid as well as other important nutrients. In fact, in 1992, the United States Public Health Service recommended that all women of childbearing age consume 400 micrograms (mcg.) of folic acid daily to reduce the risk of having a pregnancy affected by Spina Bifida and other neural tube defects (NTDs). Since this requirement began, there are about 1,300 babies born each year in the United States that would have had a NTD if women had



not consumed folic acid.

There are four types of Spina Bifida: occulta, closed neural tube defects, meningocele and myelomeningocele.

1. **Occulta** is the mildest and most common form in which one or more vertebrae (bones of the spine) are malformed. The name *occulta*, which means “hidden,” indicates that a layer of skin covers the opening in the vertebrae where the bone has not fully closed around the spinal cord. This form of Spina Bifida is present in 10-20% of the general population. It rarely causes disabilities or symptoms.
2. **Closed Neural Tube Defects** are the second type of Spina Bifida. This includes several types of issues in which the spinal cord has malformation of fat, bone or meninges (the three membranes covering the brain and spinal cord). In most instances, there are few or no symptoms; in others, there is partial paralysis and urinary and bowel problems.
3. **Meningocele** is when a vertebra doesn’t close around the spinal cord and the spinal fluid and meninges push through a vertebral opening. The bulge contains no brain elements or spinal cord elements and may or may not be covered by a layer of skin. Some individuals with menin-

gocele may have few or no symptoms. Others may experience complete paralysis with bladder and bowel problems. For help in learning how to pronounce this condition, go to <http://dictionary.cambridge.org/us/pronunciation/english/meningocele>.

4. **Myelomeningocele** occurs when the spinal cord/neural elements are exposed through the opening in the spine, resulting in partial or complete paralysis of the parts of the body below the spinal opening. This may be so severe that the affected individual is unable to walk and may have bladder and bowel problems. For help in learning how to pronounce this condition, go to <http://dictionary.cambridge.org/us/pronunciation/english/myelomeningocele>.

A Mom's Story

"I wish I had known that every county in Florida has an early intervention program called Early Steps for every child born with Spina Bifida, no matter what form. Early Steps helps coordinate a plan to help the whole family who has a child birth to age three who is at risk of having a developmental delay. As a Mom with three young children, it was a huge blessing to have therapists come into our home to work with our whole family in finding ways to help our son meet his milestones instead of me dragging him to another medical office. They gave me the tools to truly help my child and also equipped me with the knowledge I needed when facing doctors. While pregnant, I had done a lot to find out about community resources but missed hearing about Early Steps. When my child was born, I thought that we did not qualify for any programs because of having an average income. CMS had told us we did not qualify for any of their programs. I found out 17 weeks into my pregnancy that I was pregnant with twins and that one baby had Spina Bifida. I met with many medical professionals and no one told me about Early Steps... only CMS, which is income-based. Early Steps is not income-based. I was even in the hospital four weeks before the delivery, and no one mentioned Early Steps. Much to my surprise, before Andrew turned two months old, I got a call from Early Steps asking if someone could come to our home to chat with us about how to give Andrew the best start possible in life. I was shocked... someone wanted to help us, and they were asking to do this without me beating down their door first."

Parenting a child with Spina Bifida will depend on the severity of the disability. Many people, including children, may have the mildest form and never even know it. For others, there may be more severe forms with anywhere from a few complications to quite severe ones. The biggest problems for most who are parenting a child with Spina Bifida are bladder control and bowel control. The social issues regarding acceptance caused by the

sight and smell of these problems are far greater than other limitations. People born with severe forms of Spina Bifida must often use a catheter to empty their bladder. If they do not employ this procedure, they constantly leak urine into their clothes, carpeting, sofas, bed and bedding. They must empty their bladder every 4 hours, except at night when they are sleeping, in order to stay dry. Besides the social concerns, the medical impacts can be severe. A person with Spina Bifida is at risk of kidney failure if he or she refuses to use a catheter. This can cause irreversible damage due to kidney reflux; basically, the toxic fluids in urine back-flows into the system, damaging the kidneys.

Youth with Spina Bifida usually develop normally in intellect. They will have the usual emotional development and issues of adolescents. Problems handling anger, issues with fitting in, trouble deciding who they are (identity) and other normal developmental issues will probably become more extreme as they deal with catheters and other issues less common to typically developing teens. As a parent, you will find ways to support their self-care while focusing on their abilities.

Resources

Spina Bifida Resource Center: <http://www.spinabifida.net/>

Spina Bifida Association: <http://spinabifidaassociation.org/>

Center for Parent Information and Resources: <http://www.parentcenterhub.org/repository/spinabifida/>

Center for Disease Control - Living with Spina Bifida:

School Ages: <http://www.cdc.gov/ncbddd/spinabifida/school-age.html>

Toddlers: <http://www.cdc.gov/ncbddd/spinabifida/toddler.html>

Infants: <http://www.cdc.gov/ncbddd/spinabifida/infant.html>

OTHER DISABILITIES

A list of categories of developmental disabilities with brief descriptions can be found in Appendix A. This includes the definitions from the Individuals with Disabilities Education Act (IDEA) for diagnoses not covered above.

Resource

National Organization for Rare Disorders: <http://rarediseases.org/>

An Expert Opinion

“Parents of children with developmental disabilities find themselves becoming experts in lots of different areas, including laws and regulations, research and treatments and the various specialists that support the health of their children.”

- Adapted from Charisse Montgomery, Home Care CEO:
A Parent’s Guide to Managing In-home Pediatric Nursing



Chapter 5: *Autism Spectrum Disorder*



All children with developmental disabilities need support and respect for their individuality, challenges, strengths and contributions. The incidence (the number of children newly diagnosed) for most developmental disabilities has remained relatively constant over the last decade. However, the number of children diagnosed with autism and related disorders (now called autism spectrum disorder or ASD) have increased in new cases at an alarming rate. Currently, ASD is believed to occur in 1 out of 68 births, a huge increase from the approximately 1 in 30,000 births a couple of decades back. Males are much more likely to be diagnosed on the Spectrum for a condition other than Rett syndrome, which almost solely affects girls.

WHAT IS AUTISM SPECTRUM DISORDER (ASD)?

There have been some changes in the diagnosis of autism spectrum disorder. Many parents are still hearing about the five disorders under the umbrella of ASD that are laid out in the Diagnostic and Statistical Manual of Mental Disorders, 4th edition (DSM-IV). The idea of a “Spectrum” came out based on research that showed similarities in causes, symptoms and outcomes for various disabilities. The DSM-IV spectrum includes three subtypes of autism and two other conditions that share some factors.

1. Autism (or autistic disorder)
2. Asperger syndrome (or Asperger’s)
3. Pervasive developmental disorder not otherwise specified (PDD-NOS), sometimes referred to as “atypical autism”
4. Rett syndrome (or Rett’s disorder)
5. Childhood disintegrative disorder (CDD)

Some professionals still use these, and the use of “autism” and “Asperger’s” is quite common. Later in this chapter, we discuss how autism spectrum disorder has been described since 2013 in the DSM 5th edition (DSM-V).

While each child is different no matter how he or she is developing, and there are differences in the different disabilities on the Spectrum, there are four factors that have been consistent with children on the Spectrum across decades of research:

1. Developmental challenges begin before 2.5-to-3 years of age
2. Social development problems that have a number of special features that are not consistent with the child’s intellectual level are displayed
3. Language development is delayed or atypical in predictable ways that are also not consistent with the child’s intellectual level
4. Poor adaptation and the child becoming easily upset by changes,

insisting on everything staying the same, including possible repetitive movements or patterns of play, with aggressive resistance to change being displayed

Next, the disorders on the DSM-IV described disabilities are briefly described.

Autism or Autistic Disorder

Autistic disorder is a neurological and developmental disorder that usually appears during the first three years of life. A child with autism appears to live in his or her own world, often showing little interest in others or little interest in how to interact with others in expected ways. The focus of a child with autism is on a consistent routine and includes an interest in repeating odd and peculiar behaviors. Children with autism often have problems in communication, tend to avoid eye contact and show limited attachment to others.

CDC Causes and Risks of Autism

- Most scientists agree that genes are one of the risk factors that can make a person more likely to develop ASD.
- Children who have a sibling with ASD are at a higher risk of also having ASD.
- ASD tends to occur more often in people who have certain genetic or chromosomal conditions, such as fragile X syndrome or tuberous sclerosis.
- When taken during pregnancy, the prescription drugs valproic acid and thalidomide have been linked with a higher risk of ASD.
- There is some evidence that the critical period for developing ASD occurs before, during and immediately after birth.
- Children born to older parents are at greater risk for having ASD.

Asperger Syndrome

People with Asperger syndrome, or Asperger's, are often seen as being awkward, isolated and shy and having eccentric behavior in childhood. There are always problems in verbal and non-verbal communication, although these can differ in degree. Though understandable, their speech may sound peculiar due to an odd choice in words or tone. Clumsiness in movement is common, especially large movements like walking. Persons with Asperger's usually have a limited number of interests. This often leaves no room for more common interests, and their interests may not always be age appropriate, e.g., collecting toy cars well into adulthood. Other examples from actual persons with Asperger's are interests in trains, French literature, door knobs and hinges, cappuccinos, meteorology, astronomy and history.

Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS)

Pervasive Developmental Disorder is a general category used to describe a pattern of behavioral differences in socially relating, communicating and showing attention/interest. Children who demonstrate a number of features or symptoms in these three areas, and whose problems are not better explained by other diagnoses, may receive a diagnosis of PDD. This diagnosis may also be applied if the child exhibits a variety of the symptoms associated with autism but in an unusual pattern.

Rett Syndrome

Rett syndrome is a neuro-developmental disorder that affects girls almost exclusively. Rett syndrome starts with normal early growth and development, but it is followed by a slowing of development, loss of purposeful use of the hands, distinctive hand movements, slowed brain and head growth, problems with walking, seizures and intellectual disabilities. Rett syndrome is estimated to affect one in every 10,000 to 15,000 live female births in all racial and ethnic groups worldwide. Since the disorder occurs spontaneously in most affected individuals, even though it is a genetic disorder, the risk of a family having a second child with the disorder is less than 1%.

Childhood Disintegrative Disorder

CDD is also known as Heller's syndrome. It is a very rare condition in which children develop normally until at least two years of age, up to as old as four years of age, but then have a severe loss of social, communication and other skills. Unlike autism, someone with CDD shows a severe loss of abilities after several years of normal development, with a more dramatic loss of skills than a child with autism does.

The majority of persons on the Spectrum are diagnosed with autism or Asperger's. If your child is found to have ASD, you are likely quite anxious, confused and not sure what to do. You might wonder "Why your child?" and "Why so many children now compared to not-so-long ago?" You might wonder, if you have noticed some of the behaviors described above, how to go about getting a diagnosis. You might be unsure and wonder what the "red flags" are for ASD. Or, maybe you have already found out that your child is on the Spectrum and wonder what that means for your family. Hopefully, we will answer some of your questions in the next sections.

THE DSM-V AND ASD

Diagnosis since 2013 has moved away from using different diagnostic names and concentrating on common problem areas and looking at the level of impairment (the severity level). The changes recommended by the American Psychiatric Association for the DSM-V criteria for ASD are a better reflection of the state of knowledge about autism. It is believed that a single umbrella disorder will improve the diagnosis of ASD without lowering the accuracy of a diagnosis. The new criterion also asks if there are accompanying issues like intellectual or linguistic impairment. The two main areas of assessment include:

1. **The person's difficulty with the social use of verbal and nonverbal communication.** People with ASD tend to have communication deficits, such as responding inappropriately in conversations, misreading nonverbal cues (body language) or having difficulty building friendships appropriate to their age.
2. **The degree that restricted, repetitive patterns of behavior, interests or activities are present.** People with ASD may be overly dependent on routines, highly sensitive to changes in their environment or intensely focused on inappropriate items.

There are several examples of symptoms under each main assessment area. Each symptom present is assessed for its level of severity, using a three-point scale that identifies the amount of support needed. The symptoms for each individual will fall on a continuum, with some individuals showing mild symptoms and others having more severe symptoms. This Spectrum allows clinicians to account for the variations in symptoms and behaviors from person to person.

Under the DSM-V criteria, individuals with ASD must show symptoms from early childhood, even if those symptoms are not recognized until later. This criteria change encourages earlier diagnosis of ASD, but it also allows people whose symptoms may not be fully recognized until social demands exceed their capacity to receive the diagnosis. This is an important change from DSM-IV criteria, which was geared towards identifying school-aged children with autism-related disorders, but it was not as useful in diagnosing younger children.

INCREASE IN NUMBER DIAGNOSED OVER THE LAST DECADE

Why the big increase in the number of children diagnosed on the Spectrum? That is a natural question for the parents of a child with ASD and for



anyone planning to become a parent. There have been many responses to this question, but only two have found some consistency in research:

1. That the true number of children with autism is rising due to an environmental cause
2. That the rise in numbers is mostly due to increased monitoring and changes to the definition of autism

Let's look at the first. Environmental causes would be toxins, pollutants, dyes in foods and others. There is limited evidence about dyes and other food issues, e.g., gluten, but you should educate yourself and decide on what you are comfortable with your child eating. This includes the mother's diet before and during pregnancy, after pregnancy if breastfeeding and the child's diet going forward. There is suggestive evidence about foods and dyes, but there is nothing absolute based on strong research. Similarly, information on toxins and pollutants is unclear. It is true that heavy exposure to lead can cause intellectual disabilities, but the link of toxins and pollutants to ASD is much less clear.

You may be asking yourself, "What about vaccines?" You may have heard discussions (or even arguments) over whether there is a link between vaccines and autism. The main evidence for the supposed link between vaccinations and autism was that the number of diagnoses of autism increased dramatically at the same time that the number of vaccines routinely given to children increased in the 1990s. There was also a onetime spike in cases of autism due to a tainted mercury-based preservative (Thimerosal), which is no longer used in routine childhood vaccines, used around the same time. **Because two things happen at around the same time does not mean that one caused the other.** This is like saying that the number of flu cases in people increased at the same time that more people got smartphones in a community, so smartphones caused the flu. The evidence is clear that vaccines prevent many childhood diseases that could have very serious effects on children. As a parent, you must make decisions about vaccines based on evidence, advice from your doctor and your own beliefs.

The second reason for the ASD increase is changing the definition of autism and the increase in the ability of medical and other professionals to detect new cases (better diagnosis, tests, reporting, etc.). A prime example would be the changes from the DSM-IV to the DSM-V noted above. **Any time you broaden a category, the number of individuals that fit into that category is likely to increase.** For example, it was found in a 1980 study that 25% of adults that were diagnosed with developmental language disorder would have been diagnosed with ASD today under the DSM-V criteria

(Bishop 2008).

Resources

CDC Facts about ASD: <http://www.cdc.gov/ncbddd/autism/facts.html#ref>

DIAGNOSING IS COMPLICATED

There is no getting around the fact that diagnosing a child with ASD, and deciding the best way to help him or her and the family, is complicated.

There is no one specific diagnostic test for ASD. Instead, a professional will use a number of methods to diagnose and check them against the latest criteria that looks at social ability, communication (language), behaviors (especially repetition) and sensory symptoms (see Chapter 6). The professional may (taken from the Mayo Clinic best practices):

- Observe your child and ask you how your child's social interactions, communication skills and behavior have developed and changed over time
- Give your child tests covering speech, language, developmental level and social and behavioral issues
- Present structured social and communication interactions to your child and score his or her performance
- Include other specialists in determining a diagnosis
- Recommend genetic testing to identify whether your child has a genetic disorder such as fragile X syndrome

Resources

Mayo Clinic Autism Tests and Diagnosis: <http://www.mayoclinic.org/diseases-conditions/autism-spectrum-disorder/basics/tests-diagnosis/con-20021148>

RED FLAGS OF ASD

Red flags indicate that ASD **may** be present. Even mentioning red flags is done with hesitation, since many red flags can be related to other issues. However, as a parent you are likely to hear about these “red flags” if you are having your child evaluated. This is why a qualified professional is needed to determine if the red flags your child is demonstrating are in fact those of ASD. There are numerous lists from different organizations on these signs, with these lists having many flags in common. They have lists in categories that include general, communication, behavior, social, intelligence, sensory and motor. Next under resources are links to sites with red flags and other information.

Resources

CDC Signs and Symptoms of ASD: <http://www.cdc.gov/ncbddd/autism/signs.html>

Children's Therapy and Resource Center: <http://www.kamloopschildrens-therapy.org/autism-red-flags-preschool>

Autism Speaks: <https://www.autismspeaks.org/what-autism/learn-signs>

ASD AND THE FAMILY

Almost all parents that have had a child diagnosed on the Spectrum recall some sense of disbelief, panic and sadness. As a parent, you may feel the same thing. You may wonder about your child's ability to become an independent adult, to make friends or to make major life decisions. You may be concerned about making ends meet and affording costs. You may wonder how well your child with ASD and his or her typically developing siblings may get along.

Being prepared is the key. Read the following facts and begin to think about how you and your family will adapt. Do not be saddened by or frightened by these. As we try to be uplifting, we are also trying to prepare you. Many parents with a child on the Spectrum contributed to this guidebook, and they all have great joy in their child. The thought they all shared was that planning is critical, but it was also knowing that sometimes plans won't work and you have to think on your feet.

- Parents of children with ASD have more caregiving burdens (as you might expect), more limits on time and activities and have a higher likelihood to quit their jobs due to child care problems (Lee et al., 2008). *How will you plan to share responsibilities, as well as good times and joy?* (You may find chapters 9, 11, 14 and 17 helpful to answer.)
- Parents of persons on the Spectrum are at a higher risk for having physical and emotional problems as compared to parents of non-disabled children (Bromley, Hare, Davison & Emerson, 2004) or compared to children that have other disabilities (e.g., Down syndrome) (Allen, Lowe, Moore & Brophy, 2007).
- Stress and depression are a risk for parents. While support can reduce stress and depression, a key concern for parents is what is known as "stress proliferation" (Benson, 2006). This is the tendency for stress to pile on and pile up. For example, the stress of dealing with the behaviors of your child with ASD may pile up with work stress, making you feel worse.

We know that this sounds scary, but with good planning and taking care of yourself (the focus of Chapter 10), you will be fine. Here are some tips for adjusting your family to having a child with ASD:

- Don't let yourself feel ignored by the professionals involved in the diagnosis and the treatment you encounter as you start your journey. As a parent, you are the most important member of the team.
- Don't buy into wrong information and stress yourself out even more by trying a bunch of unproven remedies. Parents will often try many things out of frustration. In fact, in one study, 71 parents of a child on the Spectrum confirmed that they had used an average of six alternative treatments with a range of 0 to 27 (Harrington, Patrick, Edwards & Brand, 2006). For many, this was high cost with little gain.
- Take steps to get some time off (called respite). Even an hour has proven to be very rejuvenating.
- Be willing to talk about any needs that are not being met. Being strong is fine, and keeping a positive attitude is a must, but being *too* strong can leave you taking on too much and exhausting yourself.
- Seek support! There are many support groups and service organizations that can help you. The most common unmet service needs are information on services, family support services and respite care. Start early, finding and keeping track of support and service information. Support groups and similar services can often change locations, so plan to check back every so often.
- Don't be afraid to foster a relationship between your child with an ASD and your other children. The constant connection, shared space and ongoing contact between them can help their relationship and give them something to count on.

Resources

Center for Autism and Related Disorders (CARD): <http://florida-card.org/>
Autism Web: <http://autismweb.com/>

*"If you've met one person with autism, then you've
met only one person with autism."*

- Donna Hagan, Healthy Start Jefferson, Madison and Taylor

Chapter 6: Understanding Sensory Issues

When you see, touch, smell, taste or hear, you are using your senses. Children experience *sensory input* (e.g., hearing and seeing) as a natural part of development. Your child's central nervous system and brain automatically process information as sight, hearing and other senses. He or she then reacts either automatically, e.g., a reflex, or by thinking of a response. Sometimes the thought is very fast or is on "autopilot." Have you seen a child watching something on television, become thirsty and barely recognize when he or she picks up the glass for a drink? Or he or she hears the doorbell and has to respond with a more complex behavior and get up to answer it? This is all sensory processing. When your child has the ability to sense incoming information and respond to it in appropriate ways, then he or she are said to have "sensory integration."

Sensory integration refers to the ability to receive input through all of the senses and to process this information into appropriate responses. Sensations work together to provide the body with a descriptive picture of the world and our place in it.

THE SENSES

Most everyone has heard of the five senses. But did you know that there are actually a few more?

- **Touch, or Tactile**, is the first sense to develop and includes the ability to feel throughout the body. Tactile includes external (e.g., picking up a toy) and internal (e.g., the experience of indigestion or cramping). Different "sensors" in the body send information to the brain on pressure, temperature, pain and texture.
- **Vision** is made up of your two eyes working together. Visual attention is being able to watch something for a period of time. Doing an examination for proper vision is part of most evaluations given to children with developmental disabilities.
- **Sound, or Auditory**, is a sense that starts in the muffled world of the womb. As we age, we learn to attend to some sounds and to ignore others. Children that are more sensitive to specific frequencies may have an underlying issue.
- **Taste** and smell are strongly linked; both are needed to enjoy (or not enjoy) different flavors. We process five tastes: salty, sweet, sour, bitter and umami (savory) flavors.
- **Smell** is the most powerful memory trigger. We can detect over 10,000 different aromas.

Here are some senses you may not be as familiar with...

- **Vestibular** is the “balance” sense. It relies on the inner ear to inform us about movement and gravity.
- **Proprioceptive**, or the “body awareness” sense, tells us where we are in space through input from muscles, joints and connective tissue. This allows us to move and know where our body is in the dark.
- **Interoceptive** is an internal body sense that detects changes in heart rate, blood pressure, hunger, thirst, bowel sensations and bladder sensations.

SENSORY ISSUES ARE NOT AS RARE AS YOU THINK

What is hard about noticing and diagnosing sensory issues is that they can be subtle, and some of them can be caused by things other than sensory deficits. It takes a professional, often an occupational therapist, to determine what are and are not sensory issues. Everyone has preferences in what they like to hear (like music), see, taste, eat and feel. Sensory input becomes an issue when it interferes with daily living, or when it is something a person is uncomfortable with. For example, anyone might be uncomfortable with dropping four feet to the ground while climbing down the side of a hill. However, most people are not uncomfortable if their feet leave the ground for a moment when walking upstairs. Another example is that we can expect occasionally having trouble sleeping, but constant problems falling or staying asleep could have many possible causes, including sensory integration issues. Being well integrated is the normal state for most people. Children with developmental disabilities and sensory issues are the reverse: they are well integrated too little of the time.

RED FLAGS OF SENSORY CHALLENGES

Children diagnosed with ASD and other developmental disabilities often have sensory challenges. Some children with a developmental delay may have sensory issues too. They may either be more or less sensitive to the environment than other people are. These sensitivities can regard how things sound, feel, smell or look. They may even relate to the temperature. For example, some children are very sensitive to temperatures and may become agitated when playing outside if they become hot. Alternatively, they may not feel cold and prefer to wear shorts all year long.

Avoiding eye contact may be due to shyness or due to a sensory issue. A child may gag easily or have to separate his or her food and eat one thing at a time due to texture, temperature or other issues. A child may avoid

climbing, jumping or being on uneven ground. A child might have difficulty with the noise level in a classroom or store, or he or she may be unable to tolerate the feel of certain fabrics or the smell of a particular kind of food. A child may become consistently upset when grooming or crave a lot of heavy pressure, e.g., being tucked in a blanket like a burrito or always wearing heavy, long sleeves.

A child may be delayed in integrating his or her senses, may have a true sensory processing disorder or may have a sensory issue as part of a developmental disorder. As a parent, this can be overwhelming and confusing. You are not alone. Many professionals find it hard to determine how serious a problem is. With time and understanding, solutions are usually found.

SUGGESTIONS FOR WHAT TO DO YOU IF YOU SUSPECT SENSORY CHALLENGES

For parents, deciding whether their child has a sensory problem is like solving a mystery. If you think that your child has a sensory issue, there are some things you can do. You should make an appointment with a professional for an evaluation. If your child is not yet three years old, you can get a free evaluation at your local Early Steps office. Be sure to collect information before the evaluation, so you can fully inform the professionals. You'll see that the questions listed next have to do with behavior. A child's behavior is what clues in professionals to a sensory issue, a behavioral issue or both. Write down your answers to the following:

- What, as specifically as possible, concerns you about your child's behavior?
- How long has the behavior gone on?
- When did it start?
- Has it changed in any way recently? For instance, has it become more or less frequent?
- Is the behavior the same in different places (home, day care, grocery store)?
- How predictable is the behavior? What are the triggers, meaning does it happen only with certain people, at certain places, when doing certain activities or at certain times?

An excellent guide that provides sensory integration activities was written by two Florida occupational therapists. The book is *Advance My Baby: The Ultimate Secrets of Your Baby Birth to 3 Years* by Tarver and Martin (2011). You will find that many of the activities in the book will help your

child more fully integrate his or her senses and are enjoyable for both you and your child. Massaging your baby, rubbing body lotion in, playing with light-up toys, singing to your baby, swinging, rocking and swimming are all sensory integration activities. For older children, bike rides, pillow fights, a brisk towel rub after a bath, squeeze toys and playing with clay or putty are common activities.



CREATING A SENSORY ENVIRONMENT IN YOUR HOME

Firstly, it is very important to learn which sensory experiences are pleasing to your child. Including a professional, usually an occupational therapist, in the design of your “sensory area” can help you as you choose. Be sure to ask the therapist if he or she has had any training in building a sensory environment. Building a sensory environment helps a child to be more independent as he or she gets older. Don’t worry, you can build a sensory area without breaking the budget. You do not need a whole room, though some do find a way to dedicate an entire sensory room. The main thing about a sensory area is that the child can explore and make choices based on what the child feels he or she needs at that moment. Keep in mind that your goal is to help your child to engage different parts of his or her brain in a safe environment.

There are some common do’s and don’ts in creating a sensory area (adapted from Maureen Wallace and others, e.g., <http://www.sheknows.com/parenting/articles/1014235/sensory-processing-disorders-create-a-multi-sensory-experience-room>):

DO...

- Include different objects and areas that are safe and durable, giving your child options that promote self-determination.
- Include mirrors to multiply the sense area, but make sure they are safe and not overwhelming.
- Make sure to have sensory tubes, which are big plastic tubes that children can crawl through. It is important to have them in different colors if more than one tube is used. This may be substituted with one or more tents so the child can be closed in and/or cuddled. The idea is to have a safe “fort” for the child.
- Use differently colored lights with differing intensities. A simple dimmer switch can help. If possible, include a projector with slowly moving lights on a wall. Make sure the light moves from left to right, the way we read. Having a board with different switches and lights gives the child control. Try to avoid fluorescents or other lights that don’t match natural outdoor light. Lava lamps are great too.
- Keep a bucket of simple toys, e.g., balls, brushes or blocks. Different textures, hard to soft objects and different colors are important.
- Use smells. Introduce scents that you have found are not distracting or disturbing to your child. Change the scents every few days.
- Keep the area soft and padded to avoid injury if your child slips

or falls. Have more than one level, giving your child something to safely climb. Make sure that there are soft areas to relax on. Kids love bean bag chairs.

- Remember sounds, being sure to use different music at different volumes. Once you determine which music your child tolerates, it is easy to use phones and tablets to create playlists with different music. Change things up once in a while to see if your child's tolerance is growing. Make sure that the music is instrumental only. No voices or singing.

DON'T...

- Overdo it. A little can go a long way, and you can always add more in the future. A sensory area is meant to help calm the child, regulate him or her and integrate his or her senses.
- Push the child to explore. Help by guiding him or her hand-over-hand or through modeling. Try to limit talking.
- Use the space as a babysitter. If, however, your child voluntarily goes into the area to relax or play, that is fine.

Resources

Sensory Processing Disorder: <http://www.sensory-processing-disorder.com/>

Sensory Integration/Sensory Processing Disorder: http://www.brighttots.com/sensory_integration.html

Signs and Symptoms of Sensory Processing Disorder: <http://www.brainbalancecenters.com/blog/2012/04/signs-and-symptoms-of-sensory-processing-disorder/>

The American Association of Multi-Sensory Environments: <http://www.aamse.us/>

The MORGAN project and MORGAN's Place: this is an organization in Melbourne, Florida that has a facility that allows children to experience lots of different sensory interactions. The website also has resource for parents (<http://themorganproject.org/>).

Suggested Books:

- *Advance My Baby* by Paula Tarver and Jeanne Martin
- *Raising a Sensory Smart Child* by Lindsey Biel
- *The Out-of-Sync Child* by Carol Kranowitz

Chapter 7: *Mental Health and Attachment Challenges*



Attachment and bonding between a parent and a child are vital for social, emotional, linguistic and cognitive development. Whether the child has a developmental delay, has a disability or has typical development, how a parent cares for a very young child has a significant impact on the emotional health of that child. At the same time, some parents will have had distant parents that were poor models of how to be a responsive and loving parent. In this chapter, we talk about how important the relationship between the parent and the child is. We will also address what you can do to foster the strongest possible attachment to your child.

UNDERSTANDING INFANT MENTAL HEALTH

As adults, we tend to think of mental health as something within us. Though we know that others can influence how we feel, we still “own” our mental health. For infants and toddlers, mental health is just starting out. It is being developed with the assistance of others, mostly you, the parent. Infant mental health is based on the belief that ideal growth happens within nurturing relationships. Thus, the relationship between the infant and the parent is the bedrock of future social and emotional development.

Attachment and bonding are not the same thing, but they are related. Attachment is seeking to be with someone that will comfort, protect and calm us. A child attaches to the parent as his or her primary source of love, comfort, care and survival. Although the parent is also attached to the child, it is different, as the parent is the strong one. This bond from the parent to the child is the instinct to provide comfort and protection. Every time you respond to your child’s cries with food, cleaning, soothing or playing, you are protecting your child, strengthening both your bonds and strengthening your attachments.

As an adult, you know that some adults are easier to understand and be around than others. Similarly, infants and toddlers that are really active, hard to engage, withdrawn or difficult to understand can make nurturing more challenging. A challenging child does not mean an unhealthy one. Infant mental health is a product of the relationship between the parent and child, as well as that child’s temperament. Temperament is the typical way a person reacts or behaves. As adults, one might be called social or shy. Similarly, an infant might be considered easy or difficult. Activity level, biological rhythms of eating, sleeping, eliminating, moodiness/type of mood, distractibility and other factors are all parts of temperament.

THE CRITICAL ROLE OF THE PARENT

A child has an inborn need to attach to one main person. As babies, the way we are held, talked to and cared for teaches us about who we are and how we are valued. This profoundly shapes who we will become. The first days, months and years of life are when the adults who care for us can truly promote strong and positive mental wellbeing. You, a parent, may have had a rocky time growing up. Maybe you experienced trauma or loss as a child, adolescent or adult. Sometimes these experiences can get in the way of nurturing others, because we are unsure about sharing our emotions. This may make it harder to give ourselves fully to the bond with our child.

If you are worried that you are having a hard time connecting with your child, you are not alone. Some parents may feel distant from a child with an obvious disability, because they are confused and afraid. They don't know what to expect. This can be on top of their own possibly difficult early experiences, making things even more confusing and stressful. A new infant is a scary responsibility, especially for new parents. If the baby is premature, underweight, difficult to comfort, hard to feed or failing to thrive, he or she is at risk for developmental delay, even if on the surface he or she do not have a recognizable disability like Down syndrome. Such responsibility can be quite stressful.

It is helpful when service providers and professionals you see have an infant mental health point of view: looking for familial strengths, listening actively to the family's needs, helping the family identify stressors and helping the family to keep the baby in mind. Make sure when you begin receiving services that your provider is consistent with these points.

ATTACHMENT TO A CHILD WITH A DISABILITY... THE DESTINATION IS THE SAME

By now, you know that babies have "mental health." They are deeply feeling beings that are developing a sense of who they are, their value and their worth from day one. This process begins with the sharing that takes place during everyday moments, like feeding. The journey to attachment and bonding may be different if your child has a disability, but the destination, or goal, is the same. Indeed, for a child with a disability, the importance is even higher for you as a parent to be a safe haven. A child with a disability may have additional needs or may take longer to respond to your parenting. Do not give up and do not despair. You will learn the language of how to respond to your child and grow a bond and attachment.

Some parents are in the stressful position of having to care for a child with a fragile medical condition. This can mean that treatment by the parent may cause pain to the child to improve health. If this applies to you, then you know how traumatic this can be for both you and your child. You need to believe that all the other interactions — the smiles, gentle words, caresses and comfort — more than offset having to be strong and do for your child what he or she cannot do for himself or herself.

PARENTS, YOU PROMOTE MENTAL HEALTH AND ATTACHMENT EVERY DAY

We know all this can seem both hopeful and depressing at the same time! Children with disabilities are more likely than other children to develop social, emotional and behavioral difficulties. Perhaps even more than other children, they need interactions with caregivers to shape their ability to learn, to love, to be confident, to be empathic and to be curious.

The main thing to remember is that all behavior has meaning. The more you understand your child, the better you will meet his or her needs and the stronger the bond and attachment will be. As you get to know your child, protect him or her by planning ahead. For instance, if you know your child is slow to warm up in new situations, make sure to keep him or her close to you as he or she looks around and gets comfortable. If you know your child has a hard time with transitions, which is very typical of a child on the Spectrum, bring a special toy or another familiar object in the car when going somewhere. As you get to know your child, you'll know what is specific to him or her that you will need to adapt to.

Remember these as well...

- Mutual joy between a child and parent is a direct road to attachment. Touching the child, gazing into each other's eyes and enjoying the comfort of mutual contact stokes the fire of attachment. You may be a parent with a child that is in, or was in, a Neonatal Intensive Care Unit (NICU), or you may have been kept from holding your child for some other reason early on. You can and will "catch up" with attachment. When your child leaves the NICU in your arms and with your family, you can immediately start putting into action the suggestions in this chapter... and let the bonding begin!
- You can't overdo it. Spoiling a baby by too much attention is impossible. This is especially true for a child with a developmental disability or delay. If your child does have special needs, you may need to take extra care in following the child's lead. Your child may

be more sensitive to touches, light, sounds, tastes and smells. If so, take your time. All children have a built-in resilience. As you learn about him or her, you and your child will adapt.

- Don't panic or withhold from your child if he or she is having a hard time or seems to be experiencing painful feelings. Now is the time for bonding. Be strong, patient and gentle. A baby crying for hours can be frightening. The child may fall asleep only when he or she is exhausted. Remember that your patience is the most important thing. Despite all the child may be feeling, he or she is very aware of your commitment and presence.

How do you learn more about this? The Circle of Security (COS), <http://www.circleofsecurity.net/>, is a good online resource that also has support groups across the country. The main message of COS is to be a strong resource and leader for your child...

*Always be bigger, stronger, wiser and kind
Whenever possible, follow your child's lead
Whenever necessary, take charge*

ATTACHMENT AND DEVELOPMENT

Did you know that attachment behaviors are directly linked to development? For instance, the more that parents talk to their child, the faster the child learns language, and the more that parents hand toys to a child and play, the better the child's skill with objects are. Smiling, laughing and showing different expressions to a child improves his or her social skills. The more parents stimulate, respond to and appropriately meet needs of hunger, fatigue and a messy bottom, the stronger the attachment becomes. In fact, it's been proven that strong eye contact between a mother and a child leads to crying to stop faster. When you talk out loud to your child about feelings, he or she begins to learn about what different feelings are, what to call them and how to talk about them.

Infants and toddlers use their parents as a safe base and a shelter. They explore the world, having the experiences that support development only when they feel safe and comfortable enough to do so. When your child comes to you when feeling hurt or needing comfort, when he or she looks back at you when exploring, when he or she gets excited to see you when you have been away — all of these support development. Remember, you are not trying to stop your child from having any distress. A child has to cry to signal to you that he or she needs something. Children learn to han-

dle frustration by dealing with it in small amounts. As an attentive caregiver, you are trying to keep the distress within reasonable limits.

If your child is having problems that you think might be related to attachment or development, don't hesitate to get help. One of the biggest problems with the term "mental health" is stigma. Don't fall into the trap of worrying about what others will think. What matters most is what you think about yourself and your child. Getting help *is* good parenting.

TRAUMA AND BRAIN DEVELOPMENT

It is an unfortunate truth that children and infants can experience trauma. This can be from parents, siblings or many others. It may also be due to a car accident or something else tragic and unexpected. Obviously, there are many factors that contribute to mental health difficulties in infants and toddlers. Let's review briefly what happens to the brain of an infant/toddler when it is exposed to trauma. The main point here is that very real changes can happen, and you are strongly encouraged to get an assessment for your child if he or she is exposed to trauma. A strong bond will help buffer the child from the impact of trauma, and attachment can help reduce the long-term impact.

During the first few years of life, the brain undergoes extraordinary changes. Millions of neurons (the thinking cells) in the brain begin reaching out and connecting to each other. The connections are made from the synapse to the synapse of each neuron. The synapse is the part of the neuron that communicates with other neurons. Depending on how important it is and where it is located, a cell can have many synapses. Connections made during sensitive periods directly influence specific learning. For example, an infant's repeated exposure to language helps his or her brain build the links between the neurons needed for him or her to learn words. Attention, sensitive care giving and responsive parenting help build connections in the brain.



Unfortunately, few lives go without some trauma. We and our children are quite resilient. If they have a good attachment, the effects of trauma can be limited. However, some children get exposed to many traumas. They are the most at risk for mental health problems as they get older.

We have all been scared speechless at some point. Our heart races, our mouth goes dry and we cannot think of anything but how to escape. There is a more basic part of our brain where emotions are generated, as well as responses to trauma. Part of this system is our danger- warning system that activates our body's stress response. You have certainly felt very aware when something makes you afraid. That was this system pushing all other considerations aside for self-protection. A couple of things you may not know are...

1. The more trauma a child experiences, the more the parts of the brain literally change physically to react faster and faster. This includes reacting to things that remind him or her of the original trauma, even years later. Then, he or she has a harder time slowing it down, and when no danger is present, turning it off.
2. The part of the brain that controls speech actually reduces activity when a person is experiencing something dangerous or traumatic. Thus, it is hard for you or a child to put your experiences into words. This can linger for years. Maybe those people frozen in fear in horror movies, the ones that make us wonder why they just don't call out, had a reason after all!

Children who have been traumatized can lose their belief in the generally good universe that they are in. They constantly look closely at their environment, expecting the worst. In fact, they may actually help cause the worst by being suspicious and distant. Others may simply pull away, reinforcing to the child that no one cares. For a traumatized child, the whole world becomes full of triggers.

If you believe your child has been traumatized, and that this may be due to abuse from someone, neglect (not meeting the basic needs of a child, resulting in chronic distress), being around loud and angry people much of the time, being bitten by a dog or other traumas, seek help immediately. If there is an injury, medical care is, of course, the first step. Ask your medical provider about local resources for childhood trauma. If your medical provider does not know, look at the websites listed next under resources. Contact them directly if you do not find what you need on their websites. If you need to, call the police immediately (911) and/or call in an abuse report using the Florida Abuse Hotline at (800) 96-ABUSE.

Having a child evaluated is the responsible thing to do. If trauma occurs, increase your bonding behavior. Spend time holding your child. Be calm and soothing with him or her. Do not ignore the trauma, but help to model that there are many positive things in the world too. Help your child focus on these positives. Be aware of any changes in your child's social and emotional development, which is the subject of the next chapter.

Resources

Florida Association for Infant Mental Health:

<http://faimh.org/>

The Florida Center for Early Childhood:

<http://www.thefloridacenter.org/infant-and-early-childhood-mental-health.php>

The Circle of Security:

<http://www.circleofsecurity.net/>

Children's Home Society of Florida:

<http://www.chsfl.org/page.aspx?pid=368>

Florida State University Center for Prevention and Early Intervention Policy:

<http://floridatrauma.org/>

The Florida Diagnostic and Learning Resources System (FDLRS):

<http://www.fdlrs.org/>

*“To the world you may be just one person,
but to one person you may be the world.”*

- Brandi Snyder

Chapter 8:

Social, Emotional, and Behavioral Challenges



Chapter 7 introduced attachment and bonding and talked about how important the parent's or primary caregiver's relationship is to the social and emotional development of your child. It all comes back to the parent as a secure base. When infants or toddlers feel secure, they are able to turn their attention to other tasks like learning how to get along well with other children and expressing emotions appropriately. In this chapter, we talk more about social and emotional development, as well as provide some hints if behavior becomes a challenge.

THE NECESSITY OF SOCIAL INTERACTION

Early relationships are crucial for the development of trust, empathy, compassion, generosity and conscience. These are the qualities of a person who has good emotional development. Yet, you may wonder what exactly social-emotional development means. A child with good social-emotional development is able to do the following in the family, the community and culture.

- Form close and secure relationships
- Experience, regulate and express emotions in socially and culturally appropriate ways
- Explore his or her environment and learn

People are social, and we live, in most cases, closely with others in our homes and community. Remember Tom Hanks in the movie *Cast Away* when his only friend was a volleyball? Remember how he spoke to it? Being with other people, trusted people, from the moment of birth is absolutely necessary for development. This is just as true for a child with a profound developmental disability.

UNDERSTANDING SOCIAL-EMOTIONAL DEVELOPMENT

Like most of the domains of development of those that have typically developed, we take our social and emotional development mostly for granted. You probably don't remember the earliest years when you were learning to communicate, share, control your anger, express joy and be a friend and family member. Like any person, young children experience a range of emotions in unique ways. As adults and parents, it is our job to help our children to learn to experience emotions without overruling their judgment, decision-making and common sense. In other words, we help our children to have emotional stability.

Not all children have positive experiences, strong role models or typical neural (brain) and physical development. Children with developmental disabilities have a higher risk of experiencing problems with mental health. Mental health problems for infants and toddlers might be reflected in physical symptoms such as poor weight gain/slow growth, delayed development, unstopable crying, sleep-related problems, aggressive behavior and paralyzing fear. Symptoms of depression, anxiety, post-traumatic stress disorder and other mental health disorders can begin to emerge in infancy and toddlerhood.

How do you know if your infant is developing correctly? Here are a few things to look for in an infant's/toddler's social-emotional development...

- Keeping eye contact with parents and other people he or she regularly sees
- Socializing through smiles and smiling when smiled at
- Regulating, meaning crying when he or she needs something but calming when you feed, change or comfort your child
- Sleeping peacefully
- Being aggressive, pushing away when distraught or angry, but then becoming calm when soothed. Normal emotional development includes being angry.
- Learning to do what you tell your child to do. Remember, as was said in Chapter 7, you must be the strong leader that protects and raises your child.

As you successfully parent your child, helping him or her to self-regulate and mature, you might ask yourself, "How do I know that my older child or adolescent has developed well?" Here are a few qualities that you might recognize in yourself too...

- Being confident
- Accepting and giving affection
- Having a healthy and positive self-esteem
- Resolving conflicts with others in healthy ways
- Being generous
- Respecting others and being respected

SOCIAL-EMOTIONAL DEVELOPMENT AND THE BRAIN

A baby is born with more than 100 billion brain cells. Some of these cells are already connected to other cells at birth. Babies are also born with a set of very useful instincts for surviving and orienting to their new environment. They prefer human company (a face, a voice, a touch or a smell) over

everything else. They naturally prefer people's faces and prefer listening to talking or singing over any other kind of sound. Babies also show a preference for faces with open eyes. When given a choice between fearful and smiling faces, newborns look longer at the happy, smiling faces. All of this not only supports attachment, but it is also crucial for language development.

During the first months and years of life, children's brains develop at an astonishing rate. During this period, children begin to develop not only their cognitive abilities but also social and emotional skills that will be key to their success in school and life. Did you know that a three-year-old's brain is twice as active as an adult's brain? By about age three, brain cells have made most of their connections to other cells. Over the next several years, connections are refined based on experience. Eventually, the adult brain will have far fewer connections but will be more efficient. All of those extra connections when he or she is so young affects how a child experiences and controls his or her feelings. As a parent, when you model proper social behavior, while teaching your child limitations, you are helping him or her choose the right connections to keep.

Young children need loving, responsive and predictable care and experiences, such as gentle touching, talking, reading, singing and rocking. Too many new experiences at once can overstimulate a young child and will not help with brain development. Young children need time to process what they have experienced and learn before they are ready for something new.

You will eventually help teach your young child to express anger and frustration in appropriate ways. He or she will learn to pay attention for reasonable stretches of time. When a child is able to interact with teachers and classmates nicely, he or she is at a great advantage upon reaching school.

A WORD ON STRESS: Brain development is responsive to experiences starting right from birth. Because the brain so easily changes and develops in the first few years, the earliest experiences of stress shape the way that neural pathways are formed. Children's brains will access those same neural pathways again and again as they grow up in order to determine how they should respond to stress. Thus, stress early on can have a profound impact on social-emotional development. When experiencing stress, it is natural to feel fear, frustration and anger. Children who experience stress with the help of a trusted adult learn to deal with negative experiences and emotions in a healthy manner. These early experiences guide the way your child deals with painful emotions and stress.

EXECUTIVE FUNCTIONING

Executive functioning involves the ability to solve a problem, to make decisions and to reassess a plan over time as new information is received. This develops slowly and is not complete until ages 19 to 25 in typically developing persons. Developmental disabilities will affect executive functioning, and children with even mild intellectual disabilities may have trouble making decisions later in life. This is because the connections between the prefrontal cortex (the brain center right behind the forehead), where “working memories” (the memories we access to make it through the day) are, and sensory areas of the brain (sight, hearing, etc.) may not develop as expected. Imagine how much harder it would be to make a decision or solve a problem if the senses we count on to tell us what is happening in the world around us, and the memories we need, the “data,” are not working in harmony with our decision-making. This is especially important to parents, because executive functioning is critical to being independent.

Everything is not lost, though. You can help by starting early to improve executive functioning. This is likely to be a lifelong support task of parents with a child with an intellectual disability. However, even a little improvement can help your child gain greater independence. Support starts by establishing routines for your baby. Repetition improves learning. Knowing what to expect helps babies feel safe, confident and in control of their world. Try to keep daily routines in the same order and at the same time each day. For example, there may be a morning walk, then a diaper change, then a bottle and then a few stories. Keep routines as the child ages. Help him or her make decisions by helping him or her understand how time and tasks intersect. An example is helping a child decide what to do in the few minutes before leaving for school. The families that have a morning routine, with each member knowing the steps to leaving the house on time, have a much easier existence than the families who seem to “wing it” each day. Keep routines throughout your child’s life. This can be frustrating, but remember that repetition is essential for improving executive functioning.

WAYS FOR PARENTS TO SUPPORT SOCIAL-EMOTIONAL DEVELOPMENT

Parents promote social, emotional and cognitive development by nurturing healthy relationships and creating opportunities for play, exploration, communication and learning. As a parent, you are the primary support for social and emotional development in your child. The good news is that you do not have to learn anything fancy or do anything superhuman. In fact, look at the following and rate yourself. If you rate yourself from okay to

great, just keep on going! Do you...

- Make frequent and lengthy eye contact with your child?
- Recognize your child's efforts? (Not successes, but efforts! We learn a lot from when we fail!)
- Give frequent, but not unearned, praise and encouragement?
- Have warm body language, voice tones and positive word use?
- Respond when your child tries to communicate, even if you are not sure what he or she is trying to communicate?
- Talk openly about experiences, emotions and behaviors?
- Make sure that you are physically close, holding and soothing your child while expressing affection?
- Hold your infant when feeding, not propping him or her up with a bottle?
- Spend time on the floor, interacting, playing and reading?

If you scored yourself high, congratulations! If not, that's what this manual is for. Try focusing on one or two of the above. Add more in when you are ready. There are so many other ways to support your child. Here are some for a few different ages of your child from the Zero to Three National Center website. To support social and emotional development in the first year of life, a parent should:

- Provide his or her baby with a consistent schedule
- Respond when the baby initiates interaction (smiles, cries, laughs, babbles or reaches)
- Praise the child as he or she masters new tasks
- Remain calm and be consistent as he or she deals with frustration and anger
- Support his or her developing sense of identity by introducing the child to language, music and food
- Nurture him or her through cuddling, talking, singing, reading and playing



To support his or her 1-year-old, a parent should:

- Observe, compliment and praise the child as he or she learns new skills
- Create opportunities for the child to play with other children
- Help him or her practice taking turns
- Distract and redirect the child to other tasks if he or she becomes frustrated or angry
- Provide him or her with stable routines and let him or her know about upcoming activities

To support older toddlers, a parent should:

- Schedule activities with peers, assisting children as they “pretend play” their way through different situations and experiences
- Help children learn to name and express emotions in constructive ways
- Assist children in observing and responding to friends’ emotions and experiences
- Provide toddlers with opportunities to practice sharing, taking turns and working through conflict
- Help him or her complete new tasks and praise your child’s success in problem solving and task completion
- Teach your child how to resolve conflict through discussion
- Help your child understand the rules and the benefits of cooperation

BEHAVIOR IS COMMUNICATION

Here we emphasize that behavior is communication, especially for young children or children with developmental issues that prevent them from clearly using language. When frustrated, it is easy for adults to think that their children are trying to make them angry or upset on purpose. Behavior is a form of communication that you or others may be having a hard time translating.

For some children with developmental disabilities, particularly those on the Spectrum but others as well, a repetitious behavior (e.g., banging, tapping, rocking or twirling) may be self-soothing and not a form of communication per se. Yes, this may mean that the child is experiencing anxiety or fear. He or she could possibly be showing a fear of change or reacting to a change in his or her environment. However, for other children, it is simply a habit of their nervous system. If you feel your child is self-soothing, make sure he or she is safe and unable to harm himself or herself by accident.

Talk to your service provider or doctor about your concerns.

Knowing your child, seeing all of your child's behavior in relation to development and not just focusing on the disturbing behavior is critical. All children have positive behaviors too. By focusing on the positive, you lessen power struggles and other issues. In fact, a sure way to make yourself frustrated as a parent is by comparing your child to others. All children are unique, and children with disabilities will have abilities too. Let yourself off the hook and enjoy what your child can do, including his or her unique qualities. Help your child with his or her behaviors.

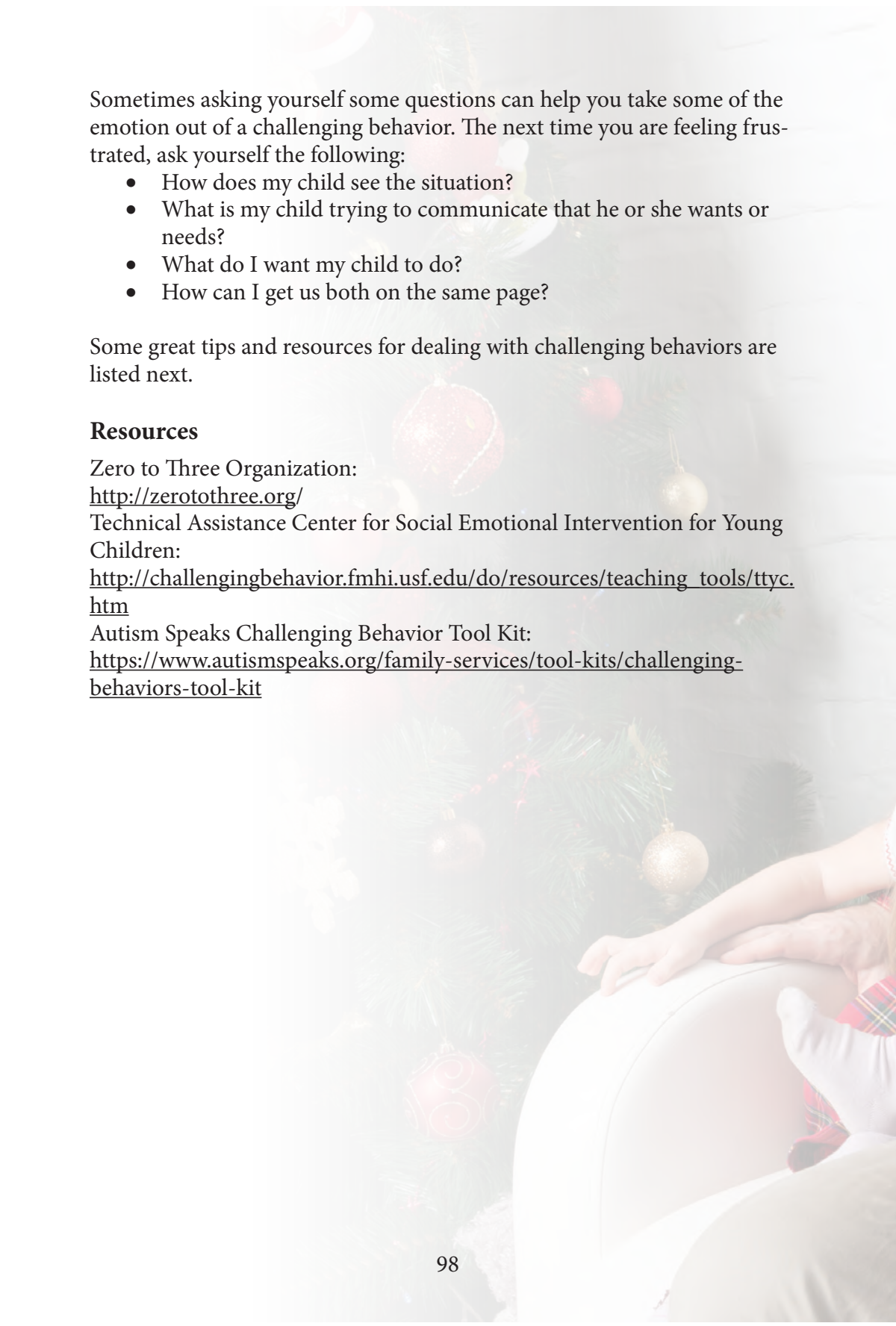
HELPING YOUR CHILD WITH HIS OR HER BEHAVIORS

The best estimates of serious behavioral concerns in children two-three years of age are between 10-15%. Around 10% of children that are of one-two years of age may have behavioral problems. Some children outgrow these issues, though over half of them do not. Problems should always be taken seriously but with hope. Remember that many of these problems do improve with care.

Not all children begin life in the warmth of their parents' loving arms. For these children, persistent stress (absence of responsive caregiving) can be toxic and harmful. This stress can be cause for social-emotional disorders, challenging behaviors and learning difficulties later on. These children, with and without disabilities, may learn habits of communication and responding that are self-defeating and lead to punishment instead of support. Again, focusing on the positive will help them begin to change their behaviors and redirect their neural pathways.

Finding your strengths, the strengths of your family and support system and, of course, the strengths of your child is important. Your feelings as a parent are incredibly important, and we strongly support talking to other parents and to trusted others (professionals, family members and friends) about them. Children can be taught the skills of self-expression and that their self-expression does not necessarily have to be through words. This helps them to better use behavior as communication. When children can have their needs met, they are less likely to engage in negative behavior.

A way to consider challenging behavior is an iceberg metaphor:
Tip of the iceberg = the observed challenging behavior
Just beneath the surface = the social-emotional skill needing support
Down deep = some possible unmet need of the child



Sometimes asking yourself some questions can help you take some of the emotion out of a challenging behavior. The next time you are feeling frustrated, ask yourself the following:

- How does my child see the situation?
- What is my child trying to communicate that he or she wants or needs?
- What do I want my child to do?
- How can I get us both on the same page?

Some great tips and resources for dealing with challenging behaviors are listed next.

Resources

Zero to Three Organization:

<http://zerotothree.org/>

Technical Assistance Center for Social Emotional Intervention for Young Children:

http://challengingbehavior.fmhi.usf.edu/do/resources/teaching_tools/ttyc.htm

Autism Speaks Challenging Behavior Tool Kit:

<https://www.autismspeaks.org/family-services/tool-kits/challenging-behaviors-tool-kit>



Chapter 9: Parents, Parenting, Feeling, and Thoughts

Children are not born with instruction manuals. The pressure of child rearing is further complicated by the diagnosis of a disability. For families raising a child with special needs, the paperwork alone can feel unbearable at times. At first diagnosis, a family raising a child with a disability may be simply trying to make it through one more day or sleepless night. Many parents who have a child with a disability report being unsure as to how to parent their child. They cannot rely as much on what they were taught and thus turn to other sources for information and support.

“It takes a village” is never more accurate than when raising a child with a disability. Family is the single most important influence on the growth and development of ANY young child. Did you know that over 20,000 families in Florida have a child diagnosed with a disability each year? You are not alone. There are many other families that, just like you, are just starting their journeys. Seek out these families and allow yourself to grow. Make some of these people part of your “village” of support and wisdom.

Early childhood intervention recognizes the importance of the family throughout the life of a child with a disability. For all children, parents are the primary and most important caregiver. The brightest star in the sky for any child is his or her mom and/or dad. Parents set the tone for the attitudes and beliefs of the family. For those parenting a child with special needs, unique challenges will be part of the journey. This chapter will address these challenges and will offer strategies for you to move forward on your journey as a parent. There are some important challenges and changes to consider, and in this chapter we help you to think about parenting a child with special needs.

NURTURING PARENTING

Healthy family functioning is directly linked to child development. Parents who experience high levels of stress, particularly from economic difficulties, may be less responsive and less affectionate with their children and more likely to demand compliance, as compared to parents without such stress.

Being a nurturing parent is about what your child *can* do, not what he or she is *supposed* to be able to do. Nurturing parenting focuses on helping

a child to improve developmentally, one step at a time, through patience and repetition. Furthermore, a nurturing parent will improve the social and emotional development of his or her child. Children who are cared for develop the capacity to trust. They learn to care for and respect themselves, other people and other living creatures.

How to be a nurturing parent:

- **Acknowledge and empathize your child's abilities and perspectives:** Even if you cannot do something immediately about a problem or issue, children respond to being understood, cared for and soothed. Let him or her know you understand, even if he or she is behaving in a way that is unacceptable at the moment.
- **Allow your child to express himself or herself while setting limits to avoid self-harm or loss of control:** Children with disabilities have a language that they will teach you if you listen and watch, even if they are non-verbal. At the same time, biological differences may make it harder for them to understand you or to learn limits. All children want to express themselves in voice or with movement. Do not inhibit your child from expressing himself or herself unless you are concerned for the safety of your child or others.
- **Listen, watch and touch for feelings:** Whenever a child expresses himself or herself, he or she may be expressing hunger, sleepiness, pain or many other physical states. Emotions or feelings are more complex. All children will experience anger, joy and other emotions. However, each will express these emotions differently. Children with physical disabilities that have the awareness of their differences may feel sad or frustrated more often than not. Listen for underlying emotions and watch their expressions and movements. Touch them when they are happy or upset, so that you can learn how their bodies feel as they are experiencing different emotions. Children with disabilities may have limitations in certain senses, so parents need to use as many senses of the child (and themselves) as possible.
- **Provide warmth, affection and positive touches:** Positive touches includes physical gestures such as hugging, cuddling or gently patting your child in a respectful way. Positive touching conveys positive emotions to the child, such as "I understand that you are feeling sad right now" or "I know you are feeling angry and out of control, so I am calm and can help you to feel more in control."
- **Help your child to solve problems:** A child with a disability will have additional obstacles to overcome, and you can help him or her

in making decisions. These decisions can be as simple as choosing a toy. This also includes helping your child learn to do things that appear simple, like stacking blocks or reaching for an object, but are really important building blocks to his or her development. Helping your child to learn is not the same as doing things for your child. Being patient is central, even though this may feel impossible at times. It may take your child longer to solve an issue, but the benefits and confidence are well worth the time. Strike a balance between being protective and supporting risk-taking. Learn to let go a little and push your child out into the world, even though it may be a little scary.

- **Play, play and play some more:** Playing enhances development. Help your child play and use the shared time to build your attachment. Help your child to learn his or her abilities and your boundaries at the same time. Play can be very relaxing for the child and for you.
- **Celebrate small victories:** Learning what your child can do is part of being a nurturing parent. Helping him or her to slowly expand his or her limits while remaining safe, and keeping frustration balanced with success, is key to nurturing. Remember to help your child, not just do things for him or her all the time. Using routines like bathing, brushing teeth, putting on clothes, eating and playing are ways to improve development. Remember to praise both efforts and successes.

What are the benefits of using a nurturing parenting approach?

Children and parents both want to feel good about themselves and about each other. A nurturing parent is focused on the positive, like what can be done, and he or she is experiencing the joy of success right alongside his or her child. What do you both get from nurturing parenting? You get a way of parenting with proven success, a close and trusting relationship with your child and less conflict. As a parent, you also learn to nurture yourself, remaining strong and accessible to your child who really needs you. You learn to experience empathy for your child while teaching your child empathy as well. You learn to be gentle in your touch and balanced in discipline. You and your child learn to express feelings to each other and to communicate. You both feel greater confidence and self-worth.

When a child experiences high levels of stress, something children with disabilities are at a higher risk for, this may result in more stress hormones and less calming hormones. If you notice the following in your child, use

the ideas in this chapter to help soothe and relax him or her:

- Your child feels sad, low or appears to lose his or her motivation.
- Your child has difficulty focusing.
- Your child has a harder time than usual expressing himself or herself.
- Your child runs away or gets defensive and angry easily.
- Your child is overly worried or watchful.
- Your child is more silly and active than normal for an extended period of time.
- Your child is having trouble sleeping and/or appears tired.

PARENTING IS NOT A SMOOTH ROAD

Parenting is meant to help a child learn, adapt and develop the highest levels of self-determination possible. A person has self-determination when he or she has a sense of control over his or her life and can set goals and work to attain them. These do not have to be goals as big as graduating from college. They can be very important small goals, like choosing an outfit or dressing oneself. Researchers have found that students with disabilities who have high levels of self-determination are more likely to become adults who are employed, satisfied with their lives and living with support or independently outside of family homes. Of course, some children with disabilities have medically complex conditions that must be accounted for as well.



Milestones are met at different times and in different ways by every individual child. In Chapter 1, milestones were described and some examples were given. It is not a failure to alter your expectations based on the realities of your child's needs. At the same time, however, it is important to maintain the expectation that development will continue. Having the input of a professional that understands development, e.g., through Florida Early Steps, the local school system or Vocational Rehabilitation, will help you have the information you need to observe and celebrate improvements.

As a parent, work to maintain the quality of relationships with family and friends. Having a child with a disability does not mean that everything changes. You will adapt and experience some inevitable changes, but your relationships with family and friends should be nurtured. You may find you need to ask for more help, but don't keep track of the help you get. For those that are helping you, you will someday help them or someone else. Enjoy the blessing of help, and pay it forward when you can. Remember, it is okay to ask for help. Soon after your child gets a diagnosis is when you may get the most offers from friends and family to help. Jot down every single name, as you may need to call upon every one of those offers over the next couple of years. You need support and love, so you will be able to provide your child with your best self. Do not feel guilty when asking for help. Allow those who care for you to give you this much-needed gift. That person has offered support because he or she cares about you, so you need to feel comfortable in accepting it.

If you do not have a support network, it is vital that you become connected to one. Your service provider would be happy to connect you to groups of families on a journey similar to your own. These are the people who will become your lifeline over the years. Examples of groups that can provide you with support are churches, moms groups, support groups, disability specific organizations, not-for-profit groups or online groups.

As a parent, plan for your child's experiences. You will be the person that sets the tone for balance within your family. Do not be tempted to believe that the more therapy your child has, the better off her or she will be. Yes, therapy can bring about positive results with children, but it is not the only strategy to help with a child's development. A child with a disability is always a child first; he or she wants to play, explore, create things and have friends. Play with your child, give him or her opportunities to play with others his or her age (local libraries always have wonderful baby/toddler groups for this) and enjoy your child. You should also let him or her see you having fun. Keep your child part of a community that is known for

promoting inclusion (the topic of Chapter 12).

As a parent, set routines in your home. Children are comforted and learn from routines. Going to bed, eating meals, waking up... all of these should be as consistent as possible. If you find that your child just does not do well with routines, consider adding visuals with pictures for your child to view. FLDRS provides free workshops for families to create charts specific to the needs of the child. This really helps support family expectations and routines. Boardmaker® is a software program that allows families to create at-home, symbol-adapted schedules, behavior charts, books and flashcards. The software can be ordered at www.mayer-johnson.com. Consistency, patience and flexibility are needed to truly establish lasting family routines. In fact, flexibility is your routine!

As a parent, maintain health and safety. Your health as a parent is one of your greatest assets. We focus on this in the next chapter. Keeping your child with a disability safe, as well as his or her siblings, other family members and friends, is your first concern. Some children with disabilities are more physically challenging than others. If you are concerned, please seek help from a professional. In most cases, there are ways to improve a child's behavior and safety.

As a parent, remember that influence goes both ways. Do not be alarmed or feel guilty if you find that your child with a disability supports you emotionally sometimes. It is natural to expect that you will always be the one giving to your child. In fact, in the early years this is especially true. As children get older and develop their abilities, they are more likely to be able to give back emotionally. If you find that your child comforts you when you hold him or her, enjoy it!

MOMMA BEAR AND PAPA BEAR... DEALING WITH DISCRIMINATION AND MISUNDERSTANDINGS

To parent a child with a developmental delay or disability requires you, as a parent, to be empowered, to empower your family and to be a strong and steady advocate. In many ways, your child will bring out strengths you may not even know you have. This does not mean that you have to be super-parents, nor does it mean you must ignore your own needs. It means keeping vigilant to assure your child's needs are being met and your resources are available. This means compromising at times, and at other times it means not taking "no" for an answer. This takes energy and focus on your part. Indeed, taking care of your health is essential to you becom-



ing an empowered advocate. In Chapter 12 we talk about inclusion, which is often the result of empowered advocacy.

There are several essentials to being an empowered parent and family. The most important one is that, when you feel empowered, you feel ready to advocate for your child.

- Advocacy is insisting on the services, supports, resources and essential needs for your child, your family and yourself.
- Advocacy is making sure that you receive what is rightfully yours and your child's under the law.
- Advocacy is demanding the same rights for your child, your family and yourself that families with children that are typically developing enjoy.
- Advocacy includes helping to make changes for all persons with disabilities. This may be changes in laws, regulations, policies, practices or organizational structures. The goal is to empower individuals with disabilities to achieve greater independence, productivity and inclusion within the community and the workforce. In other words, while you are always the main advocate for your child when helping to teach him or her to be a self-advocate, some parents may choose to try to influence the system.

There are opportunities to further research and become a stronger advocate. Below in the Resources section are a number of Florida-based associations and organizations that specialize in helping to develop strong advocates for persons with disabilities.

Read the following and ask yourself how well these can/do fit you and your family. If you answer "yes" to all of these, then, once again, you are on track! If not, then do not worry. This just means you now know some area(s) to improve on:

1. Do you understand your rights, the rights of your child and your responsibilities? (Chapter 13 goes into these in detail.)
2. Do you participate in activities and education when you can? We know that families have many claims on their time and resources. Again, you do not have to be super-parents!
3. Do you effectively communicate your child's needs? Are you getting the information you need when you request it? Sometimes changing the question, or having a discussion versus asking a specific question, can help you frame it more accurately. Written communication will provide you with a record that you may need to refer back to at a later date. E-mail communication is helpful, because it

documents the date and time of each correspondence.

4. Do you weigh information and make informed choices? Are you able to delay a choice until you have sufficient information? Are you able to resist pressure from professionals that often want an answer based on their time frame and perhaps not yours?

A final word on advocacy regards the importance of helping your child cope. You must do this while being aware that persons with disabilities are more likely to be bullied than typically developing individuals. Stay aware of your child's experiences in day care, pre-school, school and other places. Ask adults who monitor and support your child about your child's social behaviors around others. Be especially aware of cyber-bullying (online bullying), the fastest growing form of bullying, as your child gets older and begins to use social media.

PARENTING ADVICE

There are many places to obtain parenting advice, and some are listed in the Resource section below. Dr. McGill-Smith lists several that, if taken and used by you, will ease your journey and build your confidence. Consider the following:

- **Seek the advice and assistance of another parent.** No one knows the journey you will take. There will be ups and downs, and as we say throughout this guide, every journey is different. But at the same time, there are commonalities. Call friends and family or local organizations and school systems. Find another parent with a child who has a disability. Ask this parent to talk about his or her journey and to give you initial advice. Remember, you will be building a large extended family.
- **Talk with your family and significant other.** Isolation leads to depression, stress and other painful states (see Chapter 10). Don't worry about making sense or solving problems. That will come with time. Express your feelings, ask how others involved are feeling and don't keep it all bottled up. This does not mean talking non-stop; it means being willing to talk when you feel you have something to express.
- **Rely on positive sources (and resources) in your life.** Talk to friends, counselors, clergy, family and anyone else you find comfort from. As Dr. McGill-Smith emphasizes, "Whenever your feelings are painful, you must reach out and contact someone. Call or write or get into your car and contact a real person who will talk with you and share that pain. Pain divided is not nearly so hard to bear as is

pain in isolation.” These are words to live by, not just survive by.

- **Take one day at a time.** Live in the reality of each day. No matter the development a child has, you can only predict so much. If you live in the moment, you do not worry as much about the future and are more likely to see the good things that happen.
- **Learn the terminology.** Ask questions about terms you do not know. Do not let jargon bog you down or prevent you from truly understanding something about your child.
- **Seek Information:** This is a common theme for this guide. Knowledge is preparation and understanding. Ask questions whenever you are unsure, and write down questions as they come up, so you won't forget them.
- **Avoid intimidation.** Never view yourself as a bother. This individual is *your* child. Professionals have entered a field to work with persons who have disabilities because they are caring people, or for some, because they have someone they know or care about that also has a disability. As Dr. McGill-Smith notes, “Many parents feel inadequate in the presence of people from the medical or educational professions because of their credentials and, sometimes, because of their professional manner. Do not be intimidated by the educational backgrounds of these and other personnel who may be involved in treating or helping your child. You do not have to apologize for wanting to know what is occurring.”
- **Find programs for your child.** Begin looking immediately. If you have a child younger than three years old that you are concerned about and have not approached Early Steps yet, make an appointment for an evaluation! Ask them for directions. Talk to the Agency for Persons with Disabilities (APD), the school system and representatives of similar organizations like the Family Care Council. Go online and access the APD resource directory.

Citation

Smith, P. M. (2003). Parenting a child with special needs. *News Digest: A Publication of the National Information Center for Children and Youth with Disabilities*, 20(3), 1-6.

Resources

Wrightslaw

Special education law and advocacy training programs are hosted all over the country. For more information: <http://www.wrightslaw.com>

Disability Rights Florida:

<http://www.disabilityrightsflorida.org/>

Agency for Persons with Disabilities Resource Directory:

<http://resourcedirectory.apd.myflorida.com/resourcedirectory/>

The ARC of Florida:

<http://www.arcflorida.org/>

Family Care Council Florida:

<http://www.fccflorida.org/>

Florida Association for Centers of Independent Living, Inc.:

<http://www.floridacils.org/>

Florida Association of Rehabilitative Facilities, Inc.:

<http://www.floridaarf.org/>

Florida Developmental Disabilities Council, Inc.: Building Self-Determination and Advocacy:

<http://www.fddc.org/about/building-self-determination-and-advocacy>

Florida Developmental Disabilities Council, Inc.:

Partners in Policymaking:

<http://www.fddc.org/about/partners-in-policymaking>

The IEP Advocate, Inc.:

<http://www.theiepadvocate.com>

“You can’t keep rescuing me like this. You’re supposed to be the one leaning on me, and I’m supposed to be the one who comforts you and shows you that life is worth living.” -Adapted from Molly Mirren (a mother to her child with a disability), To Each Her Own

“Parents don’t care how much the professional knows until they know how much the professional cares.”
- Alex Demolina, Parent and Family Resource Specialist



Chapter 10: The Critical Need for Parental Self-Care

INITIAL REACTIONS

When you first learn that your child has a developmental delay or disability, you may experience the news as a tremendous blow. Whether you expect this news or it comes as a surprise, you probably are not fully prepared to hear it on that first occasion.

All parents plan for the arrival of a healthy, perfect child. When told that there is a difference in your child's health or development, you are forced to give up this idea of an "ideal child" and readjust your plans to fit the new reality. *But what is that reality?* Initially, you probably have no idea and may ask yourself many questions like...

- What is the cause of my child's disability?
- Could it have been prevented?
- Did I do something wrong to cause it?
- Am I to blame?
- Why did this have to happen to us?
- How severe are my child's delays?

Asking questions like these is a normal reaction, and they are the types of questions we all ask ourselves when something unexpected happens in our lives. Gradually, as you begin to understand your child's diagnosis or delay, you will experience a wide range of emotions as you ask more questions and seek new information. What is most important right away is being willing to stay connected, seek support and not give into guilt. A developmental disability is something that happens without fault. Your child will become so much more than the diagnosis that is ringing in your ears when you first hear the words. You are the most important person in the whole world to your child. Remember that. You are privileged to be a parent. It is a new challenge and a new reality.

From a Parent

"I'd like all future parents to know that you are the perfect parent for your child. You are the brightest star in his or her sky. Your heart will feel emotions deeper and greater than you have ever experienced before because of your child. Your heart will swell with pride more times than you can count. You are important, and your expectations and attitudes will shape and mold your wonderful child."

Family Acceptance of Disabilities

Traditionally, the stages of grief identified by Elizabeth Kubler-Ross (1997) have been used to describe the reactions of parents and families when it comes to the birth of a child with a disability. The stages of denial, anger, bargaining, depression and acceptance were assumed to describe a typical reaction, but have not been strongly supported by research. Some parents agree that these fit them, yet many do not. A different description fits a larger number of parents. This is called the Level of Awareness Cycle. These levels are based on experiences, sometimes called “transformational”, where the family and child have experiences that bring out strong emotions. These emotions highlight the child’s and family’s strengths and resilience, moving them to the next phase. As you read these, think about where your family is. We hope you read this with excitement and hope.

Level of Awareness Cycle

Level 1: The Ostrich Level. The first level is really a lack of awareness and knowledge, not a wish to hide away. Some families develop reasons for why a child isn’t reaching their milestones like, “He is really shy, so he just won’t talk or look at people.” Or, “She has so much energy that she is constantly flapping her arms.” Grieving theories may call this denial, but denial assumes that the person knows enough to be in denial. At first, parents usually have very little information about the diagnosis given to their child. A doctor, therapist or teacher may have tried to explain the diagnosis, but the human mind can only digest so much when hit with such shocking news. In this level, families are in the process of learning about the diagnosis.

Level 2: The Labeling and Problem Solving Level. Here, parents recognize that a disability is present and want to do something about it. You may look for specific services, read everything you can, join organizations and may even demand to know what professionals are going to do about your child’s special needs. This is the “identify the problem and solve it” level that usually fades when something happens related to the family’s quality of life. Often, parents begin to realize that more is not better and begin to refocus on their other children, their relationship and adapting to the needs of their child with a disability in more sustainable ways. This is not saying that services are not needed. It is much to the contrary. This is where you as a parent start to better match services to the child’s needs and come to terms that this is a long distance race, not a sprint. With astonishment, you may find that this does not slow the progress of the child, and everyone in the family feels relieved and a little happier.

Words to Follow

"Never let a problem to be solved become more important than the person to be loved." - Barbara Johnson

"Trust yourself. You know more than you think you do."
- Dr. Benjamin Spock

"An exhausted parent can't provide the best care, but we have all had to do so."
- Adapted from Charisse Montgomery, Home Care CEO: A Parent's Guide to Managing In-home Pediatric Nursing

"Sometimes when you are in the midst of being a mommy you forget about yourself as a person. You are so focused on what your family needs from you that you forget about what you need. If you have ever taken a flight and heard the flight attendant go over emergency procedures, you have heard that you are to put the air mask on yourself before you help others with theirs. Why is that? You are of no use to others if you are lacking oxygen. You will die. So while you are feeding your family, remember that you need to be "fed."

- From, The Lost Apron, Offering Encouragement to Moms



Level 3: The Normalization Level. Here, you'll begin to see more similarities between the child with the disability and his or her siblings and classmates. Families often seek more opportunities for their child to fit in. You come to terms with what your child can and cannot do, just like any child. Families here often seek experiences to really know what their child can and cannot do. The transformation here is often not only acceptance of the disability, as well as the strengths of your child, but the knowledge of what other children can learn from your child.

Level 4: Insight and Resolution Level. Parents at this level realize that being different is not better or worse. Yes, your child needs and may always need supports, but you have learned from your child how he or she wants those supports to be delivered. This emphasis on self-determination is one of the greatest gifts you can give your child. You may find that this frees you and your family to be even more "stigma proof." You may also find that helping other families reach this level is something you want to do.

COMMON THOUGHTS AND FEELINGS

The emotions you feel when you face the reality of your child's disability are likely to be normal reactions to this news, the same ones most parents experience. One of the first reactions is that of shock and disbelief. You may say, *"This cannot be happening to our family," "I do not accept this"* or *"Maybe it will go away."* It simply may not feel real to you. Anger is also an early emotion you might experience. You might direct your anger towards the medical or educational personnel who gave you the diagnosis, or you may feel angry toward everyone you encounter. Your anger may seem so intense that it influences everything you do. This is a normal reaction to the feelings of grief and deep loss that you can't explain to others, let alone understand yourself. You may have difficulty communicating with your spouse, parents or other family members because you feel certain that no one can understand the depth of your sadness and sense of loss.

Another early emotion you may experience is fear. Having a diagnosis is often better than having no information, but it typically leads to more questions and troubling uncertainty about your child's future. Questions like: *"What does this diagnosis mean?"*, *"Will my child learn to walk or talk?"* and *"Will my child be able to learn to read and write?"*

You may also have fears about yourself and your family. You might wonder if you will be able to really love this child, and if your partner or other family members can accept him or her. If you have other children, you may

worry about how they will be affected. *“Will my child be a burden for his or her siblings after we are gone?”* If you don’t have other children, you may begin to wonder if it’s safe to have another child. You may also worry about society’s reaction to your child: *“What will people think of him or her? Will they be accepting?”*

Many parents experience confusion and anxiety in the initial stages of coming to acceptance of their new normal. Because you are in the midst of a new and challenging situation, you might not be able to take in all the new information coming at you about your child’s disability. You may feel overloaded, both mentally and physically, and you may have trouble concentrating or sleeping at night. You will probably also experience feelings of powerlessness to change what is happening to you and your child. All of a sudden, you are forced to depend on people who seem to know more about your child than you do. This can make you feel shut out, sad or disappointed in your situation. Some parents speak of depression and rejection of their child, sometimes even having a “death wish” for the child in their moments of deepest despair.

As hard as it may be to believe, all of these emotions are normal reactions to a child’s disability. As a parent, you should feel safe in recognizing and accepting all of your thoughts and feelings. These reactions all serve a purpose, and you can allow yourself to experience all of these feelings without guilt or remorse. You are not “going crazy,” although you may feel out of control for a time. Eventually, these emotions will begin to move you towards an acceptance of your child as a unique individual with strengths and needs, likes and dislikes and abilities and disabilities. Normalization, insight and resolution are on the horizon. They may feel a lifetime away, but you will get there sooner than you think. Think of the opportunity to know someone truly unique, to bond with and accept this person, to enjoy and be surprised by him or her. You are adding to your possible dreams and increasing your family’s resiliency. Hopefully, at some point, you are grateful for the challenges and how you and your family have accepted and grown with this child.

Many mental health professionals refer to acceptance as the final phase of the “grief process.” Acceptance is a natural part of insight and resolution. Certainly these events are life-altering in their impact, but loss and sorrow are only part of what parents will experience when they face these challenges. Still, other parents have reported that they don’t want to be “told” how they are going to feel according to a textbook model. They feel what they feel. Sometimes it’s orderly and sometimes it’s messy. However you

choose to experience and express yourself, know that you are right. *There is no wrong.* What is important to know is that you are not alone in your feelings, and that even though you may not move step-by-step through a series of stages or levels, you will undoubtedly experience a number of these thoughts and reactions. These feelings may come and go at different points in your life, and some will never completely go away. This too is normal.

THE UNPLANNED JOURNEY

Before it happens, no parent expects or plans for a child to be sick or in need of special services. When it happens, an unplanned journey begins. Like any journey, it will have ups and downs, starts and stops, some wrong turns and some moments of extraordinary awe. Along the way, families will make adjustments and develop strategies to move beyond sadness and grief. Although your emotions may continue to be intense, and even overwhelming for a time, there are many actions you can take to return some stability to your life.

Stay Attached and Avoid Being an Island

One of the most critical things to remember is to stay connected to others. It may seem impossible with all you will be confronted with, but being connected does not mean finding a couple of hours every day to spend talking with others. It means to try and be open when you do have time to talk. It means sharing your anger and sadness. As you let out what will likely be waves of hurt, you heal a tiny bit and take a small step towards acceptance. For some parents, their life with a child with a disability starts in a Neonatal Intensive Care Unit (NICU). This means that you are cut off from your child for much of the time. You are traumatized, anxious and feeling very



alone. You may be feeling guilty. You may want to punish yourself. Sitting alone in a NICU waiting area or watching your child can be lonely and stressful. This is the right time to share your thoughts and feelings with your partner, family and friends. A brief call, a quick text message or a short break for coffee maintains important attachments.

When you and your child are home, you may feel anxious or unsure. You may be confused as to the best way to help your child. Feeling unsure is normal. You may have family and friends that will want to see the newborn, to be part of the solution and to be helpful. It is okay to let people help you, even if they cannot help you with your child yet. Remember, this is the birth of a child. Let people help you. If friends or family offer to bring food, clean up, shop or watch your older children, say “yes.” This allows them the opportunity to feel useful.

Building a Support System

While it is important to maintain attachments, it is also true that when you have a child with a disability, expanding your support system to include people who know about disabilities is a good idea. You may have special knowledge in other topics or issues that others will seek you out for. In most cases, you will likely be supportive, and maybe even a bit flattered, when asked to help. The special knowledge and experience you seek will bring you confidence as you learn it. In a few years, you may be the one giving advice, knowledge and support to another family starting their journey.

Seeking the Assistance of Other Parents

Across the United States and throughout the world, there are organizations that link together parents of children with disabilities. Much of the information and assistance you need is available through other parents like you. By joining a local parent group, you have the opportunity to meet other people with children who have disabilities. In these groups, parents can share information, emotional support and common concerns with each other. The feeling of being understood by another person can be extremely powerful, and mutual relationships can help to combat isolation and build confidence.

In Florida, there are many ways to locate local parent groups and associations. You can ask your provider, family doctor or pediatrician to assist you in this. You can also use the telephone directory or conduct a computer search. Family Care Councils are state-supported groups that can help to

link parents with support around the state. See Resources at the end of the chapter for more information. Additionally, in Chapter 18 you will find a list of additional agencies that can help you locate a parent group in your community.

There are also many statewide organizations in Florida formed by parents of children with disabilities. Some of these groups are organized around one particular disability (Down syndrome, Cerebral Palsy, autism, etc.), while others do not make this distinction. Asking local faith-based organizations is another source, as disability ministries are emerging all over Florida. A list of statewide organizations can also be found in Chapter 18.

At first, joining a parent group might seem like a big step. If you are not ready to share your story with a group of people, you might want to consider a one-to-one relationship with another parent of a child with a disability. Organizations such as the Family Network on Disabilities and Parent to Parent, Inc. provide this service. Through these organizations, trained and experienced parents are matched in one-to-one relationships with new parents. The matches are made based upon similarities in disability and family issues, and new parents benefit from the relationship with experienced parents who have already “been there” with their child.

Talking with the People Close to You

For many reasons, parents sometimes stop talking to each other about their child's disability. You may feel that your spouse or mate doesn't understand your feelings or that talking about your feelings will lead to a stressful conversation or argument. Although communication may be difficult for couples at these times, it is important to keep the line of communication open. Your ideas and feelings may be different, but you can support each other best by talking and understanding each other's needs.

Kurt Vonnegut, Jr., an American writer and humanist, is credited with saying, “You are not alone.” As true as that is, for a family dealing with a child with special needs, nothing feels further from the truth. Parent-to-parent support could be the one mobilizing force in integrating a family who has a child with special needs back into society. It has been shown that parent-to-parent support often leads to fewer feelings of isolation and can help families cope in times of need.

If you have other children, talk to them too. Be aware that they are affected by their sibling's diagnosis and will have questions and concerns about the effect it will have on their lives. If you don't have the emotional energy to

tend to their needs at first, try to find other family members or friends who may be able to help.

Encourage yourself to open up to the important people in your life. Allow them to help support you. You do not have to feel that you must handle everything on your own. Seek out people who have been a source of strength in your life, such as a minister, priest, rabbi, friend or professional (e.g., a physician or teacher), and talk to them.

If you feel the need for professional assistance to help you deal with your feelings, do not hesitate to ask for help. Counselors and other mental health professionals can help you come to terms with thoughts and feelings that are interfering with your daily life and your ability to care for yourself and your family.

Talking with Professionals

The vast majority of professionals are caring people. You may be surprised at how many of them work with children with disabilities because of experiences in their own families or close friendships. If you experience problems with a professional, you can help them by thinking about whether there is a mismatch in your levels of awareness. One of the most frequent concerns is that professionals and parents are not on the same page regarding what they want for the child or believe the child can do. Regardless, do not forget that YOU are in charge, and it is up to the professional to honor your requests and concerns. No matter how different it may feel, it is all parties' responsibility to build trust and communication.

TAKING CARE OF YOURSELF

With much of your attention focused on your child, you may forget to take care of yourself. You may feel that it's difficult to find enough time to take care of your child, your home and your family, especially if you are going to school or holding full-time employment. You may even feel that you don't deserve it as you burden yourself with guilt. Nevertheless, you owe it to yourself to take care of your own health and well-being, as it is important to be available to the people who depend on you. Try to get enough sleep, eat as well as possible, exercise, take time for yourself when you need it and allow others to help you. Allow yourself to laugh and enjoy pleasurable moments in your life without feeling guilty. Remember to take it one day at a time. You do not need to fix everything or deal with all the problems of the future in one day. Attend to what must be accomplished today; tomorrow is another day.

Accessing the Information You Need

One of the most important things you can do is collect information. Knowledge is power, and you will want to become knowledgeable about your child's disability, about available services and about specific actions you can take to support your child's development. You will also want to collect information on how to nurture and care for yourself, your partner and your family. Fortunately, there is a wealth of information available on all these issues. Unfortunately, there is so much information to be found that you may not know where to begin. If you are using the internet or library, be sure to bookmark sources, keep lists of sites that you find especially helpful, and track what you find. That may sound like being back in school again, but Florida parents interviewed for this guide made it clear that being organized and knowing where to go back to for information had a powerful stress-reducing effect.

One way you can begin is by learning the terminology of your child's diagnosis. The professionals who are involved with your child will use a great deal of medical and educational jargon. Don't be intimidated by this. Jargon for professionals is just a form of shorthand, so they can communicate efficiently. This is not an attempt to ignore or marginalize you. Early intervention professionals lead the way in attempting to communicate as jargon-free as possible. It is the responsibility of professionals to explain their terminology to you. If you don't understand something, you should ask. On the other hand though, it is important for you to learn this new language, so you can feel comfortable and capable of participating in all conversations about your child. A dictionary of terms is found in Appendix B to get you started.

Books and Articles Written by Professionals.

If you already have a diagnosis for your child, you will be able to find books on its topics in local libraries, bookstores and through computer searches. [Amazon.com](https://www.amazon.com) is easy to search, and the number of books and sources for almost all conditions has grown immensely. There are so many that the sheer number can be a source of stress. Read reviews by parents before purchasing. Read the lowest ratings to see if there are problems with substance, format, editing or price. Worthwhile suggestions for good sources of information can also come from professionals such as physicians, service coordinators, therapists, teachers, disability associations and other parents of children with disabilities. Additionally, you can find help at the *Center for Parent Information and Resources*.

If you have been told that your child has developmental delays or special health care needs, but you are having trouble getting a diagnosis for your child, your search will be a little more difficult. Many children have delays or developmental concerns that are difficult to diagnose. In this case, you may come to view yourself as a detective. It will be helpful for you to (a) keep ongoing records of your child's symptoms and behaviors; (b) talk to others who may be able to offer information, leads or assistance; (c) re-search the problem on your own through books, articles and web searches; (d) trust your intuition and observations to offer up your own interpretations of your child's disability; and (e) seek out multiple opinions.

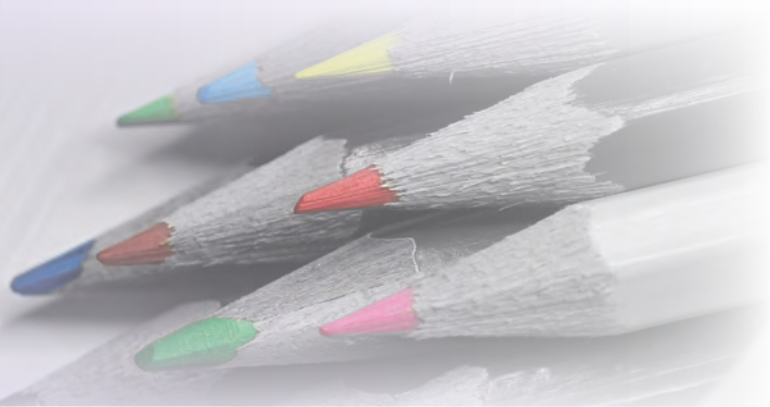
Books and Articles Written by Other Parents

You may find that books and articles written by other parents are just as valuable, or even more valuable to you, than the publications made by professionals. Just as you will feel supported by the parents you meet in support groups, you will feel understood by the parents who write about the exact feelings and experiences you are having. You will likely laugh with them and cry with them, nod your head and say, "Yes! That's just like me." While you are gaining valuable new information, you will also be soothing your emotions. Recommendations of websites that are specific to the writings of parents of persons with disabilities or persons with disabilities themselves are listed in the Resources section at the end of this chapter.

There are also a number of magazines and journals available by subscription for parents of children with disabilities, with *Exceptional Parent* (<http://ep-magazine.com/>) being one of the most popular. *Parenting with Special Needs* (<https://parentingspecialneeds.org/>) is another favorite of parents. These and other publications have websites with downloads and areas for ordering subscriptions.

Stress

There are many sources of stress, and having a child with a disability is only one potential source. Stress wears you down over time. Keeping a balance



of positive, de-stressing experiences to counter daily stress is a challenge for any family, but especially for families that may need to schedule multiple appointments for specialized services each month.

The following are symptoms of stress. Tally the numbers that applied to you more often than not in the last week. **This stress checklist is not a formal mental health evaluation!** Many of the symptoms can be the result of medical problems. Be sure to have a medical check-up and speak with your physician if you are worried about the number of items you checked. This checklist is adopted from a mental health stress screening tool.

1. More than occasional anxiety
2. Sleep problems
3. Struggles with self-doubt
4. Feelings of being overwhelmed
5. Difficulty concentrating
6. Not eating or overeating
7. Reliance on alcohol or other drugs
8. Moodiness
9. Repetitive thoughts
10. Nausea
11. Jitteriness
12. Fatigue
13. Difficulty making decisions
14. Feelings of resentment
15. Difficulty taking actions
16. Muscle tension
17. Frequent irritability
18. Digestive problems
19. Emotional outbursts
20. Emotional neediness

If you've checked three or more of these symptoms, and you feel that these things are a problem or interfering with your life, it may be helpful to see a physician or counselor. Nutrition, exercise and coping, which are all covered below in this chapter, can help reduce your stress.

Toxic Stress

For most people, life is full of stressors. Toxic stress is due to a combination of many stressors, e.g., stress related to a job, relationship or even being stuck in traffic. Toxic stress can be thought of as chronic stress that repeats. These constant stressors toxify the body and leave it vulnerable. Stress can

also kill good bacteria, while feeding bad bacteria and yeast. This can overwhelm the immune system and cause illness and disease. According to the Centers for Disease Control, as much as 90% of all disease and illnesses are stress related.

If you are feeling depressed, anxious or experiencing other issues or stresses, as well as experiencing concerns with employment, making ends meet, keeping up with education, dealing with childhood trauma or concerns of your own... it can start to add up! Keep in mind though that stress is the body's natural response to change, and it is not always a negative reaction. In fact, stress is what keeps the body alert and able to avoid hazardous situations. When the body receives too much stress for a prolonged period, the body begins to deteriorate and stress becomes toxic stress.

A common sign of stress is frequent stomach aches and/or problems with stomach acid. When a person is stressed, the body releases more acids into the stomach, causing what is known as a "nervous stomach." Hair loss can also be attributed to stress. When stressed, some of the hair follicles may become dormant, and the affected hairs eventually fall out. The hair will generally grow back once the stress is resolved.

There are ways to reduce stress and prevent most ailments caused by it. Staying active has been shown to be the best method to fight stress. The endorphins released during physical activity can provide a pleasurable sensation that relaxes the body and reduces stressful feelings. Other methods to reduce stress include a healthy diet, meditation and laughter.

Using planning tools can help you manage your stress. Have you considered...

- Using a calendar (paper or electronic)? Being able to see a month at a glance helps you to schedule and plan properly. Did you know that over 80 percent of people do not use the calendar in their smart phone?
- Delegating tasks to others?
- Setting timed goals while breaking a task into smaller parts, making progress more visible?
- Writing a prioritization list?
- Writing a list of actions based on your prioritization list and then organizing it into a plan?
- Checking to make sure your plan is working?
- Keeping one notebook to log all your questions or the answers you get from discussions with doctors and therapists? Document the

dates and times when phone calls and discussions happen. Write down important names. Being able to reference these notes from one notebook will be a priceless tool for you.

We Know, You've Heard It Before... But That Doesn't Mean It's Wrong!

How many times have you heard people say that you should take better care of yourself, and you exasperatingly agree, while rolling your eyes and wondering what they would do if they had all your pressure and responsibilities? Don't dismiss people who say these things, as they may be seeing levels of stress in you that you keep away from your own perception. Kind words mean kind feelings, and it feels much better to embrace and feel the support than to push it away as just another person that doesn't understand you.

Health, Nutrition, Exercise, Respite and Play

When stressed, we tend to overeat, exercise less and gravitate to comfort foods. While comfort foods are truly comforting in the moment, they are often a risk for overall health if they become a mainstay of any diet. We hope you are sitting down for this, but chocolate is NOT a food group! (We'll give you a moment to recover.)

There are many websites that can support advice from doctors and nutritionists on how to eat a healthy and balanced diet across many income levels. Exercise can be prioritized to a half an hour a day, if possible, and you do not need to be a professional athlete or join a gym. A 20-minute walk, coupled with five minutes of stretching and core work and then five minutes of light weights in your own home, can have a great effect on overall health. Mixing up walking routes, timing yourself and trying to set



a new “best time” once in a while, as well as listening to music or podcasts that interest, entertain and uplift you can all be done at the same time to increase benefits.

Respite (covered in Chapter 11) is a planned time to be free of as many responsibilities as possible, so that you may relax. This may be short term, so you can go shopping or see a movie without concern and guilt, or long-term, like that two-week anniversary cruise you’ve always dreamed of. Respite is a critical need of families and, in many cases, a form of play. It is okay to plan for respite. Casual respite is also of great benefit. Playing in your home with your partner, family and friends is critical. Exercise is a source of endorphins, but laughter and relaxation also provide these.

During the planning for this updated guide, we spoke to many parents around the state. Parents of older children wished that they had spent more time simply playing with their child instead of having them in therapy. Others wished that they had worked harder to get respite in place, so that their life had more balance over the years. Many of these parents are now working to increase their respite, stress control and play, and they are finding that they are more available and able to handle day-to-day stressors and emergencies with greater ease, because they are taking better care of themselves.

Coping Suggestions

Coping is meant to preserve your health. This includes emotional health, physical health and spiritual health. Coping can be *problem-focused coping* (planning and taking action), *perception-focused coping* (focused on thinking/understanding and feeling better about a situation) and *emotion-focused coping* (focused on simply feeling better). You have to decide what is needed for each situation, as coping is not one-size-fits-all. When clear steps can be taken and resources are available, then problem-focused coping is your best bet. When steps are less clear and the results of coping are more distant, changing your perspective through using coping that involves doing what you can for the problem now, then shelving it until more time and resources are available later, is the likely choice. This is using perception-focused coping that exists between problem-focused and emotion-focused coping.

Parents of children with disabilities are far less likely to use emotion-focused coping, because they feel it is wasteful or feel guilty about being “self-indulgent.” That is a mistake! Emotion-focused coping is meant to

make you feel better. It is not all fluff. Actual changes can occur even if, for example, you are adding an exercise routine or hobby that improves your health but does not improve that of your child or your family. *Selfishness and self-preservation are not the same thing!* Everyone should have a little self-indulgence when they can. Below is a list of common coping suggestions. Keep these in mind or perhaps write them down for use when you are feeling stressed. Yes, some are a bit silly, and they are in no particular order. It may take anywhere from a few seconds to a much longer period of time to do these. They may even become new hobbies! This illustrates what a wide range of possible coping strategies there are. Hopefully, you'll add many more, taken from the Your Life, Your Voice website at <http://www.yourlifeyourvoice.org/pages/tip-99-coping-skills.aspx>.

Exercise (running, walking, etc.).

Write (poetry, stories, journal).

Scribble/doodle on paper.

Be with other people.

Watch a favorite TV show.

Post on web boards, and answer others' posts.

Go to see a movie.

Do a word search or crossword puzzle.

Do schoolwork.

Play a musical instrument.

Paint your nails, do your make-up or do your hair.

Sing.

Study the sky.

Punch a punching bag.

Let yourself cry.

Take a nap (only if you are tired).

Take a hot shower or a relaxing bath.

Play with a pet.

Go shopping.

Clean something.

Knit or sew.

Read a good book.

Listen to music.

Try some aromatherapy (candle, lotion, room spray, etc.).

Meditate.

Go somewhere very public.

Bake cookies.

Alphabetize your CDs/DVDs/books.

Paint or draw.

Rip paper into itty-bitty pieces.
Shoot hoops or kick a ball.
Write a letter or send an email.
Plan your dream room (colors/furniture).
Hug a pillow or stuffed animal.
Hyper-focus on something like a rock, hand, etc.
Dance.
Make hot chocolate, milkshakes or smoothies.
Play with modeling clay or Play-Dough.
Build a pillow fort.
Go for a nice, long drive.
Complete something you've been putting off.
Take up a new hobby.
Look up recipes and cook a meal.
Look at pretty things, like flowers or art.
Create or build something.
Pray.
Make a list of blessings in your life.
Read your faith's holy book.
Go to a friend's house.
Jump on a trampoline.
Watch an old, happy movie.
Contact a hotline/your therapist.
Talk to someone close to you.
Ride a bicycle.
Feed ducks, birds or squirrels.
Color with crayons.
Memorize a poem, play or song.
Stretch.
Search for ridiculous things on the internet.
"Shop" online (without buying anything).
Color-coordinate your wardrobe.
Watch fish.
Make a CD/playlist of your favorite songs.
Plan your wedding/prom/other event.
Plant some seeds.
Hunt online for your perfect home or car.
Try to make as many words out of your full name as possible.
Sort through your photographs.
Play with a balloon.
Give yourself a facial.
Find some toys and play with them.

Start collecting something.
Play video/computer games.
Clean up trash at your local park.
Perform a random act of kindness for someone.
Text or call an old friend.
Write yourself an “I love you because...” letter.
Look up new words and use them.
Rearrange furniture.
Write a letter to someone that you may never send.
Smile at least at five people.
Play with little kids.
Go for a walk (with or without a friend).
Put a puzzle together.
Clean your room/closet.
Try to do handstands, cartwheels or backbends.
Practice yoga.
Teach your pet a new trick.
Learn a new language.
Move EVERYTHING in your room to a new spot.
Get together with friends and play Frisbee, soccer or basketball.
Hug a friend or family member.
Search online for new songs/artists.
Make a list of goals for the next week/month/year/five years.

Words of Wisdom

Parents of children with disabilities are extraordinarily generous with their time, insight and advice. The following are what parents who have been where you are want you to know. As one parent said, “Tell other parents that listening to those of us who have been there first is something that I wished I had done. I spent hours every night on the internet educating myself and trying to know as much as the professionals, because I was intimidated by them. When I joined my first support group, I all of a sudden had access to a living internet all around me. This time, the internet could hear me too.”

Do not be afraid to show emotion. There are no bad emotions! Parents noted that dads especially were often hesitant to show emotion, because they felt they needed to be strong for their child, partner or family. Sharing emotions makes the family stronger, reduces stress and leads to better decision-making.



Stay positive. A positive attitude will be one of your genuinely valuable tools for dealing with problems. There is truly always a positive side to whatever is occurring, even if it takes a while to see it. For example, one parent noted that when her child was found to have a disability, one of the other things pointed out to her was that she was a very healthy child. Over time, she turned out to be the healthiest child she had raised, with the least amount of medical concerns, despite having an intellectual disability.

Do not be afraid to say “NO” (or “YES”). It can be intimidating to say “no” to professionals, family members or partners. When you have to say “no”, do so in a kind way with an explanation. If someone is asking you for time you don’t have, or asking you to try something you don’t believe in, make the healthy choice and just say “no”. On the other hand, being buried in your routine, acting too stubborn or wanting to appear strong, therefore not saying yes when an opportunity arises, also has the potential to harm you.

Avoid pity. Self-pity, the experience of pity from others or pity for your child, is actually disabling. Pity is not what is needed. Empathy, which is the ability to feel with another person, is the attitude to be encouraged.

Decide how to deal with others. During this period, you may feel saddened by or even angry about the way people are reacting to you or your child. Keep in mind that some people simply do not know how to behave when seeing a child with differences. They may even react inappropriately. People reinforce foolish and reflexive stigmas all the time. Most aren’t even aware that they are doing such a thing. Think about and decide how you want to deal with stares or questions. Try not to use too much energy being concerned about people who are not able to respond in ways you might prefer.

Resources

Delete Stress

<http://www.deletestress.com/stresschecklist.html>

Information for Caregivers of Individuals with Developmental Disabilities:

http://www.fddc.org/sites/default/files/New%20Web-Health%20Care.5_3.pdf

Your Life, Your Voice

<http://www.yourlifeyourvoice.org/Pages/home.aspx>

University of Delaware, Books on the Disability Experience

<http://www.nlcdd.org/resources-books-movies-disability.html>

Brain Child, Books for Parenting Children with Disabilities

<http://www.brainchildmag.com/2015/01/top-ten-books-for-parenting-children-with-disabilities/>

Special Needs Book Review

<http://www.specialneedsbookreview.com/2013/01/02/top-20-books-on-parenting-or-teaching-children-with-special-needs-reviewed-by-special-needs-book-review/>

Parenting Special Needs

<http://parentingspecialneeds.org/>

Exceptional Parent Magazine

<http://www.eparent.com/>

Exceptional Parent Magazine Subscription Request Form

<https://www.magmall.com/subscribeform/exceptional-parent-magazinesubscription.pdf>

Florida Family Care Councils

<http://www.fccflorida.org/>

Family Network on Disabilities

<http://fndfl.org/>

Parent to Parent, Inc.

<http://www.p2pusa.org/p2pusa/sitepages/p2p-home.aspx>

Center for Parent Information and Resources

<http://www.parentcenterhub.org/>

Chapter 11:

Making Individual and Family Adjustments



All parents have dreams for their children. When a disability is identified, families may struggle with the loss of those dreams as they come to terms with changes and begin to fashion new dreams. At the same time, families are dealing with services they've never thought of and are learning a whole new language. A family's support is often at the center of emotional support, as well as the development of new skills and resources for all family members. Powerful, long-lasting support may come from other parents as well. Many families find they gather new family members that last a lifetime and are adding more all the time.

THE FAMILY-CENTERED APPROACH

What do we mean by a family-centered approach? Family is the foundation of a child's life. A family-centered approach builds family confidence to be a part of their child's care across the lifespan of the issue. This includes getting an evaluation and selecting services and transitions from home to school to work or whatever is in store for and within the ability of your child. Making sure your family has access to resources that build confidence and give you the tools you need for success in supporting the development of your child is vital. In a nutshell, family-centered practice includes the following. You should carefully look at the services you receive to ensure that you are receiving a family-centered approach.

1. Emphasizing strengths, not deficits
2. Encouraging family choice and control over wanted resources
3. Fostering a cooperative relationship between parents and professionals

Thus, family-centered practices treat families with dignity and respect, are individualized, flexible and responsive to each family's unique circumstances, provide family members complete and unbiased information to make informed decisions and involve family members in acting on choices to strengthen child, parent and family functioning.

Why is a family-centered approach important? Raising a child with a disability can be exhausting and rewarding at the same time. A family-centered approach has been proven to lead to greater satisfaction and success in services. It also creates a feeling of empowerment and control for families, and it gives them greater confidence in coaching and helping children to improve their development across domains.

Families are the experts about what they need. It is important for you to remember that, despite any confusion and anxiety, you are the deci-

sion-maker. You are with your child, supporting him or her every day. You have the most information. Insist that the service system supports you as a decision-maker instead of making decisions for you. To be clear, the needs of your family will change over time, particularly at transitions from early intervention to preschool services and beyond. That is all the more reason for you to educate yourself, build a strong support system and ask questions.

All families need some level of support when raising a child with a disability. This is not an admission of weakness, and parents that get support find themselves less stressed. Read the following and ask yourself how well these fit you and your family:

- Are you and professionals working together to ensure the best services are given to your child?
- Do you feel recognized and respected for the skills, knowledge and experience you bring to professional, community and family meetings/gatherings?
- Are you using all the means of communication you can, e.g., telephone, chat rooms, email, websites, blogs or Facebook, to keep your family engaged, as well as using them to find information on development and disabilities?
- Are you insisting that you receive information in writing when dealing with service or educational organizations?
- Are you comfortable with, or willing to try, family-to-family support, either individually or in groups?

If you answered “yes” to most of the above, then you are on the right track. If not, then think of ways to make each one happen. You and your family will feel better for it.

EARLY INTERVENTION

If you are just starting this journey and have a child under the age of 3 years, we strongly recommend that you become involved with early intervention (EI) services. There are specialized services available in Florida through Early Steps, a part of Florida’s Children Medical Services, Florida Association for Agencies Serving the Blind and the Center for Autism and Related Disorders, just to name a few. (Links to these are in the Resources section at the end of this chapter and in Chapter 18 at the end of the guide.)

Early intervention is based on different beliefs than you might already be

used to. It is not “medical,” in that your child is not given treatment like doctors do. Though EI services can be educational, they are not strictly for education. The purpose of EI is to help parents make the most out of daily activities and routines with their child. You, as a parent, become the major “agent of change” for your child. In fact, how well you respond to your child has been proven to have a greater effect on development than reinforcement, toys or other factors (Mahoney, 2009). Being a “responsive” parent means you have a shared give-and-take with your child, and you are expressive, animated and warm. It also means that you match your communication and requests to the developmental ability of your child.

Early intervention is not something done “to” your child, but instead it is something that is done “with” you, your family and your child. This does however require some adjustments, as well as trust and the opening of your home to professionals. In EI, no matter what services you need, they come to you in most cases. The services in your natural environment are critical to helping your child develop to his or her full potential. Here are some ways you can help get the most out of early intervention services:

- Notice what your child likes and dislikes, especially in toys and games, and share this with your EI provider. Early intervention providers will have a greater impact when they are consistent with what your child likes.
- Be open. Make sure you communicate your concerns and goals for your child to your EI provider.
- Take an active role in your child’s EI services during home visits and appointments. Some parents confuse EI with respite and, being used to medical services in the U.S., try to leave the EI professional to work alone with the child. This situation happens rarely, but parents are expected to be involved and present. Active involvement will help you learn strategies and skills that will improve your child’s development.
- Ask questions. Ask the EI providers to explain the activities they are doing with you and your child. Ask for the reasons behind the activities. Knowing these things will help you work with your child in-between visits.
- Take charge and provide lots of opportunities for your child to play, and practice new skills during everyday routines like when dressing, at mealtimes and during diaper changes.
- Learn about activities in your community that your child and family might enjoy doing, and use these opportunities to improve your child’s development.

THE POWER OF PLAY

It may sound strange to think of play as an adjustment! We include play here, because as vital as play is to a child's development, it is even more so for a child with a delay or disability. As a parent of a child with a disability, you have to be even more involved in play. What can you do to get the most out of play with your child?

Here are some suggestions:

Remember, you are your child's favorite toy!

Safety first! Your little explorer may have difficulties with gross and fine motor skills. Keep play areas picked up and small objects controlled, so your child will not accidentally trip over them or put them in his or her mouth.

Watch and wait. Children express their feelings in play, and children with developmental issues may get frustrated more easily. Do not overcompensate by rescuing too soon. Move objects closer, help in small increments and remember that play helps development. Your patience will translate into better patience from your child.

Follow the leader. Remember that children with disabilities are at higher risk for sensory problems. Some children like a lot of stimulation, and others do not. Watch closely and patiently, and let your child lead you to the amount of stimulation he or she can handle.

Developmental play. Developmental play means to start with play that is appropriate for the age of a typically developing child, see if it fits your child at that time and change if needed. Playtime for babies includes back and forth sounds like cooing and copying, peek-a-boo, singing and dancing with the child and helping him or her hold and explore objects that are different in texture, size and color. Children 12 to 24 months like to run, climb and have action. They want to do things over and over as they master their bodies. Imitating words and melodies and keeping their hands busy with different objects are age-appropriate actions too. Older toddlers like to have play dates, play music games and have quiet play where they can explore on their own. Encourage them to fantasize and imagine, playing dress up or role playing while helping them to label their feelings.



SUPPORTING THE NEEDS OF YOUR FAMILY

When a child is born with a disability, there are many types of adjustments that parents and families make. In the figure below, we list the main ones that parents are concerned about, giving you a chance to begin to think about and prepare for changes (Guralnick, 2004). Keep in mind that sometimes these changes result in amazing and unexpected results.

Parents as Individuals

As the parent of a child with a disability, you will be responsible for taking care of your child, while simultaneously trying to maintain the other aspects of your life. There is so much that you do, such as holding down a job, shopping, cooking, cleaning up and taking care of other children and aging parents, that it is not surprising that you may feel overwhelmed or exhausted. Therefore, it is very important for you to take time for yourself as an individual. Remember that stress can be harmful but there are ways to cope (Chapter 10). This may sound like a cliché, but no one can do this for you; you must do it for yourself. Make time for sleep and regular meals without feeling guilty. Try to get some exercise every day, even if it is just taking a short walk with your children.

Parents as Partners

Although many families today are single-parent families, the majority are two-parent families in which the relationship between the parents is important to the well-being of the whole family. When your relationship with your spouse or partner is strong, it enriches the family life of all members. When there are problems in the relationship, the tension will affect the rest of the family as well. Even if you are raising your child alone, you probably have at least one other adult who is important in your day-to-day life. All of these relationships must be nurtured.

The arrival of any child will change the dynamics between any two parents. When a child arrives with a disability, however, changes may be greater and more demanding and will likely place stress on the relationship. You may react to the disability differently than your partner, or you may be in two different places with regards to your adjustment. Some parents feel guilty about having a child with a disability and may deny the needed changes. If needed, seek help to support and strengthen your relationship.

It is important at this time to try to protect your relationship. The best way to do this is to make a commitment to make time for each other, perhaps

meeting for lunch or sharing activities together as often as possible. Talking to each other and really listening are also important, as well as recognizing when one person needs to have space. Many parents in this situation find it necessary and helpful to seek counseling together. You may want to consider marriage counseling, if you feel your relationship is in trouble. Like every other unexpected life event, the arrival of a child with a disability may cause the two of you to grow closer or to split apart. A relationship that was already on rocky ground may not survive the added pressures of your child's needs and routines. Some studies have found that families with members with disabilities have a higher rate of divorce, and other studies have found this not to be true, with family members saying they have grown closer because of their shared experience (Hatten, et al., 2010). Families, like individuals, are unique, and no one can predict in advance what might happen in any given family.

Things to Consider

Making a living: Hours worked; flexibility of work schedule; adequacy of financial resources; amount of coverage provided by medical insurance

Services: Availability of services; eligibility for services; sources of transportation; amount of parental involvement required

Home/neighborhood safety and convenience: Safety and accessibility of play area; alterations in home (installation of locks or fences related to safety concerns); choice of a particular neighborhood

Domestic workload: Amount of work that needs to be done; persons available to do it; amount of time spent by different family members

Childcare tasks: Complexity of child care tasks; presence of extraordinary child care demands (medical or behavior problems); number and availability of caregivers

Child peer group: Child's play groups (children with disabilities vs. typically developing children); amount of parent supervision needed; role of siblings as playmates

Marital roles: Amount of shared decision-making regarding a child with delays; degree to which child care and household tasks are shared

Practical and emotional support: Availability and use of formal (faith or parent groups) and informal (friends or relatives) sources of support; costs of using support



Brothers and Sisters

As family members, the other children in your family will be affected by the arrival of a child with a disability. Because your children are unique individuals as well, each one will react differently to the new sibling. Numerous books have been written by siblings of children with disabilities. Many of these authors describe the experience as a positive, enriching one that has given them great insight into the value of life. Others report feeling jealous or rejected as they watched their parents give most of their energy, attention, money and support to the child with special needs.

The reaction and adjustment of siblings to a brother or sister with a disability may also depend upon their age and maturity. A younger child may find it more difficult to understand the situation and think about it realistically. Older children will grow in their understanding of the disability, but they may worry about their future responsibility for their sibling, how their peers will react or whether they might pass the disability along to their own children someday.

It is important for you to carve time out of your daily routine to spend with your other children. Even a few quality minutes can be very helpful. It is also important to talk openly with them about their sibling's disability, explaining it to them according to each child's developmental level. Some of your local associations for families with children with disabilities may have special groups or activities designed just for siblings. In addition, your community may have a disability support group specifically designed for siblings as well.

Some siblings may benefit from counseling sessions when they don't seem to be dealing with issues and conflicts in other ways. Siblings may feel more comfortable expressing their feelings with someone outside of the family, especially when they know their conversations will be treated as confidential and not shared with other family members. Don't be afraid to suggest counseling to your children, if you believe they are struggling with their feelings or need a safe place to discuss their concerns.

A letter from a mother to a sibling of a child with special needs can be found at <https://parentingspecialneeds.org/article/a-letter-to-the-sibling-of-a-child-with-special-needs/>.

Grandparents and Other Relatives

Grandparents will also be affected by the arrival of a child with a disability.

In fact, they will be affected on two levels. They will be concerned about their grandchild, but they will also be concerned about you as their own child. It is important to remember that they will need support and information too. Even though you may feel that you don't have the energy, it is important to include them in what is going on with your child. If you let them get involved, they can become a great source of help, and their involvement can benefit your whole family. If your relationship with your parents has always been difficult, this may not be the time to try to fix it. On the other hand, your child may become the bridge that brings you together.

Try to give your parents and other relatives opportunities to get to know your child. This way, they can come to think of him or her as a child and not only a child with a disability. Understand that they are going to have some of the same feelings of confusion and loss that you are experiencing. As you share your feelings, you can be supportive to each other. Allowing them to get to know all of your children may allow you to spend some much needed time away from the responsibilities of parenting when they offer to babysit for you.

USING RESPITE CARE

All parents need occasional time away from the responsibilities of caring for their children, whether it is to accomplish a task, keep an appointment or just relax. This is certainly true for parents of children with disabilities as well, though it may be more difficult for you to arrange. "Respite" refers to short-term, temporary care provided to people with disabilities when their families are in need of assistance with caregiving routines. As such, it is an essential part of the overall support you may need from time to time. There are two main things to think about when it comes to respite:

1. Family caregivers need to have sufficient and regular amounts of respite time. Give careful thought to how you want to spend your respite time. Respite needs to be meaningful and purposeful for caregivers to fulfill their needs and plans, as well as safe and enjoyable for the child.
2. Respite is most effective when combined with other services and assistance, but don't wait to take your break. You may also benefit from additional financial support, educational, emotional and social support and a sense of belonging with others through services and support groups. Before you can seek out those services, respite will give you a chance to step back and recharge. Respite is a break, not another appointment!

For many parents, respite is a necessity, not a luxury. In many cases, relatives, friends and neighbors can provide the temporary care you need. Other times, especially if you need assistance with care overnight or for more than a few days, you may find that the people close to you may not always be available to help. Respite care can occur in a separate facility outside of your home or in your home for varying lengths of time, from a few hours to a few days or weeks, depending on the services available in your community.

Without assistance, finding someone to care for your child can be challenging. Caring for a child with severe or multiple disabilities can be a 24-hour commitment, requiring knowledge of the child's specific needs and routines. When you decide to leave your child in the care of someone else, either in or outside your home, you may experience a number of concerns. Fears and concerns common in this situation are: (a) your child may not get the same quality of care you can give, (b) some things, such as medications, may be forgotten or (c) the caregiver may not be able to comfort your child, who will then be left crying. The anxiety caused by these fears can lead some parents to believe that respite care is just not worth it.

There are many reasons to reconsider this decision. First, if you allow yourself to believe that you are the only person who can take care of your child, you set yourself up to never deserve a break or a day off. You may actually become accustomed to having no time for yourself, and you may become unaware of the impact that this constant sense of responsibility is having on you and your family. Allowing someone else to care for your child lifts the burden of believing you are the only person who can successfully fill this role. Although this realization can be difficult to admit sometimes, most parents find it to be a liberating experience.

Another reason to consider using respite care is so you will have an established system in place in case an emergency arises. If an emergency causes you to have to be away from your child when you have never identified and trained an alternate caregiver, your emergency situation may become even more difficult to manage, as you try to figure out who may be able to help you.

A final reason to consider respite care is that your child can benefit from care from other caregivers. Children can build new relationships and learn to interact with other adults, which may strengthen their social abilities and foster independence.

In Florida, respite services can be provided by a number of different types of organizations. Respite care may be provided by local chapters of national organizations such as The Arc, Easter Seals or United Cerebral Palsy. There are more and more faith-based groups starting ministries for people with disabilities that include respite. It can be provided by local organizations such as schools or other nonprofit agencies. In addition, respite care can be made available by for-profit businesses such as home health care agencies. Individuals can also be respite care providers. Unfortunately, not every area has adequate respite care. If your area does, take advantage of it! If not, talk to organizations and ask if they are considering developing a respite service.

Respite services are furnished in many ways, depending on the provider, by the needs of the family and available funds. Some programs receive public funding for their services, while others charge fees on a sliding scale based on family income. Nonprofit organizations may also receive donations or other sources of funding. Eligibility for respite services is usually established by the provider and may be based on the child's age and disability. Family income may also be considered.

In-home respite services are good if you are more comfortable in your home or if your child is medically fragile. The home is usually already equipped for special needs. Home-based services, sitter-companion services and consumer-directed respite care (a trained service provider that the family chooses) are in-home types. Out-of-home respite services are rarer but can include family care homes or host families and respite cen-



ters at churches or agencies for scheduled or unscheduled services. Some sites host respite events scheduled for specific times, usually on a weekend afternoon.

The number and quality of respite care programs will vary from community to community. Most large cities in Florida have respite-care services, but smaller towns and rural communities may have limited options. An online resource for locating respite in your area is Access to Respite Care and Help (<http://archrespice.org/respitelocator>).

Licensure or registration for respite care providers is not currently required in Florida. The Agency for Persons with Disabilities does require providers to meet certain qualifications in order to receive state funds. Ultimately, you will need to make the final decision about the quality of the respite care providers you locate. You should examine characteristics of the providers such as staff training, monitoring by outside agencies and adherence to health and safety standards.

CHOOSING CHILD CARE

A child care setting may be another part of your child's daily life. Looking for good child care is hard work. There are many families looking for services and a limited number of child care programs. The search can be even more difficult if your child needs some special attention or services due to a disability or special need. You may have already put in a lot of time searching for other support services for your child, and you may wonder if you have the stamina for this new task. Take heart. The passage of the Americans with Disabilities Act (ADA) in 1990 makes your search a little easier, because many more child care programs now have experience serving children with disabilities.

The Americans with Disabilities Act has many important provisions for all people with disabilities, and it is designed to prevent discrimination in the workplace and in the community. One of the most important implications for young children is that the ADA prohibits family child care homes and child care centers from discriminating against children with special needs on the basis of their disability. All child care providers must make "reasonable accommodations" for your child, and in most cases, may not charge you more for your child's care than they would charge any other parent. There is much more to know about the ADA, but the main point here is that you can feel confident in approaching all child care providers to discuss the possibility of enrolling your child. That does not mean that every

child care setting in your community will be an appropriate one for your child, but it does mean that every provider should be willing to talk with you. Perhaps you have other children who attend child care, and you may therefore want all of your children to be enrolled in the same program. That is not an unreasonable expectation, and it should now be an option for you.

For some children, educational programs may take place in a child care setting. In this same setting, they may spend all of their day receiving early intervention or special education services, along with routine care, meals and rest. Other children may receive their special services in a public or private school classroom during the six-hour school day and then be transported to a child care setting for additional hours of care while their parents are working. Some children may need child care services only during the summer months. Given all the possibilities, many parents find that they need child care services for their child at one time or another.

Your need for child care will also depend on your family's situation. If you are a "stay-at-home" mother or father, you may not need child care on a regular basis, but rather you will only need occasional "drop-in" care for a few hours while you tend to an appointment or shopping. You may also need occasional respite care through a respite care program.

There are several different types of child care to investigate. Each one has certain advantages and disadvantages, depending on your wants, needs and your family's situation.

Family Child Care Homes

Family child care homes are operated by a child care provider in his or her own home. In Florida, family child care homes can be either registered or licensed (depending on the county) by the Florida Department of Children and Families (DCF). Some counties in Florida require all family child care homes to be licensed; others do not. Friends, neighbors and relatives can also provide child care, as long as they do not care for children from more than one other family in addition to their own children. In this case, the provider is not required to register or obtain a license from DCF. Currently, DCF child care licensing staff is responsible for the inspection and licensure of child care facilities and homes in 62 out of 67 counties in Florida, as well as registration of family day care homes in those counties which do not require licensure. Five counties have elected to regulate licensing of child care facilities and homes as provided in 402.306, *F.S.* Those counties

are Broward, Hillsborough, Palm Beach, Pinellas and Sarasota.

Family child care homes can provide care for up to a certain number of children (depending on ages and local regulations), and large family child care homes (with two or more adults) can provide care for larger numbers of children. Some family child care providers have experience caring for children with disabilities who may be other children in their care or members of their own families. Other providers may be willing to learn to care for your child. Often, family child care providers are able to be a bit more flexible in their hours of operation and their practices than child care centers. Because of this flexibility and smaller group size, family child care homes can often be a good option for young children with disabilities. Of course, you must take great care in selecting and monitoring the care your child receives inside someone else's private home.

Child Care Centers

Child care centers are operated in facilities in the community. In Florida, all child care centers must be licensed by Florida DCF, with the exception of some faith-based facilities, which may choose a religious exemption, or some programs based in public schools that may choose a public school exemption. Licensing by DCF establishes standards that all centers must meet and maintain. These standards generally address health and safety features of the programs and do not guarantee that the educational program is of high quality. You must bear the responsibility for examining the daily operations of a child care center to make sure it is providing services that meet your expectations. Most experts advise you to make several visits to a center before making your final decision.

You can review the licensing inspection reports for each center by contacting the local licensing agency in your county or by accessing them online at <http://www.myflfamilies.com/service-programs/child-care/parent-resources> and selecting "Provider Search." These reports can assist you in making your decision. You can also receive help and advice from the educational professionals who are involved with you and your child through your disability services system. Even though you may not have as many options for your child as parents of children without disabilities do, you should still be careful in choosing the place your child will spend time each day. If you are uncomfortable, keep asking and keep looking.

In-Home Caregivers, Babysitters and Nannies

These individuals are people who come into your home to care for your

child. Generally, you are responsible for finding, interviewing and hiring such individuals, although some cities in Florida have established “nanny” services that can do this work for you. As noted, the State of Florida strictly regulates licensing for child care facilities but *does not certify or license employees, nor does it require nannies who work for single families to be licensed*. Paying for care in your home is often more expensive than paying for family child care or center care is. Great attention should be given to selecting an individual who will provide child care in your home. However, using this type of care also gives you the opportunity to find a person who has experience or willingness in caring for a child with a disability. Consider using in-depth interviews, reference checks and trial periods to determine if an in-home caregiver will be appropriate for your family. One website that specializes in finding nannies for children with special needs is [Care.com](http://www.care.com). Visit the link for special needs care and enter a zip code to see what is available near you: http://www.care.com/special-needs-care-p1087-q18890605.html?null&_qs=1.

Shared In-Home Caregiver Arrangements

In this arrangement, two or more families combine their resources to hire one caregiver who will take care of their children. The care may take place in one home, or rotate among homes, and is generally less expensive than each family hiring its own caregiver. You may have friends or coworkers with children who would benefit from this type of arrangement. One benefit for children with disabilities would be having interactions with typical peers, while still being part of a relatively small group. Participating parents would need to work out the details of the arrangement to everyone’s satisfaction and would need to carefully interview and screen the potential caregivers. All families should have equal say, and all should interview each prospect. Caregivers will likely charge more than for a single child, but there will still be a cost savings when spread across two or more families.

In-Home Support Services

There may be times in your child’s life when you need the services of a trained nurse or support worker in your home. Some of these times might occur when your child returns home from a hospital admission, when your child becomes seriously ill or when you are unable to perform required medical procedures for your child. In-home support services are generally covered by your private medical insurance or by Medicaid, administered through the Florida Agency for Healthcare Administration. In either case, in-home support services are subject to certain limits, generally on an



annual basis. In addition, it is important to check with the agency covering your costs for in-home services for restrictions based on age and on certain categories of disability that may not be eligible.

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Resources

2-1-1

Call 211 on your phone and ask specifically for early intervention services in your area.

Many cities and counties have their own 2-1-1 website that you can also use to search for information. Just type 2-1-1 and the name of your city or county and state into your search engine (Google, Firefox, etc.), and you will be able to find your local 2-1-1 website.

Early Steps

<http://www.floridahealth.gov/AlternateSites/CMS-Kids/families/early>

[steps/eligibility.html](#)

Center for Autism and Related Disabilities

<http://www.florida-card.org/>

Florida Association for Agencies Serving the Blind

<http://faasb.com/resources/>

<http://faasb.com/members/>

Department of Children and Families Child Care Website

<http://www.myflfamilies.com/service-programs/child-care>

“What your child needs most is a healthy, loving parent. You can give him that by taking care of yourself.” - Rhonda Krah

“Because of your child, you will meet some truly amazing people. Andrew has been a bridge to meeting people, as he is as extroverted and friendly as can be. He is a joy giver, and people young and old are drawn to him. His beaming smile melts hearts.”
- Rose Mary Lumm

“Three grand essentials to happiness in this life are something to do, something to love and something to hope for.” - Joseph Addison

Chapter 12:

Recognizing the Value of Inclusion



The term “inclusion” is used widely in educational circles and particularly in the disability field, but there is actually no single official definition for this word. The word “inclusion” does not appear in the Individuals with Disabilities Education Act (IDEA), and it has never been defined in federal legislation.

In fact, there is a great deal of confusion about the term “inclusion.” In the past, the words “mainstreaming” and “integration” have been used to talk about bringing children with disabilities into the “mainstream” of life, but neither one really means the same thing as inclusion.

“Mainstreaming” became a popular term in the early 1970s, when efforts to include children with disabilities in regular programs and classrooms first began to gain recognition. At that time, children still usually received most of their education in a separate setting but were “mainstreamed” for a part of their day into a regular education setting. The term “integration” was borrowed from the civil rights movement of the 1960s on behalf of African-American citizens. This movement helped the nation realize that segregation wasn’t good for anyone, including children with disabilities. But the term “integration” didn’t quite capture the essence of being fully included in society, so the word “inclusion” came into use.

WHAT IS INCLUSION?

In a sense, inclusion is a philosophy. It is a value that supports the right of all children, regardless of their abilities, to participate actively in “natural settings” in their communities. “Natural settings” are those places where a child would spend time had he or she not had a disability. These settings include, but are not limited to, home, preschool programs, Head Start programs, kindergartens, public school classrooms in the child’s home school zone, child care centers, places of worship, recreational sites (such as community playgrounds) and other settings that all children and families enjoy (restaurants, theaters, hotels, etc.). In general, **inclusion is full participation in family and community life for all people, including persons with disabilities.**

In essence then, inclusion is about belonging and participating in a diverse society. Inclusion is not just a school issue; it extends to the communities in which children and their families live. Inclusion is not only a disability issue; all children and families have a right to participate and be supported in their schools and community.

Individuals (e.g., teachers, families, administrators) define inclusion differently. Priorities and responsibilities influence one's definition of inclusion, and people within the same system (e.g., one's school or one's school district) may have extremely different views on inclusion. For instance, parents don't necessarily see school as the only place for their children to have inclusive experiences and tend to interpret inclusion much more broadly, encompassing all community offerings (e.g., camp, library programs and religious organizations). A national sample of local directors of exceptional student education/special education defined inclusion in a variety of ways, with some arguing that inclusion is for everyone and others arguing that inclusion is for some children, but not for those with behavior-related disorders and other significant disabilities.

When talking about education for children, inclusion means placement in the programs and classrooms where a child would be enrolled if he or she had not had a disability. This means a regular child care center, a regular preschool program or a regular classroom in the school for which he or she is zoned. Even though the word "inclusion" is not specifically mentioned, there is legal support for inclusion in the IDEA within the concept of "least restrictive environment."

The search for the "least restrictive environment" for every child begins with a regular education classroom in the child's home school; therefore, that is the first option that the Individual Family Service Plan (IFSP) or Individualized Education Plan (IEP) committee must consider. Only after it is determined that the child cannot be successful in a regular education class, even with "appropriate aids and supports," can the committee recommend a more restrictive placement for the child.

Inclusion has become an issue of much discussion in recent years. On one hand, advocates of inclusion have evidence – legal, educational, social and moral – that inclusion is the best way to serve children in our schools and communities. On the other hand, there are organizations and individuals who are concerned about the movement toward inclusion. Some school administrators worry about placing children in regular classrooms without the supports and services they need to succeed. They worry about the effects of such placements on teachers and other children. Administrators note that rural areas face special problems in implementing policies on inclusion and providing a full spectrum of special education services.

Some teacher organizations are concerned that teachers of regular education do not get adequate training in their college classes to prepare them to

meet the educational needs of children with disabilities. It is likely almost everyone agrees with inclusion in theory, but when it comes to making decisions about individual children, some disagreement can be expected.

This is also true for the parents of children with disabilities. As a parent, you no doubt want your child to be fully accepted into society. Yet when it comes to enrolling him or her in, for example, a regular child care center, you may have doubts or concerns. Other parents strongly believe in the value of inclusion for their children and work for inclusion as actively as they can.

Does that mean that one view is right and the other is wrong? No, not at all. There is not just one right answer for every family. You will come to your own decisions about the value of inclusion for your child, and your decision will be based on many factors. The severity of your child's disability will probably be one of these factors. Your perceptions about available services and supports will be another, and your beliefs about people and society in general will also figure into your feelings about inclusion. In general, American society is moving towards greater inclusion of persons with disabilities, and most people would agree this is right and good. In fact, nearly all parents of children with disabilities would agree that the philosophy of inclusion is a good one; nevertheless, those parents who are not seeking inclusion for their own children have shared the following reasons:

- Parents believe that the type or severity of their child's disability will prevent him or her from benefiting from being in a regular education classroom. Parents have cited characteristics such as medical needs, sensory impairments, lack of self-help skills, lack of language, the presence of seizures and the presence of multiple disabilities as reasons why they feel regular classroom placement would not be appropriate for their children.
- Parents believe that inclusion would overburden teachers or have a negative impact on other children in the class. Because a child with a disability might require additional care or attention, some parents feel that teachers could not adequately meet the needs of all children. Parents may also have concerns about the lack of specially-trained teachers and assistants.
- Parents may believe that their child's needs could not be met in a classroom that has an emphasis on an academic curriculum of reading, writing, math and other subjects. These parents often report that they would prefer to have their children in an environment that emphasizes basic living or functional skills.
- Parents may be fearful that their children would be mistreated,

- harmful or ridiculed by other children in regular education settings.
- Parents worry that their children would be neglected in general or at the least would not receive the individualized attention or specialized services they need in a regular education classroom.
 - Parents believe that there is a benefit to having other children with similar needs and disabilities in their child's classroom for the formation of friendships and the enjoyment of similar activities.
 - Parents report that such relationships can be important in their child's life. This line of thinking supports the idea that friendships between children with disabilities are no less valuable than friendships with non-disabled peers.

Other parents are strong supporters of inclusion programs for their child's education. These parents tend to place great emphasis on the social and emotional aspects of their child's daily experience. They are not necessarily parents of children with less severe levels of disability, because we know that parents with children at all levels of disability can be devoted advocates for inclusion. Parents have reported these as some of the reasons for supporting inclusion for their children:

- Parents believe that other children in regular education will become more sensitive and knowledgeable about disabilities, thereby leading to a greater acceptance of persons with disabilities in the general society as these children grow up.
- Parents believe that their children will learn more in regular education programs due to higher expectations and the presence of peers with typical developmental skills as role models.
- Parents believe that their children will grow in their social development, even if they don't show as much improvement in their academic work, meaning that parents believe that having typical friends and being included in society is more important in the long run than education alone.
- Parents want their child with a disability to go to the same school as their other children or with other children in the neighborhood.
- Parents believe that inclusion is the right thing to do and that children with disabilities should not be segregated into separate classrooms.

The truth is that there are no simple answers about inclusion for individual families. Just as the individuality of each child must be respected in the planning of educational services, so must the individual nature of families

be respected as well. One size does not fit all. Given support and information, families will generally make decisions for their children that best serve their family system and priorities.

INCLUSION IN FLORIDA SCHOOLS

There is no cap on the number of students with disabilities who can be placed in a general education classroom. What is true is that Florida's Class Size Reduction Amendment in Article IX section 1 of the Florida Constitution applies to all students. How children with and without disabilities are distributed in classes depends a lot on the number of children with disabilities, also known as the "natural distribution," in the school. For example, if out of each 100 children, 80 are typically developing and 20 are not, then classrooms should have 20 percent of children with disabilities in each classroom. Naturally, there are other factors that could affect this decision. This is one way, although a common one, schools may take. Whatever the formula, inclusion does focus on increased accountability, using data and looking at outcomes for all students.

Using a "collaborative classroom" model, two teachers, one with special training for children with special needs, work together. This is the favored, but not the only, model in Florida. This allows for flexible lessons and assessments, flexible grouping of students resulting in many combinations of shared learning and a better understanding between all students. Parents do need to be vigilant. In a survey of parents for this guide, one of the biggest concerns of parents is that students with disabilities do not have the support they need for learning in inclusive settings due to unavailability of resources.



WHAT DOES INCLUSION LOOK LIKE?

There is still much to be done to make inclusive school settings available to all children. The encouraging news is that educators know how children with disabilities can best be served in regular education settings. Even though it is not yet happening in all places, the practice of inclusion has been studied for more than 30 years.

Though inclusion is still debated for what it is and how it looks, there are three parts to what is considered high quality inclusion:

- 1. Access:** Removing physical barriers, providing a wide range of activities and environments and making necessary adaptations to support optimal development and learning for individuals
- 2. Participation:** Using a range of instructional and intervention-based approaches to promote engagement in play, socialization, work and learning activities and a sense of belonging for every person
- 3. Supports:** Creating an infrastructure of system-level supports for implementing high-quality inclusion, including physical, social, education, employment, recreation, transportation and other factors

Expanding on these three key parts, it is now known that a number of additional conditions must be present in order for inclusion to be successful for children. These conditions can be organized into five categories:

1. Attitudes and Beliefs

- Teachers of regular education believe that children with disabilities belong in their classrooms.
- All regular education staff accepts responsibility for the educational outcomes of children with disabilities. They do not believe it is someone else's job.
- Teachers of regular education are given preparation and information that a child with a disability will be joining the class.
- Children are helped to understand their classmates' disabilities, and interactions among the children are supported.
- Parents are kept informed and support their child's placement in the regular education setting.
- All special education staff is committed to working together with the regular education staff.
- All school staff (including paraprofessionals, counselors, lunch

room staff, bus drivers, etc.) receives training in the value and practice of inclusion.

2. Services and Accommodations

- All services needed by the child are available, such as speech therapy, occupational therapy, physical therapy and transportation. Additional staff members in the classroom and behavioral supports are available as needed.
- Accommodations needed by the child are made, such as accessibility to the classroom and playground, adaptive toys and equipment, environmental modifications (such as noise levels) and assistive devices.

3. Collaboration

- Members of the special education staff are part of the planning and instructional team.
- A team approach is used for problem-solving and implementing programs.

4. In the School

- The director, administrator or principal understands the needs of children with disabilities and supports their inclusion in the program.
- An adequate number of personnel is available.
- Policies and procedures are put into place to support and monitor the progress of children with disabilities.

5. Instructional Methods

- Teachers have the knowledge and skills needed to adapt the curriculum to meet the individualized needs of all children.
- A variety of instructional methods are available.
- Teachers create a cooperative learning environment and promote socialization among all children.

If all these conditions could be met in every classroom, you probably would agree that it would be a good place for your child. If everyone can agree on that, then everyone can probably agree that this “ideal situation” is what we must work towards for all of our children. In fact, research has found that among the many definitions of inclusion, almost all have five things in common that are similar to the conditions described above. Ask yourself if these fit your beliefs on inclusion. Remember, whether it is now

or later, you may end up having to strongly advocate for your child to be included.

1. Inclusion means being in the natural setting on a daily basis or all types of activities in the natural proportion for the school.
2. Students are all together for instruction and learning.
3. Supports and modifications needed occur in the regular classroom and school community.
4. All students share a sense of belonging, membership and acceptance.
5. Teachers work in teams to plan, implement and evaluate instruction.

What we see then is that *programs, not children*, have to be “ready for inclusion.” The most successful inclusive programs view inclusion as the starting point for all children. Inclusion can be appropriate for all children, but successful inclusion requires planning, training and support. What it comes down to is that *adequate support* is necessary to make inclusive environments work. This means providing supports to adults and children in the setting. Support includes training, personnel, materials, planning time and ongoing consultation. Support can be delivered in different ways, and each person involved in inclusion may have different support needs. When deciding how inclusive a school, recreational location, community agency or other place is, parents should ask how inclusion is defined and how people were trained to be inclusive. In other words, inclusion is not just something that happens in which can be passively enjoyed. As parents you have responsibilities too. This is the subject of the next section.



THE RESPONSIBILITIES OF PARENTS

Historically, parents have played an important role in the United States in gaining services for their children with disabilities. Even though it may not always feel this way, you can have a big impact on getting improved services for your child and on improving services for all children over time.

You have already realized that you are the most important advocate that your child will ever have. From seeking medical care to advocating for inclusive settings, you have an important role to play in making changes in the systems that serve children with disabilities. It may not be a role you asked for, but it is a role you now have. You may even surprise yourself when you find out how passionate you can be when you are advocating for your child's rights and needs. Inclusion for your child refers to much more than his or her educational setting, but this will be one of the first places you will come face-to-face with decisions about inclusion.

Try to keep your mind open to the benefits of inclusion. No one wants to go back to the days of institutions and an "out of sight, out of mind" way of thinking. If you choose a special education setting or residential school for your child, try to think of other ways that you can expose your child to his or her typical peers, such as at the playground, in play groups or other in programs in the community.

Here are ways you can help your child have the maximum inclusion possible in educational, early learning, recreational or other environments:

- Clearly explain your vision, long-term goals and how you would measure success for your child.
- Learn what is already happening in each environment you are concerned about. Ask questions like...
 - "How much time will/is my child spending with peers without disabilities?"
 - "How many hours/minutes a day is my student included in the classroom?"
 - "Is my child ever removed from the general education classroom because of his or her behavior or sensory needs?"
 - "Can you show me the data taken on the amount of time my child is removed from the classroom?"
- Work with the program or education team in each location. Different places will have different visions and ideas of inclusion. This can be exhausting, but perseverance will pay off. Equally important is that you as the parent are supporting the team to get the best

results.

- Know the law. The most important language in the law you should know in order to support inclusive practices in schools comes from the federal law governing special education (IDEA). The provisions for inclusion are found under the section entitled “Least Restrictive Environment” or LRE. The link to the IDEA language specific to LRE is <http://idea.ed.gov/explore/view/p/%2Croot%2Cstate%2CIDEA%2C612%2Ca%2C5%2C>.
- Plan an inclusive Individual Education Plan (IEP). We talk more about the IEP in chapter 15. It may be important to rehearse your dialogue for the IEP and to consider bringing an ally at first as you learn the process better. An ally may be a family member or friend for moral support if you are confident, a friend or family member with experience with IEPs that can help you or even paid professionals that specialize in providing IEP support and lead the meeting at your request. His or her and your sole purpose is making sure your child receives all necessary services and supports.

THE BENEFITS OF INCLUSIVE EDUCATION

You may or may not agree that your child will receive the best educational experience in a regular education setting at this time. Many experts agree, however, that when inclusive education is done well, there are many benefits that can be expected. These benefits can affect not only children with disabilities but also children with typical development, their families, classroom teachers and the community at large according to these categories:

Children with special needs may

- Experience a more complex environment that stimulates developmental progress
- Increase their social skills and language through interaction with typically developing peers
- Develop a better understanding of the real world
- Be better accepted within the community if they participate in a natural setting, thus growing up feeling included rather than excluded

Children with typical development may

- Learn about differences in human growth and development
- Become more accepting of their limitations
- Become more accepting of individual differences as they learn to work and play with a wider range of children

- Learn how children with special needs can be models for perseverance and determination in spite of adversity
- Learn how children with special needs are similar to all other children

Families of children with special needs may

- Develop more positive attitudes towards their children
- Gain an understanding about a real-world perspective for interpreting their children's accomplishments and challenges
- Increase their knowledge of typical child development
- Learn about age-appropriate activities
- Feel less socially isolated
- Improve their perception of themselves as parents

Families of typically developing children may

- Have opportunities to teach their children about differences in growth and development
- Develop a greater understanding of persons with disabilities
- Become more sensitive to the needs of families with children who have disabilities
- Become advocates for community integration

Classroom teachers may

- Receive additional training, such as learning how to enhance social interactions, which will help them with all children
- Develop positive, realistic attitudes towards inclusion
- Develop new relationships with professional colleagues from various disciplines
- Receive the personal satisfaction of helping all children make progress and become friends

The community may

- Understand that if the potential of all children is maximized, children with disabilities are helped to become productive members of society
- Understand that providing intervention early in a child's life saves money in the long run, because the effects of disabilities can be modified to varying degrees, enabling children to become more independent

FOSTERING FRIENDSHIPS FOR YOUR CHILD

All parents know that having friends is an important aspect of a child's life. Like all parents, parents of children with disabilities want their children to be loved, feel a sense of belonging and share experiences with their siblings and other children.

Children with disabilities are sometimes at risk of having social interactions only with the adults who work with them, but all children need to interact with other children. Although some friendships develop naturally, it is still important to provide opportunities where friendships can get started. Because your young child can't make these arrangements by himself or herself, you will need to help him or her. Here are some ways you can expand your child's social circle:

- Find activities your child enjoys. Learning does not end when the school day ends. By building on your child's strengths and interests, you can help him or her find friends who enjoy the same things. Identify activities that keep your child's attention, bring out the best in your child and bring a smile to his or her face.
- Use resources in your community. Find out what classes, organizations and programs are available in your community. Many communities offer a variety of weekend or after-school classes for activities such as swimming, soccer, horseback riding, martial arts, music, dance and art. Other community resources include churches, libraries and parks.
- Share information and raise awareness. It is useful to share information about your child with caregivers, babysitters, Sunday school teachers and so on, especially if they have not had experience with children with disabilities. Sharing might include specific information about your child's strengths, preferences and ways to encourage his or her participation in activities.
- Encourage a variety of social relationships. Create different opportunities for your child to connect with other children. For example, you may set up a regular "play date" at your house for one or two other children in the neighborhood. Be sure to prepare in advance to make certain the experience is a positive one. Choose toys that bring children together, such as balls, bubbles or water play, instead of toys that encourage children to play alone, such as books or crayons. You might want to organize a specific activity like baking cookies or a trip to the park. Keep play dates relatively short, so children want to come back soon.
- Identify children who show an interest in your child. Find out who

your child plays with at school, or which children show a special interest in him or her. Use this information to decide which children you may want to invite for play dates or other ways to socialize with families in your neighborhood.

- Teach your child specific social skills. Before an interaction can take place, someone must initiate it. Learning how to greet others with a “hello”, a wave or a smile is a skill that children can use throughout their lives in many different situations. If your child has difficulty with mobility or speech, you can try talking to other children and suggesting specific ways they can talk to or interact with your child. If your child is able, you can practice some basic social skills at home together, like walking up to each other and saying “hi” or offering to trade one toy for another.

THE IMPORTANCE OF ASSISTIVE TECHNOLOGY

Assistive technology (AT) refers to any device that helps a person with a disability to complete everyday tasks. If you break your leg, a TV remote control can be assistive technology. If you have poor eyesight, your glasses or contact lenses are assistive technology.

Assistive technology includes many specialized devices as well, such as “typing telephones” (TTY) for people who are deaf and motorized wheelchairs for people with limited mobility. Assistive technology can be “low-tech” (simple and low-cost), like a pencil grip, or “high-tech” (sophisticated and higher-cost), like a computer. Assistive technology can be critical for the person using it. As an example, if you are dependent on your eyeglasses, think how hard it would be to get through a day without them. Assistive technology assists people with disabilities to be a part of their homes, schools and communities.

When the IDEA was revised in 1997, it recognized the importance of assistive technology for children in special education programs. Now, IEP teams must consider your child’s need for devices to help him or her function as a better “student,” “family member” or “friend.” If the need for assistive technology seems likely, the school district must provide these services:

- A qualified evaluator must conduct an assistive technology evaluation.
- If the evaluator recommends a device, it must be provided.
- If you, your child or the staff in your child’s classroom needs training to use the device, that training must be provided as well.

Types of Assistive Technology

Research shows that AT can help young children with disabilities to learn developmental skills. Its use may help infants and toddlers to improve in many areas:

- Social skills, including sharing and taking turns
- Communication skills
- Attention span
- Fine and gross motor skills
- Self-confidence and independence

Many of the skills learned in life begin in infancy. Assistive Technology can help infants and toddlers with disabilities to learn many of these crucial developmental skills. With AT, they can often learn the same things that typically developing peers learn at the same age, only in a different way. You may be reluctant to begin using an AT device. You may believe it will discourage your child from learning important skills or prevent this child from really trying to improve. In truth, the opposite is true. Research has shown that using AT devices, especially augmentative communication devices, may encourage a child to increase communication efforts and skills. The earlier a child is taught to use an AT device, the more easily the child will learn to accept and use it.

The right type of assistive technology can improve a child's ability to communicate. This in turn may help to reduce some negative behaviors. There are many types of assistive technology. Here are some examples:

- **Access and Environmental Controls:** Switches, special keyboards/mice and remote controls that allow a child with a physical disability to control things in his or her environment, including things that help people get around the community, like ramps, automatic door openers and Braille signs
- **Aids to Daily Living:** Special tools for daily activities, like brushing teeth or dressing, and specially designed toilet seats for children who need help with self-care
- **Assistive Listening:** Hearing aids, cochlear implants, FM systems, sound field systems, amplifiers, captions on TV and typing telephones that help a child who is deaf or has a hearing loss
- **Computer-Based Instruction:** Software to help children with learning difficulties in reading, writing, math and other subject areas
- **Mobility:** Wheelchairs, walkers and adapted bicycles that allow a child with a physical or visual disability to move safely through the community

- **Positioning:** Adjustable chairs, tables, standers, wedges and straps that help a child with a physical disability remain in a good position for learning without becoming tired
- **Visual Aids:** Large-print books, books on tape, magnifiers, talking computer software and Brailleurs that give a child who is blind or has low vision access to information
- **Augmentative/Alternative Communication:** Picture boards, battery-operated communication devices, communication software and computers that allow a child who cannot speak, or whose speech is not understood by others, to communicate

Augmentative and Alternative Communication (AAC)

Augmentative and alternative communication is one of the most essential forms of assistive technology. All children have the right to express what they want and how they feel, but this is not always easy for every child. Some children are not able to speak clearly enough for people to understand them, while others are not able to speak at all. Using AAC, parents and caregivers can help children with communication difficulties find ways to express what they want, need and think.

Augmentative and alternative communication refers to any strategy that helps a child communicate with others. Some strategies may be as simple as having your child point to a picture, use a gesture or use some basic sign language. For example, a child might point to a picture of a glass of juice as a way of telling you that he or she wants juice. As his or her abilities develop, more and more pictures can be put together on a “communication board,” including pictures of both objects and emotions. Symbols can also be used in place of pictures to extend the types and complexity of thoughts your child wants to express.

Other strategies are considered more “high-tech” and are more complicated than pictures or symbols on a communication board. For example, on a “voice output communication aid” (VOCA), a child can press a button or picture on the device, and a prerecorded voice will speak the word or message. For example, if your child pressed pictures of himself or herself, “drink” and “juice,” the device will create a message spoken by the computer that says “I want juice” in a voice easily understood by others.

If you believe your child might benefit from AAC, request an ISFP or IEP meeting to discuss a reevaluation of your child’s need for assistive technology. If your child is already receiving speech therapy, you can talk with

your therapist about the evaluation. If your child is not currently receiving any speech or language services, you can contact the pre-kindergarten program office in your local school district. If there is one in your area, you can also contact a college or university that offers speech and language therapy services. Many times, these schools can provide AAC evaluations or can help you find someone who is qualified to conduct the evaluation.

Accessing devices can be confusing. Early Steps, the Agency for Persons with Disabilities and your insurance company can help you find sources. Many schools and communities have special lending libraries where parents can borrow toys with switches, computer software and other devices. These libraries, such as the Tech Tots libraries sponsored by United Cerebral Palsy chapters around the country, give parents an opportunity to try various devices before deciding whether to purchase them.

Resources

Best Buddies Florida:

<https://bestbuddies.org/find-programs/florida/>

Autism Society of Florida:

<http://www.autismfl.com/>

F.R.I.E.N.D.S. (Families Raising, Inspiring, Educating and Networking for Down Syndrome):

<http://www.friendssupport.org/>

FAAST (Florida Alliance for Assistive Services and Technology), Inc.:

<http://www.faast.org>

Special Olympics International

<http://www.specialolympics.org/>

Center for Parent Information and Resources

<http://www.parentcenterhub.org/repository/priority-selfadvocacy/>

Words to Follow

“Coming together is a beginning; keeping together is progress; working together is success.”

- Henry Ford

“This country will not be a permanently good place for any of us to live, unless we make it a reasonably good place for all of us to live.” - Theodore Roosevelt

“Another myth that is firmly upheld is that people with disabilities are dependent and people without disabilities are independent. No one is actually independent. The world has been built to accommodate certain needs and call the people who need those things independent, while other needs are considered exceptional. Each of us relies on others every day. We all rely on one another for support, resources and to meet our needs. We are all interdependent. This interdependence is not weakness; rather, it is a part of our humanity.”

- Adapted from A.J. Withers

“Be the change you wish to be in the world.” - Mahatma Gandhi

“A community that excludes even one member is no community at all.” - Dan Wilkins

“Our lives begin to end the day we become silent about things that matter.”

- Martin Luther King, Jr.



Chapter 13: Knowing the Rights and Responsibilities of Parents and of Children with Disabilities

THE HUMAN RIGHTS OF ALL CHILDREN AND YOUTH

In 1989, the Committee on the Rights of the Child of the United Nations General Assembly held the *Convention on the Rights of the Child*. As a result, a charter was written and approved by the members of the United Nations which is intended to guide the treatment and protection of children and youth throughout the world.

We can read this list of children's rights (Figure 1) and think about children who live in the poorest of nations, where they lack food, shelter, basic medical care or even clean water. We understand that their basic human rights, the rights that everyone is entitled to, are being violated. We also know there are children who live in our own communities who do not have adequate food and shelter, and we feel a sense of injustice for these children who suffer through no fault of their own. As a parent of a child with a disability, you may look at this list and realize that you and your child may also have to stand up for some of these rights. No matter your income, you know that it may not always be easy to guarantee that your child will receive an appropriate education, be allowed to make his or her own decisions or be free from the discrimination and societal attitudes that may stand in the way of your goals for him or her.

Section 393.13, *F.S.*, is designated as the “Bill of Rights of Persons Who Are Developmentally Disabled” (Figure 2), and it ensures that the rights listed in the figure cannot be denied to your child on the basis of his or her disability. The full Bill of Rights can be found at the Agency for Persons with Disabilities (APD) website (<http://apd.myflorida.com/training/docs/bill-of-rights-2008.pdf>).

Any time you feel that your child's basic human rights or his or her rights as a citizen of Florida are being violated, you have the right to say so. It is important to know your child's rights, so that when something being suggested does not seem appropriate to you, you will feel empowered to question the professionals who are working with you. Human rights belong to all children, and all children really means ALL children. Two resources for you to consider if you feel your child's rights are being violated are Disability Rights Florida (<http://www.disabilityrightsflorida.org/>) and the

Department of Education's Program Administration and Quality Assurance Bureau (<http://www.fldoe.org/academics/exceptional-student-edu/dispute-resolution>). Disability Rights Florida has a number of resources and services. If your child is experiencing violations of his or her rights while in school, you can access resources through the Department of Education's Program Administration and Quality Assurance Bureau. Resources available include information on dispute resolution, mediation, state complaints and due process hearings. This will be the resource you go to when you have not had any response or changes made after addressing the issues with your child's teachers, school administration and school board. Though there may be things going on that can be resolved through meetings with teachers and school staff before going to the Department of Education, it's important to know that you have this resource available to you if you need it.

Figure 1. The Human Rights of All Children and Youth

The human rights of children and youth include the following indivisible, interdependent and interrelated human rights:

- The human right to a standard of living adequate for a child's intellectual, physical, moral and spiritual development, including adequate food, shelter and clothing
- The human right to freedom from discrimination based on age, gender, race, color, language, religion, nationality, ethnicity or any other status, or on the status of the child's parents
- The human right to the highest possible standard of health and access to health care
- The human right to a healthy and safe environment
- The human right to education, to free and compulsory elementary education, to readily available forms of secondary and higher education and to freedom from all types of discrimination at all levels of education
- The human right to protection from neglect and all types of physical or mental abuse
- The human right to protection from economic and sexual exploitation
- The human right of the child to express an opinion about plans or decisions affecting his or her life
- The human right of the child to live in a family environment; when families need assistance and support to meet this fundamental need of the child, it should be provided.

Adapted from the Convention on the Rights of the Child of the United Nations Committee on the Rights of the Child (1989)

Figure 2. Florida Law Section 393.13

Under this Statute, all persons with developmental disabilities in the state of Florida have:

- The right to dignity, privacy, and humane care
- The right to religious freedom and practice
- The right to receive services, within available resources, which protect the personal liberty of the individual and which are provided in the least restrictive conditions necessary to achieve the purpose of treatment
- The right to participate in an appropriate program of quality education and training services, within available resources, regardless of chronological age or degree of disability
- The right to social interaction and to participate in community activities
- The right to physical exercise and recreational opportunities
- The right to be free from harm, including unnecessary physical, chemical or mechanical restraint or isolation, excessive medication, abuse or neglect
- The right to consent to or refuse treatment
- The right to participate in any program or activity that receives public funds
- The right to vote in public elections

Adapted from Section 393.13, F.S., Bill of Rights of Persons who are Developmentally Disabled

THE RIGHTS OF PARENTS

When you become the parent of a child with a disability, you still have the same rights you have always had. Your rights do not change. That may sound like an obvious statement, but many parents report that they experience reactions that make them feel as if they have lost their rights as parents. You may now feel that you must need to be strong and responsible all of the time, like you have lost the right to break down and cry in a difficult situation. You may feel like you've lost the right to get angry with your child because to do so would make you feel guilty. *After all, it's not his or her fault, right?*

Be assured that you have not lost your rights as a parent, a person or a citizen. Just as you have not lost your legal rights, neither have you lost your human rights. Many times, when professionals talk about parents' rights with regard to children's disabilities, they are talking about their legal rights under the public education laws. But over the years, many parents have

come together to create another set of rights that matter most in their day-to-day lives with their children. These rights will become just as important to you as the ones written down as laws.

The “twelve rights” that follow are adapted from an article written by parent Kay Ferrell in the November 1985 issue of *The Exceptional Parent*. The parents that reviewed this guide clearly stated that these are timeless. They were written by parents, for parents, and they come out of the real-life experiences of parents who are living what textbooks can only describe, not truly convey. They are not meant to be harsh, but rather “real.”

1. *The right to feel angry.* Nothing in life has prepared you for having a child with a disability, and it may seem unfair. You did not ask for this, and there is little you can do about it. Your sense of control over your life, and the life of your child, is at risk. Friends and family may try to comfort and reassure you by making statements like “God only picks special people for special children,” but you probably won’t be feeling special at that moment. It’s okay to feel angry, but make sure your anger does not begin to rule your life.

2. *The right to seek another opinion.* It makes good sense to seek a second opinion before having surgery, before investing money or before buying a used car. It should be no different for you and your child, whether you are looking for medical care or an educational program. If you hear of a new treatment or strategy that could help your child, look into it. Times change and so do treatments. Do not, however, allow yourself to be rushed into a decision you are not ready to make. Unless it is an emergency procedure or surgery, you should not have to make up your mind immediately, or even overnight, regarding changes in your child’s care. You may need time



to read about the alternatives or to talk with other parents whose children may have similar disabilities or medical needs. In the end though, you have to live with the decisions you make, and you deserve the time needed to make those decisions.

3. *The right to privacy.* In the same way that you may not want to share certain parts of your life with others, you may not want to share everything about your child. Many parents report the effects that a disability has on their family's privacy when suddenly new people are brought into the family circle who examine, give advice and sometimes even appear judgmental. Some aspects of your life may not be anyone else's business. If you, for example, do not want to discuss something or do not want your child's picture taken, it is your right to say "Not right now" or "I'll think about this and get back to you."

4. *The right to keep trying.* Parenting is not easy, but most parents try to do the best job they know how to do. It can become harder when people who mean well tell you that there are some goals they think your child will never be able to reach, that you must stand back and accept the fact that your child will never do some things. A doctor, family member or friend may tell you or imply that you are wasting your time if you persist in a particular course of action.

There is nothing wrong with you if you are not willing to give up. All children have the potential to learn one more thing, and then another and another, and no one knows what event or combination of events might make a difference in your child's life. Again, you will live with the consequences of your decisions, not the well-meaning advisors who come and go in your life.

5. *The right to stop trying.* Well-meaning friends and professionals have also told parents that they do not work hard enough or long enough with their child with a disability. They have made statements such as "If you would just do this at home for 15 minutes a day and on the weekends, it would make such a difference." The truth is, it could just as easily make no difference at all, and the instruction may in fact be getting in the way of enjoying your relationship with your child. When every activity becomes a "therapy session," a lot of pleasure that would have otherwise been shared by you and your child can be lost. You are the one being asked to do "one more thing." If perhaps you cannot do something tonight or seven days a week, then you can't. That is your decision.

6. *The right to set limits.* There are limits to what one person can do. You shouldn't expect yourself to think about your child all the time, and your child shouldn't expect to be the center of attention all the time. It's easy to let a child's disability set the schedule and tone of your family's life, but don't fall into this trap. You have limits and so does your child. You don't have to be a "super-parent."

7. *The right to be a parent.* You are not your child's teacher or therapist. You are a mommy or daddy or grandma or grandpa. Therapy and educational activities done at home can certainly be beneficial, but you and your child still need time to just be silly, snuggle, laugh, tell stories and just do nothing in particular. Those times are just as much a part of your child's education as the time you spend on scheduled activities.

8. *The right to be unenthusiastic.* No one expects you to always be ready for addressing the disability of your child. Sometimes you feel sad, or maybe you are worried about money or your other children, or you are sick. If other people take that as a sign you're "not adjusting" or "not accepting" your child's disability, then that is their dilemma, not yours. No one is excited about work every day. It can be tedious one day and new and interesting the next. The same is true of parenting. There will be days when your child thrills you with joy, and other days when parenting seems like the world's most boring job. You have the right to be "up" on some days and "down" on others, just like every other parent.

9. *The right to be annoyed with your child.* Only a parent can say this, but it's true. There will be days when you like your child and days when you don't. This does not mean that you don't love your child, or that you are experiencing a problem "adjusting" to the disability. Children with disabilities, for the most part, are just as capable of being ornery as other children. Therefore, they should be disciplined in appropriate ways. It is up to you as the parent to figure out what is misbehavior and what is behavior related to the disability. When you are certain that your child is intentionally misbehaving, you need to have the courage to provide discipline. You and your child will both benefit, even though you may feel guilty at first.

10. *The right to have time off.* As a parent, you need time for yourself with your spouse, partner or other family members or friends, especially without the presence of children. Many parents describe a tremendous feeling of freedom the first time they go to the grocery store alone after their child is born, even if they don't talk to anyone but the checkout clerk. There are many parts to your life in addition to your child and each one deserves



your attention. You will be a better parent in the long run.

11. *The right to be the expert-in-charge.* You know your child better than anyone else. You are the one who lives with, and spends the most time with, him or her. Teachers and therapists come and go, but you are the expert with the most experience, as well as firsthand knowledge about your child. As the expert, you have the right to be in charge of your child's educational, medical and social decisions, at least until your child is able to do this for himself or herself. Professionals do not have to live with the consequence of their decisions the same way you do, so while you will value their knowledge and opinions, remember that these are "informed" opinions, though not necessarily fact. No one has the right to tell you that you are wrong, that you will regret it, that you are selfish or that you're not looking far enough ahead. Nor should they make you feel guilty or pressure you into a decision.

12. *The right to dignity.* You have the right to be respected and treated equally as a human being. You expect to be neither pitied nor admired, but you do expect to be listened to and supported in a nonjudgmental way. You expect to be treated the same, whether or not your child has a disability. You expect the truth from doctors, teachers, social workers and therapists who are there to help you. You deserve to know why a doctor is examining some part of your child's body, and if the reason is not explained to you, you deserve to ask. You deserve to be talked to as an adult. If you feel a professional is talking down to you or talking "above your head," speak up and say so. Many times, you will need to be assertive or even aggressive in order to obtain the dignity you are due.

From your friends, neighbors and family members, you deserve a chance to be someone other than the "parent of the child with a disability." Most of the comments and suggestions you receive from others can be accepted as advice that you may or may not wish to take. Even the comments that sound most offensive to you could be meant with good intentions. It is your decision what to do with them.

PARENT EMPLOYMENT RIGHTS

In addition to the above rights, and those guaranteed under the Individuals with Disabilities Education Act (IDEA) that are talked about in Chapter 15, you also have rights that help protect yourself from discrimination in your job. Some of the laws that protect you against discrimination in your job are:

- The Americans with Disabilities Act (ADA) prohibits most employers from firing a parent or excluding a parent from a job opportunity or benefit because the parent has a child with a disability. An employer may not treat an employee differently because his or her child has a disability.
- The Employee Retirement Income Security Act (ERISA) is a federal law governing certain employee benefit plans.
- The Family and Medical Leave Act (FMLA) is a federal law which provides important job protections to parents who take time off from work to be with children receiving medical and psychiatric care or who are recuperating from serious health concerns. As of January 2013, FMLA has been extended to include caring for children with special needs who have matured into adulthood.

For more information on these protections, you can visit Wrightslaw (<http://www.wrightslaw.com/info/protections.index.htm>) that has a wealth of information about the laws that affect you and your child.

THE RESPONSIBILITIES OF PARENTS

You are likely to be the most important resource in your child's life. Just as you need to know your rights and the rights of your child, you must also be aware of your responsibilities. It is important to take good care of yourself, making it possible to take good care of your child. That makes taking care of yourself a responsibility, not a luxury. That's not the same thing as saying that you should put yourself first, however. In many ways, it will not be helpful to put yourself first. For example, you may feel so sad or overwhelmed for a time that you cannot get out of bed in the morning. Short periods of feeling this way are normal, but if the feelings persist, you have the responsibility to seek help for yourself. In this circumstance, it is also your responsibility to arrange for alternate care for your child temporarily, so that someone is acting in the best interest of your child.

Because your child is dependent on you, you have the responsibility to take action. Learning that you have the power to make things happen will be satisfying to you and beneficial to your child. *Taking action* means:

- Getting information: Get as much information as you can about your child's disability.
- Becoming an expert: Learn as much as you can about available services and treatments for your child's disability.
- Keeping records: Keep copies of everything you learn about your child's disability, as well as copies of every form and report that has

to do with your child.

- Being proactive: Don't wait for others to offer the services your child needs. Prepare in advance and ask for what is needed.
- Expecting the best: Don't always settle for what is offered to you, if it seems like the wrong thing. Aim high for your child.
- Becoming an advocate: When you are ready, step outside of your comfort zone and speak out on behalf of all persons with disabilities.

WORKING WITH PROFESSIONALS

Many parents feel inadequate or unsure in the presence of people from the medical or educational professions because of their credentials or because of their professional manner. Try not to feel intimidated by the educational backgrounds of these and other personnel who are involved in your child's life. You and your child are the reason they do what they do!

The Family-Centered Approach is optimal (see Chapter 11), and it is okay to demand this. The best relationships between parents and professionals are characterized by mutual respect, trust and openness. In this situation, both you and the professional can share information and ideas about the best care, medical intervention or educational program for your child. You must also be willing to share information about the needs of your family. You and the professional both need to speak clearly about issues and listen carefully to each other about them.

Both of you have important information to share. You, for example, have intimate knowledge of your child and can contribute valuable information regarding his or her routines, development, history, strengths, weaknesses, likes and dislikes. The professional needs your unique insight in order to make an accurate diagnosis and determine appropriate services.

The professional has specialized knowledge to contribute: the knowledge of his or her discipline. Often, you will need to rely on his or her expertise and judgment in matters that are critical to your child's well-being. How comfortable you feel with the professional person, how well you feel he or she relates to your child and how openly he or she responds to your concerns will determine whether you continue to work with that person or decide to seek the services of someone else. If your relationship is not a good fit, do not feel badly about seeking other services.

Overall, the parent-professional relationship should be reciprocal. Both

you and the professional need to trust and feel trusted, admit when either of you are wrong or when you do not know something and need to negotiate with each other. This relationship can take time to develop and may require effort on both sides. A number of parents of children with disabilities have made these suggestions in the area of working with professionals:

- Ask other parents of children with disabilities when you are looking for a specialist. Often, they can suggest the name of a good therapist, doctor, dentist, school, etc.
- Write down what the professional says. This is particularly useful in medical situations. You can then go back and review the notes after the visit ends.
- Ask questions if you don't understand the terminology a professional is using. Say, "What do you mean by that? I don't understand."
- Learn as much as you can about your child's disability. This will assist you with your child, and it can help you participate more fully in the team process.
- Prepare for visits to the doctor, therapist or school by writing down a list of the questions or concerns you would like to discuss with the professional.
- Keep a notebook in which you write down all information about your child. This can include medical history, test results, observations about behavior and other similar information.
- Say something if don't agree with the professional's recommendations. Be as specific as you can about why you don't agree.
- Consult with as many professionals as necessary so you feel certain you have explored every possibility for your child.
- Measure a professional's recommendations for intervention and home activities against your own schedule, finances and other commitments. You may need to select those you can realistically do.

Resources

A Guide to Effective Consultation with Settings Serving Infants, Toddlers and their Families: Core Knowledge, Competence and Disposition. Department of Health and Human Services: <http://www.acf.hhs.gov/programs/occ/resource/effective-consultation>

Pediatric Services 16 Tips for Working with Professionals: <http://www.pediatricservices.com/parents/pc-16.htm>

The Visible Parent 10 Things to Ask Professionals Working with Your

Special Needs Child: <http://www.thevisibleparent.com/ten-things-to-ask-of-professionals-working-with-your-special-needs-child/>

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Working with professionals. (1997). NICHCY News Digest (2nd Ed.). National Dissemination Center for Children with Disabilities. Washington, DC: NICHCY. Retrieved from <http://www.kidsource.com/NICHCY/parenting.disab.all.4.4.html#Working>

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Chapter 14: Taking (some of the) Confusion Out of Medicaid, SSI, and Insurance

The medical costs associated with your child's disability will depend on many factors, including the type of disability and your family's income. Be persistent, and try to investigate all your options. Because you will talk to dozens of agencies and people, it's a good idea to keep a notebook by your side whenever you make telephone calls, allowing yourself to write down notes, contact names and phone numbers for any referrals you are given. Although your work might seem like an endless paper jungle, you will be rewarded with a better understanding of "the system" and the opportunity to find the services your child needs.

The search for programs to help you carry the responsibility of meeting your child's medical needs can be challenging. The best advice other parents have given is to be organized, knowledgeable and persistent. The key is to keep trying to get more information, to follow up on leads and to continue applying for various types of financial assistance. **Note: There is a lot of information in this chapter, and a Quick Facts Guide is included at the end to help you.**

ESTABLISHING A "MEDICAL HOME"

The term "medical home" refers to a partnership between the families of children with special health care needs and their primary care physicians. A medical home is not a place, but rather an idea. The purpose of this concept is to make certain that children can receive continuous care from a physician who knows them and their families well. Too often, children with special health care needs see a massive number of health care providers (doctors, therapists, clinicians, etc.), and often services are not coordinated among these providers. In addition, some families rely on emergency room treatment for their child's needs, resulting in care by a series of doctors who do not really know their "whole child." Regardless of income, insurance or disability, every child has the right to a medical home.

In a medical home, families and physicians work together to identify and access all the medical and non-medical services needed to help children and their families reach their potential. In this partnership, everyone works together for the good of the child. Some of the characteristics you can expect from a medical home include:

- Your child's primary care doctor and office are available and accessible.
- Your office staff members know you and understand how to help you.
- Your doctor respects you and listens to your observations and concerns about your child.
- Your doctor works with you to plan your child's care.
- Your doctor and office staff members support you as a caregiver.
- Your child's doctor and staff members help you to coordinate your child's care.

If you feel that you and your child are not receiving care in a medical home, talk to your doctor. If he or she does not seem responsive to your ideas, try talking with other parents of children with special health care needs. As always, they are often the best source of information. You can also read much more about medical homes at the website of the American Academy of Pediatrics at www.aap.org.

SUPPLEMENTAL SECURITY INCOME (SSI)

Social Security is the largest support program of the federal government. Most people who work for any length of time have Social Security contributions deducted from their paycheck, which are matched by contributions from their employers. A part of the money collected in this way is set aside for families who have a member with a disability. If you are a worker who acquired a severe disability before the age of 65, or if you have met your retirement age, you may be eligible for Social Security benefits. In addition, the children of retired, disabled or deceased workers are also eligible for Social Security benefits, provided that they are either under 18 years of age or have a severe disability before the age of 22 and continue to have this disability.

The Social Security Administration (SSA) also administers the Supplemental Security Income (SSI) program. Depending on your family's income, you will want to apply for SSI benefits on the basis of your child's disability. The basic purpose of SSI is to provide a minimum level of income to people who are elderly, blind or have a disability and have limited income and resources. Under SSI, a child is considered to have a disability if:

- The child has a physical or mental condition(s) that very seriously limits his or her activities; and
- The condition(s) must have lasted or be expected to last at least 1 year or result in death.

After reviewing the information you gave, a state agency makes the disability decision. They will also ask for information from medical and school sources, as well other people who know about the child. If the state agency needs more information, they will arrange an examination or test for the child, which they will pay for.

A child may be eligible for SSI benefits based on a disability as early as his or her date of birth (there is no minimum age requirement) and remains eligible until age 18. At 18, your child is reevaluated based on the disability definition for adults. At any age, a person with a visual impairment may be eligible for SSI benefits if the impairment meets the definition of blindness under the SSI law.

Applying for SSI

The website address to apply for benefits online is <https://www.ssa.gov/disabilityssi/>. If you need assistance in locating your local office, visit their local office locator website at <https://secure.ssa.gov/ICON/main.jsp>, or if you prefer, you can apply or find your local office by calling the toll-free number (800) 772-1213. Representatives there can make an appointment for your application to be taken over the telephone or at any convenient Social Security office. People who are deaf or hard of hearing can call the toll-free “TTY” number (800) 325-0778, between 7 a.m. and 7 p.m. Monday through Friday. You can download the starter kit (see next link), which will walk you through the application process.

Resources

SSI Child Disability Starter Kit (for children under age 18): http://www.ssa.gov/disability/disability_starter_kits_child_eng.htm

PROGRAMS AVAILABLE THROUGH THE STATE OF FLORIDA

Medicaid

Medicaid is administered by the Agency for Health Care Administration (AHCA) in Florida and is financed by federal and state funds. Medicaid provides services for persons in financial need who are unable to pay for necessary medical and health care services.

Many people are covered by Medicaid. Anyone who receives Temporary Assistance to Needy Families (TANF) or Supplemental Security Income

(SSI) is eligible for Medicaid. Under Medicaid, there are many different eligibility categories, with varied requirements such as different income and asset levels. We review some of these below, but to find out more about these eligibility categories, visit the Department of Children and Families website at <http://www.myflfamilies.com/serviceprograms/access-florida-food-medical-assistance-cash/medicaid>.

To find out more about Medicaid programs, contact the local Medicaid area office nearest to you. To obtain a listing of Medicaid area offices in Florida, visit their website at <http://ahca.myflorida.com/Medicaid/Areas/index.shtml>.

Eligibility

The Department of Children and Families (DCF) determines Medicaid eligibility for:

- Parents and caregiver relatives of children
- Children
- Women who are pregnant
- Individuals formerly in foster care
- Non-citizens with medical emergencies
- Individuals who are aged or disabled and not currently receiving Supplemental Security Income (SSI)

Applications for individuals not determined eligible for Medicaid will be referred electronically to either the Federally Facilitated Marketplace or Florida Healthy Kids (more on these later).



Many children will be eligible for Medicaid because of their disability. Florida residents who are eligible for Supplemental Security Income (SSI) are automatically eligible for Medicaid coverage from the Social Security Administration. There is no need to file a separate ACCESS Florida Application for Medicaid, unless nursing home services are needed.

ACCESS

ACCESS is the most common way you can apply for Medicaid. This is the online application to apply for a number of programs, including TANF and SNAP (food stamps) programs. This application can be completed online at <http://www.myflorida.com/accessflorida/>. There are a number of places you can visit in your community that have computers for you to use to complete this application. The web link to find a local agency where you can apply is <http://www.dcf.state.fl.us/access/CPSLookup/search.aspx>. The number for the ACCESS Customer Call Center is (866) 762-2237/ TTY (800) 955-8771.

Managed Medical Assistance Plans

Florida has moved almost all of those receiving Medicaid to Managed Medical Assistance (MMA) plans. In many ways, these are like a private insurance plan. You will be able to choose a plan that is available in your area. To see what plans are available in your area, and to compare services of those plans, you can visit <http://www.flmedicaidmanagedcare.com/SelectCounty.aspx>. Since MMA plans are providing Medicaid services, every plan must offer the same core services, but plans may be different in the extra services they offer. To learn more about the MMA program, you can visit <http://www.flmedicaidmanagedcare.com/MMA/ProgramInformation.aspx>.

Resources

AHCA Frequently Asked Questions:
http://ahca.myflorida.com/Medicaid/statewide_mc/pdf/mma/SMMC_MMA_FAQ.pdf

Medicaid Services

After receiving a Medicaid card in Florida, individuals will receive information on how to obtain Medicaid services. The Medicaid program will allow children to receive hospital care, nursing home care, laboratory services, physician services, dental care and other medical services. Medicaid acts a lot like other insurance plans. You will have certain doctors that

accept Medicaid that you can choose from, as well as certain services your Medicaid plan covers. The federal law states that anyone eligible for Medicaid has to be able to receive any of the services in the plan (Medicaid) they need. There are many services that individuals with disabilities will need that others will not. These are, for the most part, not available through your Medicaid plan. You will have to apply for an iBudget Waiver (see next section) to get these extra services.

iBudget Waiver (Formerly Known as Medicaid Waiver)

Depending on the disability your child has and the severity of that disability, you may need to apply for the Home and Community Based Services (HCBS) Waiver available for persons with developmental disabilities. Since all services have to be made available to those who have Medicaid, many of the services that individuals with developmental disabilities will need are not available through their private insurance or Medicaid plan. This is a way to contain costs but frequently leaves persons with disabilities without needed services. Many of these services will be available to your child while he or she is in school through the use of the school system. Unfortunately, once your child leaves school, he or she will lose many services that allow him or her to live a full, inclusive life. This is where the iBudget Waiver (also known as Medwaiver) comes in. It picks up where the IDEA services leave off, as well as provides additional services to children still of school age that are not available through their school. The purpose of the iBudget Waiver is to allow individuals to remain at home and be a part of their community rather than being in an institution. The agency that oversees this program is the Agency for Persons with Disabilities (APD).

One of the biggest problems with this waiver is that there is a very long waitlist. Some people wait 7-10 years or longer to receive services through the Waiver. This can be very hard on the individual who needs these services, and as well as the families who will have to deal with the lack of services. The best advice for parents is to begin learning about the Waiver and to apply for the waitlist as soon as possible. **DO NOT** wait until your child is in high school or about to graduate. The eligibility requirements for the iBudget Waiver are very different from Medicaid and SSI. There are specific disabilities that an individual may have that qualify them for the iBudget Waiver. If your child has any of the conditions listed next, you can apply for the Waiver while he or she is in elementary school. These are:

- Intellectual Disability
- Autism
- Spina Bifida

- Cerebral Palsy
- Prader-Willi syndrome
- Down syndrome
- Phelan-McDermid syndrome

There is also a “high risk” category, which is defined as “...children ages 3 to 5 years old with either a developmental delay in cognition, language or physical development, a child surviving a catastrophic infectious or traumatic illness known to be associated with developmental delay, a child with a parent or guardian with developmental disabilities who requires assistance in meeting the child’s developmental needs or a child who has a physical or genetic anomaly associated with developmental disability.” You should also be aware that there are income and asset limits for the Waiver Program.

Florida uses a prioritization tool to place those on the waitlist at different levels of priority. This level is based on the severity of their disability and the need for services in order to avoid institutionalization. All of this can seem very confusing for parents who are trying to understand this program and how to get their child served. Below are some useful resources for more information to help you better understand this program.

Resources

- Agency for Persons with Disabilities (APD): This is the website for APD, which has information and links regarding the waiver and available services and programs. <http://apd.myflorida.com/>
- Nancy E. Wright, Disability Lawyer, Information Blog: This is an



informative and uncomplicated blog with helpful information about the iBudget Waiver and other disability issues. <http://newrightlaw.com/practice-areas/developmental-disabilities-medicaid-waiver>

- Developmental Disabilities Individual Budgeting Waiver Services Coverage and Limitations Handbook: This has information on the types and amount of services available in the Waiver. http://apd.myflorida.com/ibudget/docs/DD_iBudget_Rule%2059G-13.070Adoption.pdf
- For finding a provider: For use when you are approved for the Waiver, if you need to find a specific service provider. <http://waiver-provider.com/>

Children's Health Insurance Program (CHIP) (KidCare)

In an effort to provide low-cost health insurance to families for their children, each state has a Children's Health Insurance Program (CHIP). Florida's CHIP program is called **Florida KidCare**. This program is made up of several different programs that are available, depending on your child's needs. If you apply for Medicaid for your child and do not qualify, your application will automatically be reviewed to see if your child is able to get health insurance through Florida KidCare. The basic qualifications for Florida KidCare are:

- Be under age 19
- Meet income eligibility requirements
- Be a U.S. citizen or qualified non-citizen
- Be out of any public institutions

There are different health plans your child may be enrolled in depending on his or her age and medical needs. MediKids is for children 1-4 years old, Florida Healthy Kids is for children 5-18 years old and Medicaid and Children's Medical Services are for children age birth to 18 with special health care needs. The good news is that you only have to complete one application to see which of these programs you are eligible for. KidCare takes into account family income and may or may not require a co-payment from the family.

Families can call (888) 540-KIDS (5437) or complete an online application at <https://www.healthykids.org/application/> to begin the application process. An application will be valid for 120 days after Florida KidCare receives it. Florida KidCare will notify you if the application process is not completed within 120 days for MediKids, Healthy Kids or Children's Medi-

cal Services. To restart the application process, call (800) 821-KIDS (5437). An application that is older than 120 days may still be used to determine if your children are eligible for Medicaid.

Resources

Healthy Kids Website: <https://www.healthykids.org/>

MEDICARE

Medicare is the federal health insurance program for people 65 years of age and older, certain younger adults with disabilities and people with End-Stage Renal Disease. The program is funded through Medicare taxes paid by employees and their employers throughout their working years. Children with disabilities who have reached adulthood, who receive Social Security benefits based on their parents' employment history can receive Medicare benefits.

Eligibility for Those Under Age 65

There are a number of eligibility categories of eligibility for Medicare hospitalization insurance for those under 65. For more information, go to the Social Security Administration website listed below.

To see if your child is entitled to Medicare, call Social Security at (800) 772-1213. If you have questions about claims or what is covered by Medicare, call Medicare at (800) 633-4227 or visit their website at <https://www.medicare.gov/>.

Resources

Social Security Administration. (2014). Medicare. <http://www.ssa.gov/pubs/EN-05-10043.pdf>

DCF SSI Medicaid Fact Sheet. <http://www.dcf.state.fl.us/programs/access/docs/ssifactsheet.pdf>

PRIVATE INSURANCE AND THE AFFORDABLE CARE ACT

Private Insurance Companies

Many families have a private insurance policy, usually through the workplace of one or more of its members. If you have private medical insurance, one of your first steps will be finding out exactly what services and supplies are covered. To do this, contact the benefits department of your insurance

carrier. Be sure to request all information in writing and take notes on your own, including the name of the person giving the information. It may be helpful to follow up on your telephone conversation with a brief letter or email stating your understanding of your benefits. Always keep copies for your own files.

When filing a claim, fill out all forms carefully and completely. Provide as much information as possible, including photographs, detailed descriptions and background medical data. Keep a copy for your records. Always ask to speak with the same claims processor, rather than speak with a different person each time you call. You can ask for a case manager to be assigned to your case, so that one person becomes familiar with your child's medical history and needs.

Affordable Care Act

Many children with developmental disabilities have multiple health concerns, which makes the need for health insurance that much more important. Finding health insurance that provides the coverage for the services your child needs can be difficult and feel overwhelming. Some of the changes that have been implemented because of the Affordable Care Act are:

- Health insurance companies cannot deny coverage based on a pre-existing condition. A preexisting condition is something, such as a developmental disability, that is present before the person applies for health insurance.
- Children can now remain on their parent's healthcare plan until they are 26 years old. This helps prolong the time your child will have to find other health insurance. This can be your child's own plan with an insurance company, Medicaid, etc.
- Insurance companies can no longer impose benefit caps. This means that there is not a limit to how much an insurance company will pay for medical services, either within a year or within the time that the person has a health insurance plan through that company. This is very important, as many children with developmental disabilities may have extensive medical expenses.
- Health care plans must now cover preventative care. Plans that are purchased after 2010 cannot charge co-payments for these services.
- Florida has chosen not to expand their coverage of Medicaid. However, income levels for eligibility are not allowed to be lowered to make it more difficult for families to qualify until 2019.
- Children in foster care will be able to keep their Medicaid coverage

until they are 26 years old.

- Families can now qualify for health care subsidies that will help cover the cost of their monthly premiums when they purchase private health insurance plans.

If you do not receive insurance through either your own or your spouse's work, you may choose to purchase a plan through the Federal Exchange. This is an online tool that allows you to apply for a healthcare subsidy that will pay part of your monthly premium and find information on different health plans from different insurance companies that are offering health-care plans in your state/area. The website to begin your application and find more information is <https://www.healthcare.gov/>.

You may also want to work with a healthcare navigator. These are specially trained individuals or organizations that will help you through the process of applying for and choosing an insurance plan. Navigators are unbiased support and do not charge for their services. To find a navigator in your area, visit <https://localhelp.healthcare.gov/#intro>.

Resources

- The Arc. (n.d.). The Affordable Care Act: What Disability Advocates Need to Know. <http://www.ncbi.nlm.nih.gov/pubmed/22550688>. You can access this resource through a Google or another internet search.
- Szilagyi PG., Future Child. 2012 Spring; 22(1):123-48. PMID: 22550688
- This site has a number of publications on this issue: Catalyst Center - <http://www.hdwg.org/catalyst/publications/aca>
- Association of Maternal and Child Health Program. (2012). AM-CHP Issue Brief: The Affordable Care Act and Children and Youth with Autism Spectrum Disorder and Other Developmental Disabilities. www.amchp.org/policy-advocacy/health-reform/resources/documents/aca_autismfactsheet_5-3-12.pdf

U.S. DEPARTMENT OF VETERANS AFFAIRS

Civilian Health and Medical Program (CHAMPVA)

CHAMPVA is a comprehensive health care program for eligible military veterans. If you are a veteran who has a service-related disability, your spouse and/or child may be eligible for CHAMPVA benefits. You can contact the Health Administration Center at the Department of Veterans Affairs for more information at (800) 733-8387 or on the web at <http://>

www.va.gov/health/. For information on benefits for spouse and children visit http://www.va.gov/healthbenefits/apply/family_members.asp). For information on the Affordable Care Act and VA benefits: <http://www.va.gov/health/aca/FamilyMembers.asp>

Survivors' and Dependents' Educational Assistance Program (DEA)

The DEA Program provides education and training opportunities to eligible dependents of deceased and disabled veterans whose disability is a service-related event. Certain special provisions apply to dependents with disabilities. You can contact the Department of Veterans Affairs for more information at (888) 442-4551 or online at http://www.benefits.va.gov/gibill/survivor_dependent_assistance.asp.

U.S. DEPARTMENT OF DEFENSE

TRICARE is the Department of Defense's managed health care program for persons who are on active military duty and their families, as well as for retirees from active military duty and their families. If you are currently serving in the military or are retired, your spouse and/or child may be eligible for a health insurance plan which may cover some medical visits, medications, equipment and other supplies. Spouses and children of veterans who were killed in action may also be eligible. Humana Military is the contracted agency for Florida. You can call for more information at (800) 444-5445 or visit their website at www.HumanaMilitary.com. You can also find more information on TRICARE on the web at <http://www.tricare.mil/>.



Quick Facts Chart

Program	Purpose	Eligibility
Social Security Income (SSI)	To assure a minimum level of income to people who are elderly, blind or have a disability, and who have limited income and resources	Have a physical or mental condition(s) that very seriously limits activities; and the condition(s) must have lasted, or be expected to last, at least 1 year or result in death
Medicaid	Medicaid provides services for persons in financial need who are unable to pay for necessary medical and health care services.	DCF determines Medicaid eligibility for: <ul style="list-style-type: none"> • Parents and caregiver relatives of children • Children • Pregnant women • Former foster care individuals • Non-citizens with medical emergencies • Aged or disabled individuals not currently receiving Supplemental Security Income (SSI)
Home and Community-Based Services Waiver (HCBS/Medicaid Waiver)	To allow individuals to remain at home and a part of their community rather than being in an institution	Eligible Disabilities: <ul style="list-style-type: none"> • Intellectual Disability • Autism • Spina Bifida • Cerebral Palsy • Prader-Willi syndrome • Down syndrome • Phelan-McDermid syndrome • High Risk
Children's Health Insurance Program (CHIP): Florida KidCare	To provide low-cost health insurance to families for their children	The basic qualifications for Florida KidCare are: <ul style="list-style-type: none"> • Be under age 19 • Meet income eligibility requirements • Be a U.S. citizen or qualified non-citizen • Be out of any public institution
Medicare	The federal health insurance program for people 65 years of age and older and certain younger adults with disabilities	There are a number of eligibility categories of eligibility for Medicare hospitalization insurance for those under 65. For more information, go to the Social Security Administration website at http://www.ssa.gov/pubs/EN-05-10043.pdf

Contact Information	Important Notes
<p>Apply for Benefits: https://www.ssa.gov/disabilityssi/ Call (800) 772-1213, TTY (800) 325-0778 To locate your local Social Security Office: https://secure.ssa.gov/ICON/main.jsp</p>	<p>If your child qualifies for SSI, your child will automatically qualify for Medicaid.</p>
<p>To locate your local Medicaid Office: http://ahca.myflorida.com/Medicaid/Areas/index.shtml To apply online: http://www.myflorida.com/accessflorida/ The web link to find a local agency where you can apply is http://www.dcf.state.fl.us/access/CPSLookup/search.aspx ACCESS Customer Call Center: (866) 762-2237/ TTY (800) 955-8771</p>	<p>If your child is not eligible for Medicaid, your application will automatically be referred to Florida KidCare and the Healthcare Marketplace.</p>
<p>Waiver information and application: http://apd.myflorida.com/</p>	<p>Begin learning about the Waiver; apply for the waitlist as soon as possible. DO NOT wait until your child is in high school or about to graduate!</p>
<p>Families can call (888) 540-KIDS (5437) or visit https://www.healthykids.org/application/</p>	
<p>To apply or for questions: (800) 772-1213 or visit https://www.medicare.gov/</p>	

Program	Purpose	Eligibility
Private Insurance/Healthcare Exchange	The online tool to apply for a healthcare subsidy or to find information about different health plans in your state/area	
Civilian Health and Medical Program (CHAMPVA)	CHAMPVA is a comprehensive health care program for eligible military veterans. If you are a veteran who has a service-related disability, your spouse and/or child may be eligible for CHAMPVA benefits.	
Survivors' and Dependents' Educational Assistance Program (DEA)	The DEA Program provides education and training opportunities to eligible dependents of deceased and disabled veterans whose disability is a service-related event.	
TRICARE	The Department of Defense's managed health care program is for persons who are on active military duty and their families, as well as retirees from active military duty and their families.	If you are currently serving in the military or are retired, your spouse and/or child may be eligible for a health insurance plan which may cover some medical visits, medications, equipment and other supplies. Spouses and children of veterans who were killed in action may also be eligible.

Contact Information	Important Notes
<p>Federal Healthcare Exchange: The website to begin your application and find more information is https://www.healthcare.gov/. To find a navigator in your area, visit https://localhelp.healthcare.gov/#intro.</p>	<p>If you have private medical insurance, one of your first steps will be finding out exactly what services and supplies are covered. Be sure to request all information in writing and take notes on your own, including the name of the person giving the information.</p>
<p>Contact Veterans Affairs for more information at (800) 733-8387 or on the web at http://www.va.gov/health/.</p>	
<p>Contact the Department of Veterans Affairs for more information at (888) 442-4551 or on the web at http://www.benefits.va.gov/gibill/survivor_dependent_assistance.asp</p>	
<p>Humana Military is the contracted Agency for Florida. You can call for more information at (800) 444-5445 or visit their website at www.HumanaMilitary.com. You can also find more information on TRICARE on the web at http://www.tricare.mil/.</p>	

Citations and Resources

Agency of Health Care Administration (2015). *Medicaid: Developmental Disabilities Individual Budgeting iBudget Waiver Coverage and Limitations Handbook*. http://apd.myflorida.com/ibudget/docs/DD_iBudget_Rule%2059G-13.070Adoption.pdf

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Association of Maternal and Child Health Program. (2012). *AMCHP Issue Brief: The Affordable Care Act and Children and Youth with Autism Spectrum Disorder and other Developmental Disabilities*.

Agency for Persons with Disabilities:
www.apd.myflorida.com

Florida Department of Children and Families:
www.myflorida.com

Healthy Kids:
www.healthykids.org

Medicare:
www.medicare.gov

Social Security Administration:
www.ssa.gov.

TRICARE:
www.tricare.mil

Veterans Affairs:
www.va.gov

Veterans Affairs Benefits:
www.benefits.va.gov



Chapter 15:

Navigating the Educational System



Educational services for young children with disabilities are more superior today than in any other time in our nation's history. Prior to the 1960s, special education services for pre-kindergarten children were uncommon. Today, service delivery systems can be found for individuals with disabilities from birth through adulthood throughout the United States. Currently, a greater emphasis on person-centered planning stresses the needs of the child and family.

THE FLORIDA K-20 SYSTEM

The Florida K-20 system, referred to as the K-20 Education Code in *Florida Statutes*, can be found at http://www.leg.state.fl.us/Statutes/index.cfm?App_mode=Display_Index&Title_Request=XLVIII#TitleXLVIII. At the website, scroll down to click on Title XLVIII, which then opens to review each chapter. Chapter 1000 discusses general provisions. This includes the mission and other important information that can also be found in the box below. Chapter 1001 discusses governance, Chapter 1002 discusses student and parent rights, education choices and so on. Chapter 1002 is especially relevant to parents' concerns on the education of their child in the public school system.

Mission and Priorities of the Florida Education System (Select information from Title XLVIII, Chapter 1001.03)

- (4) The mission of Florida's K-20 education system is to allow its students to increase their proficiency by allowing them the opportunity to expand their knowledge and skills through rigorous and relevant learning opportunities, in accordance with the mission statement and accountability requirements of F.S. 1008.31.
- (5) The priorities of Florida's K-20 education system include:
 - (a) Learning and completion at all levels, including increased high school graduation rate and readiness for postsecondary education without remediation—All students demonstrate increased learning and completion at all levels, graduate from high school and are prepared to enter postsecondary education without remediation.
 - (b) Student performance—Students demonstrate that they meet the expected academic standards consistently at all levels of their education.
 - (c) Alignment of standards and resources—Academic standards for every level of the K-20 education system are aligned, and education financial resources are aligned with student performance expectations at each level of the K-20 education system.

**Mission and Priorities of the Florida Education System
(Select information from Title XLVIII, Chapter 1001.03)**

(d) Educational leadership—The quality of educational leadership at all levels of K-20 education is improved.

(e) Workforce education—Workforce education is appropriately aligned with the skills required by the new global economy.

(f) Parental, student, familial, educational institution and community involvement—Parents, students, families, educational institutions and communities are collaborative partners in education and each play an important role in the success of individual students. Therefore, the State of Florida cannot be the guarantor of each individual student's success. The goals of Florida's K-20 education system are not guarantees that each individual student will succeed or that each individual school will perform at the level indicated in the goals.

(g) Comprehensive K-20 career and education planning—It is essential that Florida's K-20 education system better prepare all students at every level for the transition from school to postsecondary education or work by providing information regarding:

1. Career opportunities, educational requirements associated with each career, educational institutions that prepare students to enter each career and student financial aid available to pursue postsecondary instruction required to enter each career
2. How to make informed decisions about the program of study that best addresses the students' interests and abilities while preparing them to enter postsecondary education or the workforce
3. Recommended coursework and programs that prepare students for success in their areas of interest and ability

Currently, there are many options for schooling in Florida. The most common are the public schools, including charter schools and university lab schools, operated in all 67 counties. Private schools and charter schools have been increasing in popularity. Parents have the right to consider them but should investigate their inclusion policies and ability to educate a child with a disability with quality. If you are considering a private school for your child, as a parent you should know that your child is not entitled to free appropriate education (FAPE) that will be covered in the next chapter. Another option that has become available is home schooling, with some parents merging together into home schooling co-ops. There are mixed opinions on home schooling, with some parents believing strongly in it and others concerned that it may isolate their child. Indeed, isolation is an unfortunate outcome for many children with disabilities, and careful planning

is needed for home schooling a child with a disability to make sure he or she gets as many enriching experiences as possible.

THE BEGINNING OF SPECIAL EDUCATION SERVICES

The first special education class in the U.S. was established for students with hearing impairments in Boston in 1869. Nearly 30 years later, in 1896, the first special education class for youth with intellectual disabilities was organized in Providence, Rhode Island, followed by classes in Chicago and Boston in 1899 and New York City in 1900. A class for children with other special needs was also started in Chicago in 1899. By 1911, more than 100 large-city school systems had special day schools and special education classes. By the 1920s, over two-thirds of the large cities in the U.S. had special class programs, but they served only a small percentage of all children with disabilities. Most children with moderate to severe levels of disability were either admitted to institutions or residential schools or remained at home. Children with less severe levels of disability were often enrolled in regular education classes without any type of additional assistance. Without support, many children eventually dropped out of school.

Special education programs continued to expand until 1930, but then the momentum slowed down. During the 1930s and 1940s, special public school classes gave way to institutionalization and segregation of children with disabilities. Institutions became overcrowded and understaffed, with few actual training programs, and the level of care given to the residents was largely custodial.

After World War II, tens of thousands of young men and women came home from war with disabilities. Americans began to change their attitudes due to the return of these young soldiers and became more sensitive to their needs. First, new services were provided for the veterans of war and then gradually expanded to children and other persons with disabilities. Between 1947 and 1980, the number of students in public school special education programs increased by more than 700%.

Despite this growth, in the 1970s, only a relatively small number of children with disabilities were being educated in public schools. Soon, however, two federal laws enacted in 1975 would change this. These laws were the Education for All Handicapped Children Act (EHA) and the Individuals with Disabilities Education Act (IDEA). The EHA established a right to public education for all children regardless of disability, while the IDEA required that schools provide individualized or special education for chil-

dren with *qualifying* disabilities. Under the IDEA, states who accept public funds for education must provide special education to qualifying children with disabilities.

Although not all children with disabilities are covered by the IDEA and EHA, these two acts have been influential in ensuring a free public education to millions of children with disabilities each year since passage. Today, Americans believe that education is the right of ALL children and is a means for preparing them to meet the demands of their environment, to learn and to live as fulfilling and productive a life as possible.

EARLY LEARNING COALITIONS

Early Learning Programs (ELPs) are central for providing early education services, specifically school readiness and voluntary pre-kindergarten (VPK) services. Standards and benchmarks have been established for children birth to age five. These standards were adopted by the Florida State Board of Education in 2011. They outline what children should be able to do by the end of pre-kindergarten.

Standards and benchmarks are organized into five domains. Benchmarks are not yet available for all domains, but they are in the process of being completed.

1. Physical Development
2. Approaches to Learning
3. Social and Emotional Development
4. Language, Communication and Emergent Literacy
5. Cognitive Development and General Knowledge

There are 30 regional Early Learning Coalitions, and the Redlands Christian Migrant Association, responsible for delivering local services in Florida. As can be seen, these domains are quite similar to the domains targeted by early intervention services (see chapter 2). This is not accidental. ELPs target all youth from birth to age five across domains, while early intervention supports children with established conditions, determined through an evaluation to have a developmental delay or who are at high risk of developing a disability. The Florida State Office of Early Learning, a Division of the Florida Department of Education, supports and manages the local coalitions to promote school readiness prior to entering school (link included in the resource section at the end of the chapter). This is especially important for parents with children with mild developmental delays, attention issues or other conditions that may interfere with learning. While



ELPs focus on school readiness, they take a holistic approach that supports the total health and development of each child.

ASSESSING SERVICES FOR YOUR CHILD

Since the 1960s, many federal laws have resulted in increased funding, research, grants, teacher training and direct services for children with disabilities. The most significant legislation passed by Congress is Public Law 94-142, the Education for All Handicapped Children Act of 1975, sometimes known as the Bill of Rights for Children with Disabilities.

The Education for All Handicapped Children Act was reauthorized by Congress in 1983 and again in 1986. The Individuals with Disabilities Act was reauthorized in 1990, and it is the federal law that currently governs all public education services to children with disabilities in the United States. Each state or territory develops its own policies for carrying out this Act. IDEA was most recently reauthorized again by Congress in 2004. It was renamed as the Individuals with Disabilities Education Improvement Act of 2004.

Different services are available to your child at different ages. Learning about and getting services for your child can sometimes be complex, but there will be many people to help you along the way. Some of the words you encounter here may be new to you, but it is important to begin learning them. Many of the terms are defined in the “Dictionary of Terms” in Appendix B.

EARLY INTERVENTION SERVICES (BIRTH TO THREE YEARS)

What are Early Intervention Services?

Early intervention services are special services for eligible infants and toddlers, as well as their families, made available through Part C of the Individuals with Disabilities Education Act (IDEA). These services are designed to identify developmental delays as early as possible and to meet children’s needs in the five developmental areas described in Chapter 2:

- Physical development
- Cognitive development
- Communication
- Social and emotional development
- Adaptive development

In Florida, the Part C program of the IDEA is known as “Early Steps,” and it is administered by Children’s Medical Services (CMS) within the Florida Department of Health, along with guidance from the Florida Interagency Coordinating Council for Infants and Toddlers (FICCIT). The Early Steps network serves Florida’s infants and toddlers with developmental delays or conditions that places them at risk for developmental delay up to the age of 36 months. 15 local Early Steps sites are located across the state. The toll-free number for the main Early Steps office is (800) 218-0001, and the website is found at http://www.floridahealth.gov/AlternateSites/CMS-Kids/families/early_steps/early_steps.html.

Part C early intervention is designed to offer services and supports to families. Services are designed to enable parents to help their child develop within their communities and are offered through a variety of public or private agencies. Services are provided within the “natural environment,” or the locations where children without disabilities are found, such as at home, in educational settings, at family child care, at community recreation or at child development programs. Examples of early intervention services and supports include home-based speech and language therapy to help you increase your child’s communication skills, consultation to the child care provider by the physical therapist to help with walking within the classroom and playground and developmental resources and information for your family to identify natural learning opportunities throughout the day to support your child’s play skills.

Part C, Early Steps Initial Evaluation

Under the IDEA, a complete evaluation of your child is necessary to determine whether he or she is eligible for early intervention services; however, if your child has an “established condition,” which is a condition that has a high probability of resulting in a disability or developmental delay, he or she will not need an evaluation for eligibility. Your child will still require an evaluation to determine the child’s strengths and developmental issues to form the initial Individualized Family Service Plan. You can get the process started by talking to your pediatrician or by contacting the main Early Steps office directly. The evaluation is provided at no cost to you. Once you are in contact with Early Steps, you will be assigned a service coordinator to help guide you through the process. This service coordinator will be familiar with the policies of Early Steps and will be able to help you with your initial questions.

A multidisciplinary team will conduct an evaluation of your child to deter-

mine if your child is eligible for Early Steps services. The evaluation process will also help to identify the nature of your child's strengths, delays, difficulties and your priorities for helping your child.

“Multidisciplinary” means that the evaluation team is made up of qualified people who have different areas of training and experience. Together they have specialized knowledge of children's speech and language skills, physical abilities, hearing, vision and other important areas of development. They know how to work with very young children to discover if a child has a developmental delay or is developing within normal ranges. The team members may evaluate your child individually or as part of a group.

“Evaluation” refers to the procedures used to determine if your child is eligible for early intervention services. As part of the evaluation, the team members will observe your child, ask your child to do certain things, talk to you and your child and use other methods to gather information. These procedures will help the team find out how your child functions in all areas of development. Following the evaluation, you and a team of professionals will meet and review the results and reports. The members of the team will talk with you about whether your child meets the criteria for Early Steps services: whether your child has a developmental delay, an established physical or mental condition or is at risk for having a developmental delay. If so, your child will likely be found eligible for services.

If found to be eligible and you are interested in services and supports, additional information will be gathered through an assessment. **“Assessment”** refers to the ongoing process of gathering information and using the information to determine the types of services and supports that match your priorities for your child and family. With your consent, your family's needs and interests will also be discussed. This process is intended to identify the



resources, priorities, concerns and needs of your family. It also identifies the supports and services you may need to enhance your family's capacity to meet your child's developmental needs.

When conducting the evaluation and assessment, the team members may get information from some or all of the following sources:

- Doctor's reports
- Results of developmental tests given to your child
- Your child's medical and developmental history
- Observations and feedback from all members of the multidisciplinary team, including you as the parent
- Interviews and conversations with you and other family members or caregivers
- Any other important observations, records or reports about your child

Role of the Service Coordinator

If your child is found to be eligible for Early Steps services, a service coordinator will assist you with accessing needed services. The service coordinator is usually the first contact after a referral to Early Steps. This coordinator comes to your home and completes an initial family assessment and helps guide you through the evaluation process. In most evaluations, the service coordinator is also present, as he or she will have had met your family and can provide useful information. If your child is found eligible, the service coordinator helps to manage the services you, your child and your family receives.

The service coordinator will be familiar with the early intervention programs and services in your community. This person, along with the Family Resource Specialist, helps you locate other services in your area, such as recreation, child care, respite services or family support groups. The service coordinator will work with your family as long as your child is receiving early intervention services, and sometime after your child turns two years old, the coordinator will help your family prepare to move on to programs for children ages three to five, in a process known as making a "transition."

The Individualized Family Support Plan (IFSP)

The family and the service coordinator will work with other professionals as appropriate to develop a written "Individualized Family Support Plan," or IFSP. The guiding principle of the IFSP is that the family is the child's greatest resource and that a child's needs are closely tied to the needs of the

family. The best way to support children and meet their needs is to support and build upon the strengths of the family. Each IFSP includes outcomes to work towards that should meet your priorities but also consider the advice of the professionals evaluating your child. IFSP outcomes should be family-worded, positive statements that are action-oriented and indicate changes that you want to see rather than a description of a need.

As a parent, you have the right and obligation to be as involved as possible. Consider the following questions for IFSP discussion:

- What are your child's strengths, interests and needs?
- What are your family's strengths interests and needs?
- What do you identify as natural environments?
- Where are your child's activity and learning opportunities occurring?
- What are the identified activities and outcomes?
- What are the supports and services needed to conduct activities and reach outcomes?

Family routines are the usual events that are part of a family's schedule. Examples might include mealtime, bath time, story time or bedtime. Be ready to answer questions about routines, as they are central to the services you and your child will receive. Using the normal routines of everyday life to improve developmental delays is easier than changing your child's routine. This way, the services fit your child instead of your child trying to fit the services. Examples of routine-based questions are:

- What does your typical day look like?
- What are the things you do every day, some days and only occasionally?
- Do you spend most of your time at home? Is this by choice or because you need help in taking your child out?
- Who spends time with your child on a regular basis? How is the time spent?
- Who gets up with your child?
- Who puts your child to bed?
- Who prepares breakfast and drives or walks the child to child care?
- Does your child take a nap? What time?

Parents are the most important part of the IFSP team, and the IFSP is a plan for the whole family. Other team members will be involved on the basis of the child's needs and may include medical personnel, therapists, infant and toddler developmental specialists, social workers and others. The IFSP is reviewed at least every six months and is updated at least once

a year. The IFSP must be completely explained to you, and your suggestions must be considered. You must give your written consent before any services can begin. If you do not give your consent in writing, your child cannot receive services.

The IFSP may also identify services your family may have interest in, such as financial services or finding information about disabilities. The IFSP is different for each child and family, but the services that can be included are:

- Family training, counseling and home visits
- Special instruction
- Speech-language pathology services (commonly known as speech therapy)
- Audiology services (for children with hearing impairments)
- Occupational therapy
- Physical therapy
- Psychological services
- Medical services (but only for diagnostic or evaluation services)
- Service coordination services
- Health services to enable your child to benefit from the other services
- Social work services
- Assistive technology devices and services
- Transportation services
- Nutrition services

Although early intervention services are free, specialized services, services for older children may not be free. The cost of the services your child will receive may be covered by your health insurance, Medicaid or Indian Health Services (for American Indians and Alaskan Natives), or they may be provided at no cost to you through Early Steps (see Chapter 14). Every effort is made to provide services and supports to all infants and toddlers who need them, regardless of family income. Services cannot be denied to a child because the family is not able to pay for them. As time goes by and your child is receiving services, you will probably have more questions, such as:

- How do I know that what I am doing is helping my child?
- What do I do if I am not satisfied with my child's assessment, services or progress?
- What happens when my child turns three and is too old for Early Steps?
- Will my child still be eligible for services when he or she is ready

for preschool?

- What if I prefer that my child be seen for services outside of the natural environment?
- What about private services and programs?

For answers to your questions, you can talk with your service coordinator or contact a parent support group or a professional organization serving young children with disabilities.

THE INDIVIDUALIZED FAMILY SUPPORT PLAN AT A GLANCE

Your child's IFSP must include the following:

- Your child's developmental levels
- Family information (with your consent), including your resources, priorities and concerns and those of other family members closely involved with your child
- The major results or outcomes expected to be achieved for your child and family
- The specific services your child will receive
- Where in the "natural environment" of the child (such as in the home or somewhere in the community) services will be provided
- When your child will receive services
- The number of days or sessions your child will receive each service and how long each session will last
- Whether the service will be provided on a one-to-one basis or in a group
- Who will pay for the services
- The name of the service coordinator overseeing the implementation of the IFSP
- The steps to be taken to support your child's transition out of early intervention and into another program when the time comes

Transition from Early Intervention to Special Education

If your child's disability was identified before the age of three and your family is already receiving early intervention services, your service coordinator will help you move into special education services when your child turns three years old. This process is known as a "transition" from one program to another, and you and your service coordinator will begin transition planning well before your child turns three, so that all plans can be in place by the date of your child's third birthday.

Many families report a sense of loss and anxiety when their child ages out of early intervention services but continues to have developmental and



learning needs. The transition can be stressful, but there are some important things you can do to make the transition as easy as possible for your child and you. As a parent, you should participate in all meetings, decide what you want to have done and remember that you are in charge of your child. Be sure to give written permission to share information between early intervention and special education programs. You can lower your stress further by visiting and making informed choices about programs you are considering for your child.

Transition meetings may include the service coordinator, a school district representative (your coordinator can help you select who to invite) and representatives from other organizations you are involved with at that time [e.g., Head Start, Florida Diagnostic and Learning Resources System (FDLRS), Children's Medical Services, service providers, etc.].

During the conference, you and the service coordinator will facilitate the discussion. This will likely cover many topics, and you and the coordinator should discuss these ahead of time to make sure that you get the best result. Some topics may include, but are not limited to:

- Services available from the local school district
- How and when evaluations and eligibility determination will occur
- Other agencies and community providers that may assist your child and family
- Existing child/family information
- Family concerns regarding a transition, as well as strategies to address the concerns
- Activities that need to be completed before your child moves into the new setting
- Timeframes for when each activity should be completed
- Scheduling visits to program sites

The Florida Transition Project has an Early Childhood Transition video and other resources that help you navigate the transition from Part C (early intervention) to Part B (special education) at <http://www.floridatransition-project.ucf.edu/>, the subject of the next section.

Not all children in early intervention require or transition to special education services. Some children respond to early intervention services and “catch up” sufficiently to enter regular education classes. An exit evaluation (leaving the program at age three) from Early Steps helps to determine the next steps.

SPECIAL EDUCATION AND RELATED SERVICES (THREE-FIVE YEARS)

What are Special Education and Related Services?

Special education is instruction that is specifically designed to meet the educational needs of children with developmental delays or disabilities. It also refers to other services, known as “related services,” that may be needed to help a child benefit from special education. Special education is provided free of charge through your public school district for eligible children who are three through 21 years of age. Pre-kindergarten programs are designed for children three to five years of age, through the year in which your child “transitions” into kindergarten (the year in which your child turns five before September 1). Special education is made available through Part B of the Individuals with Disabilities Education Act (IDEA).

There are at least six steps in the process of planning and delivering ESE (Exceptional Student Education) services for your child. These may vary slightly by district but will all be accomplished in some way. At ages 3-5, your child will have either an IEP or IFSP, and this will be decided in the IEP meeting. The evaluation and IEP meeting are summarized in greater detail below.

- 1. Evaluation:** The evaluation must assess the child in all areas related to the child’s known or suspected developmental delay or disability. The evaluation results will be used to decide the child’s eligibility for special education and related services and to make decisions about an appropriate educational program for the child.
- 2. Eligibility determination:** You and a group of qualified professionals look at the child’s evaluation results, similar to the Early Steps evaluation. The professionals decide if the child is a “child with a disability,” as defined by IDEA. As a parent, you may ask for a hearing to challenge the eligibility decision, if you do not agree with the outcome.
- 3. Developing the first Individual Educational Plan (IEP) or the IFSP:** The IEP team gathers to talk about the child’s needs and write the student’s IEP or IFSP. Parents and the student (when appropriate) are part of the team. If the child was receiving Part C early intervention services, he or she will have an IFSP that will help to inform development of the IEP.
- 4. Consent for services and service provision:** Before the school system may provide special education and related services to the child for the first time, the parents must give consent. The child begins

to receive services as soon as possible after the meeting. The school makes sure that the child's IEP is being carried out as it was written. You are given a copy of the IEP. If you are not, insist on it. Each of the child's teachers and service providers has access to the IEP and knows his or her responsibilities for carrying out the IEP. This includes the accommodations, modifications and supports that must be provided to your child in keeping with the IEP.

5. **Annual reviews:** The child's IEP is reviewed by the IEP team at least once a year. However, it may occur more often if the parents or school asks for a review. If necessary, the IEP is revised. All team members must be invited to attend these meetings. You can make suggestions for changes, can agree or disagree with the IEP goals and can agree or disagree with the placement.
6. **Reevaluations:** The child must be reevaluated at least every three years. The purpose is to find out if your child continues to be a "child with a disability," as defined by IDEA, and what his or her educational needs are. Your child may be reevaluated more often if conditions warrant, or if you or the teacher asks for a reevaluation.

Available Related Services

The IDEA defines "related services" as "transportation and such developmental, corrective and other supportive services as are required to assist a child with a disability to benefit from special education." Children are not eligible for related services until they have been found eligible for special education services. Once eligible, you and the rest of the team will decide which, if any, of the related services are needed by your child. The box below lists related services.

Getting Started with Special Education Services

If your child has not been participating in early intervention services, but it is now suspected that he or she may have a developmental delay or disability, you will want to seek an evaluation for your child. If your child has



Related Services

The following services are included within the definition of related services:

- Audiology services
- Psychological services
- Speech and language pathology services
- Physical and occupational therapy
- Recreation, including therapeutic recreation
- Early identification and assessment of disabilities in children
- Counseling services, including rehabilitation counseling
- Orientation and mobility services (for children with vision impairments)
- Medical services for diagnostic or evaluation purposes
- School health services
- Social work services in schools
- Parent counseling and training
- Transportation

received an evaluation, IFSP and early intervention services, another evaluation will be needed to pinpoint the needs for Part B services. Again, your pediatrician can help by making a referral for you. You can also contact the Child Find Specialist at your local Florida Diagnostic and Learning Resources System (FDLRS) center, or you can contact the Exceptional Student Education (ESE) office in your local school district. FDLRS is a statewide network of centers that provides support services to public school district programs serving children with disabilities and their families. Each center includes specialists in the areas of Child Finding, Parent Services, Human Resource Development and Technology. “Child Find” is the program that can help you get started with the referral process.

Evaluation is Required

As with early intervention services, a complete evaluation of your child is required under IDEA to determine whether or not he or she is eligible for special education services. This evaluation is provided to you at no cost.

“Evaluation,” in this case, refers to the procedures used to determine whether your child has a disability and the extent of the special education and related services that he or she needs. The evaluation will be conducted by school district staff. The evaluation team may include staff members such as a school psychologist, educational diagnostician, social worker and speech, occupational and/or physical therapist. The composition of the

evaluation team is based on the needs of each child.

The evaluation team will begin by looking at what is already known about your child and may also recommend gathering additional information.

They may use the following sources of information:

- Doctor's reports
- Results of developmental tests given to your child
- Developmental and behavioral checklists
- Your child's medical history
- Observations and assessments conducted in your child's current educational setting (if any)
- Observations and feedback from all members of the evaluation team, including you as a parent
- Any other important observations, records or reports about your child

The Individual Educational Plan (IEP)

After the evaluation is completed, school district personnel will meet with you to go over the results and determine whether your child is eligible for services. You are a part of this decision.

If your child is found to be eligible for special education services, you and the school district personnel will develop a written plan known as an "Individual Educational Plan" (IEP). Your child's IEP is a written statement of the educational program designed to meet your child's specific needs. Every child who receives special education services must have an IEP, and you will be asked to sign the IEP to indicate your participation in the meeting. If that is your first IEP meeting, you will also be asked to sign a consent for your child to receive special education services. The IEP has two general purposes:

1. To set reasonable learning goals for your child
2. To state the services that the school district will provide for your child

The IEP will describe what your child can do and knows now, what special education and related services will be provided, when the services will begin, the length of time your child is expected to need the service, how often your child will receive or use the service, where the service will be provided (e.g., regular education class or resource room) and the annual goals that describe what your child needs to learn. The IEP team must consider the least restrictive environment (LRE). This means that your child must be

educated to the greatest extent possible with typically developing children. The IEP must explain the extent to which your child will not participate with typically developing children.

Your child's IEP team may include these individuals:

- At least one of your child's general education teachers (if your child is participating in a general education setting)
- Individuals (invited by you or the school district) with knowledge or special expertise about your child
- A school district employee who knows about special education policies, children with disabilities, the general school curriculum and available resources
- At least one special education teacher or service provider
- You, as a parent or guardian
- Your child, if appropriate
- Someone who understands and can explain the evaluation results (this could be one of the school district staff members listed above)
- Other qualified professionals, as appropriate (a school psychologist, occupational therapist, speech therapist, physical therapist, medical specialist or others)

GETTING READY FOR THE IEP MEETING

- Think about your goals for your child's long-term future.
- Make a list of things your child can do, likes to do and needs to learn.
- Make a list of the type of assistance your child needs.
- Ask to see your child's school records and evaluations. Read them carefully.
- Ask the school for a blank IEP form so you can become familiar with it.
- Let the school know in advance if you will need a translator during the meeting.
- Let the school know in advance if you need to change the meeting's time or place.
- Talk to other parents about their IEP experiences.
- Ask a friend, another parent or an advocate to attend the meeting with you. Let the school know if you have invited someone to attend.
- Ask for the names and positions of the school district staff who will be attending.

Adapted from Getting Ready for Your Child's IEP Meeting, Florida Department of Education, 2002.



Make sure to review the following list closely, since IEP meetings are very important and should focus on the needs and identify how to meet those needs. This is THE meeting that sets the stage for each year's learning. The IEP should address any of the following if relevant to your child:

- What your child knows and can do now
- What your child needs help with
- How your child's disability affects his or her success in school
- What your child should learn by the end of the school year
- What special education services, supports, accommodations or modifications and assistive technology your child will receive during the year
- An explanation of any time that will be spent receiving instruction outside the regular class
- How your child's progress will be measured
- If your child is age 14 or in the eighth grade, what type of diploma your child is working towards and other transition requirements at age 14 (see the next chapter)
- If your child is age 16 or older, your child's goals for life after high school and all transition service requirements (see the next chapter)

The school system, like any other professional group, uses many acronyms and other shorthand to discuss their clients (e.g., students and families). The following list covers the majority of young children that will be entering the school system needing special education services:

- Autism spectrum disorder (ASD)
- Deaf or hard-of-hearing (DHH)
- Developmentally delayed (for 3-5 years old only) (DD)
- Dual-sensory impaired (deaf-blind) (DSI)
- Emotional or behavioral disabilities (EBD)
- Homebound or hospitalized (HH)
- Intellectual disabilities (InD)
- Orthopedic impairment (OI)
- Other health impairment (OHI)
- Traumatic brain injury (TBI)
- Specific learning disabilities (SLD)
- Speech impairment (SI)
- Language impairment (LI)
- Visually impaired (VI)

DISPUTING AN IEP

The Florida Department of Education has a dispute system in place for if you think the IEP is not appropriate for the needs of your child, and you feel the school is not meeting their legal obligations. Some of the key points are summarized here, but you can “go to the source” at <http://www.fl DOE.org/academics/exceptional-student-edu/dispute-resolution/index.shtml>

At a glance, dispute resolution includes the following (from the website link above):

	State-Level Sponsored Facilitated IEP (FIEP) Meeting	State-Sponsored Mediation	State Complaint	Due Process Hearing
Issues Addressed	Issues related to the process of IEP development as an alternative dispute resolution method, when a formal state complaint has been filed	Any issues related to special education	Alleged violations of special education requirements in state or federal regulations	Any issue related to identification, evaluation, placement or the provision of a free appropriate public education
Financial Cost	The FLDOE provides a trained facilitator at no cost to the parent.	The FLDOE provides a third party mediator at no cost to the parent.	A FLDOE staff member is provided at no cost to the parent or district.	An impartial hearing officer is provided at no cost to the parent through the Division of Administrative Hearings.
Process	A facilitator supports the IEP team in the collaborative problem-solving process regarding decisions that are best for the student and helps parties reach a consensus when possible.	After all parties agree to participate in mediation, a third party mediator, assigned by FLDOE, meets with the parties in an informal setting and assists them to resolve the issue(s) in dispute.	Information and documentation related to the allegation(s) are reviewed by FLDOE staff. A report with findings of fact and conclusions is issued. Extensions may occur in exceptional circumstances or when both parties agree to try an alternative method.	A hearing officer listens to evidence in a courtroom-like setting and issues a written order.
Timeline	Generally less than 30 days, subject to agreement by the parties	Generally less than 30 days, subject to agreement by the parties	60 days from receipt of the formal complaint unless extended	45 calendar days after the initial 30-day resolution period, unless the timeline is extended by the hearing officer on motion of a party

	State-Level Sponsored Facilitated IEP (FIEP) Meeting	State-Sponsored Mediation	State Complaint	Due Process Hearing
How to Request	Discuss with FLDOE staff.	Refer to FLDOE's website for directions and forms.	Refer to FLDOE's website for directions and forms.	Refer to FLDOE's website for directions and forms.
Result	A revised IEP is developed.	Mediation agreements are created and signed by the parties, implemented in "good faith" by the parties and enforceable in court.	If a violation is found, the report will specify corrective action that the district must take to comply with the law. The corrective action is monitored by FLDOE for completion.	The impartial hearing officer renders a decision that determines whether violation(s) occurred and, if so, orders remedial action.
Confidentiality	Participants will be asked to sign a confidentiality statement prior to the start of the facilitated IEP meeting.	Participants will be required to sign a confidentiality statement prior to the start of the mediation session.	Written findings are subject to release, with identifiable information removed.	The hearing is confidential, unless the parents choose to open it to the public. Written findings are subject to release, with identifiable information removed.

A HELPFUL NOTE

As you can see, there is much to learn about early intervention services and special education and related services. Many of the procedures, and especially the IEP process, may seem complex at first. Don't hesitate to talk with experienced parents to learn more about these services. As is often the case, parents who have already navigated "the system" will be one of your best sources of information and support. Case workers or other professionals may be able to attend to help you get the best results for IEP meetings.

THE CONTINUUM OF SPECIAL EDUCATION PLACEMENTS IN FLORIDA (AGES THREE THROUGH 21 YEARS)

Each child may require a different combination of services and settings. In Florida, special services are organized so that children can receive instruction in one or more of the following ways:

- **Supplementary consultation or related services:** Supplementary consultation or related services are the provision of assistance to students in general education, career and technical education, or special education classes.

- Resource room: Resource room special instruction is supplemental instruction to students who receive their major educational program in other general education, career and technical education, or special education classes.
- Special class: Special class is instruction to students who receive the major portion of their educational program in special classes located in a regular school.
- Special day school: A special day school is a school which is administratively separate from regular schools and is organized to serve one or more categories of students with disabilities.
- Residential school: A residential school is a special school which provides special education and related services, as well as room and board.
- Special class in a hospital or facility: A class operated by a non-educational agency.
- Individual instruction in a hospital or home.
- In addition, districts may provide supplementary instructional personnel to public or nonpublic preschool or child care programs for the instruction of pre-kindergarten students with disabilities.
- 6A-6.0311, Florida Administrative Code

THE RIGHTS OF PARENTS UNDER THE INDIVIDUALS WITH DISABILITIES ACT (IDEA)

The IDEA clearly defines the rights of children with disabilities and their parents. In general, the law guarantees that you, as a parent, have the right to participate in the educational decision-making process for your child.

More specifically, your rights include:

- The right to a free, appropriate public education for your child
- The right to request an evaluation, if you think your child needs special education and related services
- The right to be notified whenever the school wants to evaluate your child, wants to change your child's educational placement or refuses your request for an evaluation of your child
- The right to obtain an independent educational evaluation, if you disagree with the outcome of the school's evaluation
- The right to "informed consent". Informed consent means that school staff must have your written consent before they do an individual evaluation of your child or place your child in a separate school, and they must provide time when doing individual tests or other evaluation activities as part of a reevaluation of your child. Your consent is voluntary and may be withdrawn before the activity



occurs.

- The right to request a reevaluation: The school must reevaluate your child at least once every three years, unless both the parent and the school agree that a reevaluation is not necessary. However, your child's IEP must be reviewed at least once during each calendar year.
- The right to receive communication in your primary language to the extent possible to ensure that you understand all oral and written communication, including the right to an interpreter if you are hearing impaired or if your primary language is not English
- The right to review all your child's school records and obtain copies of these records, although the school may charge you a reasonable fee for making the copies. If you feel any of the information in your child's records is inaccurate, misleading or violates the privacy of your child, you may request that the information be changed.
- The right to be fully informed by the school of all rights that are provided to you under the law
- The right to participate in the development of your child's IEP, including the placement decision. The school must notify you of the IEP meeting and arrange it at a time and place that is mutually agreeable.
- The right to request mediation or a due process hearing to resolve differences with the school that cannot be resolved informally; be sure to make your request in writing, date your request and keep a copy.

Federal Requirements Under the Every Students Succeeds Act

In 2015, the Every Students Succeeds Act (ESSA) became law. This federal law reauthorizes the Elementary and Secondary Education Act/No Child Left Behind (ESEA/NCLB) and makes several changes that will have an impact on children with disabilities. It modifies accountability provisions under NCLB that required "adequate yearly progress", and in Florida it transfers authority for accountability from the federal government to the states and school districts. Under the new law, no more than 1% of all students will be allowed to take alternate assessments that are intended for those with the most significant cognitive disabilities. If your child has a significant cognitive disability, this may make it less likely that your child will take an alternate assessment as part of the revised accountability system. If your child takes the Florida State Alternate Assessment (FSAA), ESSA prohibits Florida from preventing him or her from working toward achieving grade-level standards. To better understand alternative assessment in

Florida, go to <http://www.fl DOE.org/accountability/assessments/k-12-student-assessment/fl-alternate-assessment.stml>. Students with disabilities must participate in state and district-wide assessments and have their progress measured and reported, so the academic progress of students with disabilities is expected to become more important. As of late 2016, it is too early to tell how this law will be implemented, but you as a parent should be aware of this law and the changes intended to improve outcomes for your child and other students with disabilities. (<http://www.ed.gov/essa>)

GARDINER SCHOLARSHIPS

Eligible students with a disability may qualify for a state scholarship to purchase specialized services such as speech or occupational therapy, instructional materials, tuition at an eligible private school, contributions to a college prepaid account, and more. This program is administered by state-approved nonprofit scholarship funding organizations. To qualify, the student must:

- Be a Florida resident
- Be or will be 3 or 4 years old on or before September 1 of the year when the student applies for the scholarship, or be eligible to enroll in kindergarten through grade 12 in a public school in Florida
- Be the subject of an IEP or have received a diagnosis of a disability from a Florida-licensed physician
- Have a certain disability: ASD, cerebral palsy, Down syndrome, an intellectual disability, Prader-Willi syndrome, Spina bifida, muscular dystrophy, Williams syndrome or be a “high risk child” (as explained in the chapter 14 iBudget section)

For more information about this scholarship, go to <https://www.floridastudentsachieve.org/florida-school-choices/scholarship-programs/gardiner-scholarship-program>.

THE RESPONSIBILITIES OF PARENTS IN THE EDUCATIONAL PROCESS

Parents of children with disabilities have a vital role to play in the education of their children. Just as you have certain rights, you also have responsibilities. Knowing and following through on your responsibilities will help ensure that you are a contributing partner in the decisions made on the behalf of your child. Although these responsibilities may vary based on the nature of your child’s disability, you may want to consider these suggestions:



- Develop a partnership with the school.
- Learn as much as you can about your rights and the rights of your child.
- Keep records.
- Ask for clarification on any aspects of your child's program that are unclear to you.
- Make sure you understand the program specified in the IEP before signing it.
- Monitor your child's progress.
- Discuss any problems that may arise.
- Join a parent organization.
- When you feel teachers and school personnel are doing a good job, tell them.

ACCESSING EDUCATION SERVICES FOR PARENTS AND CHILDREN IN SPECIFIC FAMILY TYPES

Services for Military Families

You can get information about early intervention services (birth-2 years) and special education services (3-5 years) for military families from several sources.

The Specialized Training of Military Parents (STOMP) organization provides information and assistance to military families in the United States and overseas, who have children with disabilities. STOMP staff is made up of parents of children with disabilities who are trained to work with other parents. As spouses of members of the military, the staff understands the unique needs of military families. You can contact STOMP at:

Specialized Training of Military Parents (STOMP)

6316 South 12th Street

Tacoma, WA 98465

(253) 565-2266 (V/TTY); (800) 5-PARENT (V/TTY)

<http://wapave.org/programs/specialized-training-military-parents-stomp/>

The U.S. Department of Defense Education Activity (DoDEA) office provides extensive guidance for military families with children with disabilities who are living in the United States or overseas. You can contact DoDEA at the following address:

Department of Defense Education Activity

4800 Mark Center Drive

Alexandria, VA 22350-1400
<http://www.dodea.edu/>

The Florida Department of Education Bureau of Exceptional Education and Student Services (BEES) has a website that provides resources for military families, including resources for exceptional student education for military families.

<http://www.fldoe.org/academics/exceptional-student-edu/military-families>

Services for Adoptive and Foster Families with Children with Disabilities

Adoptive Families: In general, the process for getting early intervention services (birth-two years) or special education services (three-five years) for adopted children with disabilities is the same as the process for all children with disabilities.

Adoptive Families of America is an organization with a nationwide family support network of adoptive families. The main focus of this organization is to provide general help and information to all adoptive families, and its monthly parent support magazine includes information and resources for families of adopted children who have disabilities. You can contact this organization at:

Adoptive Families of America, Inc. (AFA)
108 West 39th Street, Suite 805
New York, NY 10018
(800) 372-3300
<https://www.adoptivefamilies.com/>

Foster Families: Families who provide foster homes for children who have disabilities can contact the Florida Department of Health (Early Steps, birth-2 years) or the Florida Department of Education Bureau of Exceptional Education and Student Services (3-5 years) for information about obtaining services. You may also want to contact the Florida Foster/Adoptive Parent Association (FAPA). FAPA has 20 local associations, called circuits, in Florida. The National Foster Parent Association, Inc. (NFPA) provides a great amount of resources as well. This national nonprofit organization offers information and support to all foster parents. Members of this group receive a bimonthly newsletter and have access to nearly 500 NFPA resource materials. You can contact these organizations at:

Florida Foster/Adoptive Parent Association (FAPA)
<http://floridafapa.org/>
(866) 913-0977 or (305) 213-6627

National Foster Parent Association, Inc. (NFPA)
1102 Prairie Ridge Trail
Pflugerville, TX 78660
(800) 557-5238; (888) 925-5634 fax
<http://www.nfpaonline.org/>

Services for Native American Families Living on Reservations

The IDEA requirements for early intervention services (birth-2 years) and special education services (3-5 years) include Native American children living on reservations in Florida. Information on these services is available from the Florida Department of Health (Early Steps, birth-2 years) or from the Florida Department of Education Bureau of Exceptional Education and Student Services (3-5 years). Other sources of information include the office of the tribal leader or the tribal education committee. You may also contact:

Bureau of Indian Affairs
Office of Indian Education Programs
1849 C Street NW, MS-3512 MIB Washington, DC 20240
(202) 208-9710; (202) 501-1516 FAX
<http://www.bia.gov/>

Resources

Florida Early Learning Coalitions:
<http://www.floridaearlylearning.com/coalitions.aspx>

Florida Transition Project:
<http://www.floridatransitionproject.ucf.edu/>

Florida Diagnostic and Learning Resources System (FDLRS):
<http://www.fdlrs.org/>

Florida Department of Education Bureau of Exceptional Education and Student Services:
<http://www.fldoe.org/academics/exceptional-student-edu>

Chapter 16:

Transition, Post-Secondary Education, and Employment



TRANSITION

There will be at least four times when your child will move from one school to another (e.g., elementary school to middle school) or from one service program to another (e.g., early intervention Part C services to school-based Part B services). These times are called transitions, because your child will be transitioning from one program/school to another. These can be stressful and confusing times for both your child, who is going to have to learn a new environment and routine, and for you, who will have to meet all new staff and teachers. The best advice from other parents who have been through these transition periods is that starting early and being prepared is key.

Part B to Part C Transition

Also covered in the last chapter (Chapter 15), the first major transition you and your child will go through is when your child turns three years old and leaves early intervention services (Early Steps) and begins services through the Florida Department of Education, if he or she is determined for these services. These new services are often referred to as Part B services, because they are made available through Part B of the Individuals with Disabilities Education Act (IDEA). During your child's last year in Early Steps, your service coordinator will begin to work with you to ready your family for this change. Don't be afraid to ask for help, more information or clarification if you do not understand something during these meetings.

As noted in Chapter 15, the Florida Transition Project has an Early Childhood Transition video and other resources that help you navigate the transition from Part C (early intervention) to Part B (special education) at <http://www.floridatransitionproject.ucf.edu/>.

One of the biggest changes will be that you and your child will go from having an Individualized Family Service Plan (IFSP), which is focused on not only your child's and strengths and needs but also the strengths and needs of the family, to an Individual Education Plan (IEP). This focuses on what your child needs to be successful in school. This can include special programs and classes your child will have, speech, occupational and physical therapy and special accommodations that will allow your child to be as much a part of his or her daily school life as possible, like assistive technology and supportive staff/aides.

Elementary to Middle and Middle to High School

While your child will continue to have an IEP throughout middle school, the transition from elementary school to middle school can be challenging for most families, and especially for those who have the extra considerations for their child with a disability. When your child changes schools, many things in his or her everyday routine will change. Your child will go from having one or two main teachers to one for each subject, if he or she attends classes with the general student population. This means you and your child will have to develop new relationships with all of these teachers and school staff, as well as work together with them to best meet your child's needs. Some of this will be done during the IEP meetings, but much of this will be gained through the other meetings and communication you have with these teachers.

The transition from middle school to high school will be a lot like the transition from elementary school to middle school. Your child will likely be attending a new school, and you and your child will have to develop new relationships with all new teachers and staff while adjusting to a new environment. You will have an experience similar to when your child started middle school. You will have to start new relationships with all new teachers and staff. You must also help the teachers and staff know what they will need to do to help your child have the best experience in school possible. Some of this will happen during the IEP meeting, but much of it will happen in other meetings and communications.

Another decision that will be made for students with significant cognitive disabilities in an IEP meeting is if he or she will use alternate standards called Access Points. This IEP team decision requires written parental consent before your child is changed to these alternate standards. As was noted before, students on Access Points are assessed using an alternate assessment, currently FSAA. Access Points provide access to the general education curriculum, but at a reduced level of complexity. Access Points are taught within Access courses. If your child is receiving Access Points instruction, he or she may be working towards a standard or special diploma, depending on when he or she started high school. There is more about this option later in this chapter when graduation options are discussed.

High School Graduation

The requirements for high school graduation for students with disabilities have changed in recent years. Each year, the Florida Department of Education posts an Academic Advisement Flyer - What Students and Parents

Need to Know at <http://fldoe.org/academics/graduation-requirements> that lays out graduation requirements and options. As a parent, you will want to be clear on the graduation options for your child, since these have changed over time. The IEP team makes a decision on which option a student will pursue. While this decision can be revisited at any time, it is better to make the right choice for your child sooner rather than later. Options currently available include:

- 24-Credit Standard Diploma: There are multiple options that currently apply that relate to the credits required to earn this diploma. Students with significant cognitive disabilities earn credits via Access Courses and are assessed using an alternate assessment.
- 18-Credit ACCEL Option: Students in the 18-credit ACCEL option must meet all the graduation requirements for a 24-credit standard diploma, with some exceptions.
- IB Diploma Program: The IB Diploma Program is designed for highly motivated students aged 16-19. It is based on a rigorous two-year pre-university course of study with international examinations and university credit.
- AICE Diploma Program: The option is for students aged 16-19 who are seeking advanced study to prepare for college or university study.
- Special Diploma: All students with disabilities who entered ninth grade in 2014-15 or after must work towards a standard diploma or another diploma option other than a special diploma; however, students who were already in high school and whose IEP stated that they were working toward a special diploma may continue to do so, or they can choose to work towards a standard diploma. Changing diploma options may mean that your child will need extra time in high school to complete graduation requirements.
- The Performance-Based Exit Option (“GED® Exit Option”): This is an alternate route to a diploma for students who are at least 16 years of age, do not have enough credits, have a low grade point average or are overage for their current grade level. This option is not available in all schools and school districts.

The type of diploma your child will pursue is an important decision. Once a child receives a standard high school diploma, he or she is no longer eligible for a free appropriate public education (FAPE), and this is a problem if your child needs continued services from the school district. If your child earns a special diploma, he or she may return to the school district and request educational services at any time before he or she becomes 22 years old.

Before graduation, your IEP team should explore with you if deferral of graduation is the best course for your child. This may be an appropriate option for your child if he or she needs to continue receiving school district services. Students defer in the semester when they are expected to meet all of the requirements for a standard diploma. Planning for the deferral should take place early so that the correct language is noted on your child's IEP, so that your IEP team has time to choose the best course of action for your child. Districts may allow a student who defers graduation to participate in graduation activities.

To be able to defer, your child must need continued education and services and be enrolled in one of the following programs: accelerated college credit, industry certification courses that lead to college credit, a collegiate high school, courses necessary for a Scholar designation, structured work-study, internship or pre-apprenticeship programs. School districts offer a variety of extended transition programs that meet these requirements. For some students, dual enrollment career and technical education (CTE) may be the best course. If your child is taking dual enrollment courses, he or she is enrolled in a tuition-free postsecondary course where he or she earns credit towards high school completion and a postsecondary adult vocational (PSAV) certificate or an associate or bachelor's degree. Students enrolled in CTE dual enrollment can earn credit toward a postsecondary CTE credential such as a PSAV certificate or an Associate of Science (AS) degree (for students enrolled in a state college). If your child is enrolled in CTE classes as a dual enrollment student, he or she can also earn an industry certification or reach an occupational completion point. Most CTE programs train students for a specific job, so these programs may help your child obtain employment.

There are many decisions that will be made as part of the IEP process. These decisions can make a big difference in how successful your child is in transitioning from K-12 education to adult life after he or she leaves this system, so it is important that you understand the different education options for your child. For more information about graduation and other student transition topics, go to the Florida DOE BEES Technical Assistance Paper for High School Graduation Options for Students with Disabilities at <http://www.fldoe.org/academics/exceptional-student-edu/secondary-transition.stml> or the Project 10 website at <http://project10.info>. A good resource is the Secondary Transition Roadmap for Families at <http://project10.info/Publications.php>.

High School to Postsecondary Education and/or Employment

Probably the biggest transition your child and family will go through is the transition from high school to “life after high school.” For many children, this transition ends with many young adults with disabilities not attending postsecondary education or finding a job. Beginning no later than age 16, you as a parent will work with the IEP team to develop goals that will be noted on the IEP for your child for life after high school. Again, preparation is critical. There are a number of programs and resources that can help you and your child prepare for postsecondary education, employment and other post-school adult life. This time in a young adult’s life is very exciting, but it can also be stressful and scary. Like the transition from Early Steps to school-based services, your child may now be transitioning from school-based services to Medicaid-funded services through the iBudget Waiver (more information in chapter 14). The Agency for Persons with Disabilities (APD) oversees these services (<http://apd.myflorida.com/>). It is important to note that most post-school services are based on eligibility and are not an entitlement, so your child may have difficulty accessing post-school services.

You and your child will have many decisions to make for this phase of your child’s life. There are many resources to help you and your child move forward to the goals you have set. One of the biggest decisions you will need to make is what your child will do now that he or she is no longer going to school every day. Will you child continue their education at a postsecondary school, like a technical center/technical college, state college/community college or university? Will they get a job? We will explore these options further.



POSTSECONDARY EDUCATION

Like many other high school graduates, your child may want to continue going to school. If you and your child decide this is the path to take, there are many resources that will help find the right program for your child, as well as services and resources that will help your child succeed.

Project 10 (<http://project10.info/>) is a program at the University of South Florida that helps Florida schools successfully transition their students with disabilities to postsecondary schools and programs. While this program's focus is working with school staff and teachers, there is a lot of helpful information that parents can use. This includes information on finding options, applying, receiving financial aid and gaining support for when your child is in his or her new program.

Many postsecondary schools have an office of disability or student services. This office can help your child obtain access to the services and assistance to enable him or her to be as successful as possible. This is one of the first places you will want to contact when looking at programs to find out what services and assistance will be available to your child. This will also address what you and your child need to do to access these services. Don't wait to do this until after high school. Also, don't wait to do this until after your child has been accepted in or started a program. Make this part of the decision-making process to decide where your child will attend. The types of services and assistance that are available will assist in making this decision.

Florida technical centers/technical colleges and Florida state colleges/community colleges offer career and technical education programs for adults. These are programs that provide education and training for jobs in specific fields. The website for these programs is <http://www.fldoe.org/academics/career-adult-edu/career-tech-edu>.

Once your child has been admitted to a postsecondary institution, your child must disclose their disability if he or she will need accommodations and supports to be successful in postsecondary education. The federal laws that apply are Section 504 of the Rehabilitation Act and the Americans with Disabilities Act (ADA), which are different than IDEA, the federal law that applies to your child before he or she enrolls in postsecondary education. Under the laws that apply to postsecondary education, your child may be required to provide documentation of disability. Once the disability is established, that institution must provide "reasonable accommodations," and not all requests will be considered to be "reasonable accommodations."

Alternative accommodations may be proposed. See <http://project10.info/DetailPage.php?MainPageID=136> for more information.

Postsecondary Programs for Students with Developmental Disabilities

The Florida Consortium on Inclusive Postsecondary Education has received federal Transition Programs for Students with Intellectual Disabilities (TPSID) funding to expand inclusive postsecondary opportunities for students with intellectual disabilities. Their internet site at <http://fltpsid.info> lists inclusive postsecondary programs throughout Florida, including the TPSID programs that have federal funding. This site also hosts the Florida Postsecondary Education Guide, a Florida Developmental Disabilities Council, Inc. publication that provides extensive information about postsecondary programs throughout Florida for persons with intellectual or developmental disabilities. The Consortium website may help you locate a postsecondary program that best meets the needs of your child. The Consortium also hosts the annual Hartwick Symposium, which brings together parents, students, mentors, educators and other providers to learn and share in support of the Consortium's mission of inclusive higher education.

In 2016, "The Florida Postsecondary Comprehensive Transition Program Act" became law. This legislation is intended to increase educational opportunities for students with disabilities, especially students with intellectual disabilities. Section 1004.6495, *F.S.*, created the Florida Center for Students with Unique Abilities (FCSUA) at the University of Central Florida for statewide coordination of information regarding programs and services for students with disabilities and their parents. This law also created a process for eligible postsecondary institutions (universities, state colleges/community colleges, career and technical centers/ technical colleges and certain independent colleges and universities) to apply for FCSUA approval to offer a Florida Postsecondary Comprehensive Transition Program (FPCTP) for students with intellectual disabilities. These must be comprehensive programs specially tailored to the needs of students with intellectual disabilities. Educational institutions that have FPCTP approval from this Center are able to offer state scholarships set at up to \$7000 a year for the 2016-17 school year for each qualifying student. The Center also has funding to award startup and enhancement grants for these programs. These postsecondary institutions must also pursue federal approval as a federal Comprehensive Transition Program (CTP). Federal CTP approval gives these education institutions the ability to offer federal financial aid, including Pell, work study and Supplemental Educational Opportunity

Grants (SEOG). This is financial aid that students with intellectual disabilities may not otherwise be eligible for. Why is this important information for you as a parent? Once approved as an FPCTP and CTP, these institutions will be able to offer the state and federal financial aid that can go a long way towards helping you as a parent pay the costs of their programs. <http://fcsua.org>

EMPLOYMENT

Your child may choose to pursue a pathway directly to employment. Employment offers a sense of accomplishment and self-sufficiency, as your child will be earning an income. If this is your child's goal, the Florida Department of Education, Division of Vocational Rehabilitation (VR) can assist your child in securing and maintaining employment. VR provides programs that help students with disabilities have the opportunity to participate in sponsored career counseling, work readiness training, fully integrated work experiences in the community, supported employment, customized employment and self-employment. Their Ticket to Work Program allows individuals to be employed without losing their governmental assistance. The VR site is <http://www.rehabworks.org>. For your nearest office, go to http://www.rehabworks.org/office_directory.shtml.

Your child can receive some services and supports from VR while still in high school. The Workforce Innovation and Opportunity Act of 2014 made several changes to federal law relating to VR, including the requirement that VR allocate 15% of federal funds to provide youth with disabilities age 15 through 21 the following pre-employment services: job exploration counseling; work-based learning experiences; counseling on postsecondary opportunities; workplace readiness training; and instruction in self-advocacy. In Florida, this is called the STAR Program, which is intended to create more opportunities for your child and other children with disabilities to transition from secondary school to postsecondary school and the world of work and adult life after school. http://www.rehabworks.org/stw_star.shtml

The Agency for Persons with Disabilities (APD) also provides supports that may be available to assist your child with employment. You may recall that the iBudget Waiver and who can qualify for these services was covered in Chapter 14. APD is the agency that provides funding for longer-term, ongoing supports that assists persons who qualify for iBudget Waiver services with employment-related and other needs. If your child is receiving iBudget Waiver services from APD, he or she may be able to receive support to help him or her find and retain employment. All individuals seeking

employment should first apply for services through Vocational Rehabilitation. APD will provide employment support services to help maintain the individual's competitive employment in the community. To find out what resources are available, your best sources of information are your child's waiver support coordinator or the closest APD regional or field office, which you can locate at <http://apd.myflorida.com/region>. If your child is on the waiting list for iBudget Waiver, at least 18 years old and not receiving services from VR, he or she may possibly obtain assistance in finding competitive employment through internships, transportation, resume development and job placement from the APD Employment Enhancement Project (EEP). To find out more about EEP, contact your nearest APD regional office at the internet address above. For more information, go to <http://apd.myflorida.com/customers/supported-employment>.

In recent years, the State of Florida has embraced "Employment First." The intent is to raise expectations that employment should be prioritized for individuals with disabilities. Employment First may be explained as changing a system to better support integrated, competitive employment. As with any plan for change, the first step is to determine the strengths and the barriers of state agencies and disability service organizations working to achieve better employment outcomes for individuals with disabilities. The next step is to act to build on the strengths and eliminate the barriers.

In 2013, Governor Rick Scott issued Executive Order 13-284, which formally prioritized employment for Floridians with disabilities and charged key state agencies with collaboration to improve employment outcomes for individuals with disabilities. In 2014, key state agencies and organizations entered into a five-year Employment First Interagency Cooperative Agreement. In January 2016, Employment First was codified in legislation by 413.80, *F.S.* In Florida, Employment First is defined as:

"...a job in the community where an individual is paid by an employer at least minimum wage or earnings through self-employment, fully integrated in the community workforce, with a goal of maximum self-sufficiency."

Additional information and resources for Employment First Florida can be found on the following website: <http://www.employmentfirstfl.org/>

Key employment-related resources developed by the Florida Developmental Disabilities Council, Inc. can be found on the Council's website:

- FYI Transition is a Florida website dedicated to youth with disabilities that provides information and web-based learning on transition planning, career and postsecondary education planning, job development and support, career exploration, funding, work incentives and more. <http://fyitransition-students.org/>
- *Let's Get Everyone to Work: Resource Toolkit for Students and Families* is a 45-minute video that explores strategies and approaches leading to successful employment and greater independence for individuals with developmental disabilities. It focuses on the importance of having high expectations for employment and independence and using a person-centered transition process that reflects the interests and abilities of the individual, while developing a collaborative and creative support network. <http://www.fddc.org/sites/default/files/New%20Web-Employment.5.pdf>.
- *The Changing Face of Benefits*, available in English and Spanish, provides a workbook and online training module to provide individuals, families and professionals with basic information about Social Security Disability Income/Supplemental Security Income and Medicare/Medicaid benefits, information to support informed decision-making and programs and services available to help people with disabilities move towards financial success. The self-paced workbook, supplemental workbook and online courses can be accessed at <http://www.fddc.org/sites/default/files/New%20Web-Employment.5.pdf>.
- *Connections: Tools and Resources for Adult Life*, available in English and Spanish, is designed to help individuals with developmental disabilities and their families connect to tools and resources that will help identify the options that are available to individuals with developmental disabilities in adult life. <http://www.fddc.org/sites/default/files/New%20Web-Employment.5.pdf>.

Supported Employment/Customized Employment/Self-Employment

As we take a closer look at employment options that assist individuals with developmental disabilities secure and maintain employment, there are three models often found in Florida:

- Supported Employment is a unique employment service for individuals with the most significant disabilities who require ongoing support services to succeed in competitive employment. In this model, employment specialists or job coaches assist individuals with disabilities with all aspects of securing a job (e.g., job develop-

ment, assessment, training, short-term follow-along support services). Supports may include: arranging transportation, placement, training or retraining the supported worker or developing natural supports and assistive technology, if needed, to perform job duties.

- Customized Employment, recognized by the United States Department of Labor as a valuable means of attaining employment for individuals with the most significant disabilities, individualizes the relationship between job seekers and employers in ways that meet the needs of both. Each job seeker's unique strengths, needs and interests are thoroughly discovered, so they can be fully utilized to benefit both the employee and employer. This job-seeker-driven model of job development can be a very successful alternative for individuals with the most significant disabilities.
- Self-Employment is another option recognized by the U.S. Department of Labor as a promising alternative to traditional employment for some individuals with disabilities.

Other less inclusive options (e.g., sheltered workshops, day programs, etc.) continue to be available. Recent changes in federal law are making it more difficult to offer these options and foster more inclusive options. The Workforce Innovation and Opportunity Act imposes limits on the ability of sheltered workshops to pay participants less than the federal minimum wage.

Many families worry about their adult child working and losing their Social Security and other government benefits. If your child is receiving certain types of federal assistance, *The Changing Face of Benefits*, which was earlier noted above, can help your family understand how your child can work without losing cash benefits and health coverage (Medicaid and/or Medicare).

How Self-Determination Relates to Your Child as He or She Grows Older

Nationally recognized researchers identified self-determination as one of the most important factors influencing post-school success for individuals with disabilities, regardless of the level of disability. As was discussed before, self-determination empowers the individual to take control of his or her own life and make key decisions that impact his or her life. Some individuals will always require assistance with decision-making. Person-centered planning is a form of self-determination that places the focus on the individual, while having those who know the individual best (family

members, friends in the community, etc.) involved in sharing the individual's interests, preferences, strengths and limitations. Self-determination helps your child embrace the next part of life after high school. The most important role of family members, friends and others close to your child is to be supportive and understanding of the child's goals and objectives and to advocate for those choices in all facets of post-school adult life (education, employment, adult living, community access, recreation/leisure, etc.). They also can help your child make informed and educated decisions when it comes to identifying long-term goals and objectives.

There are a number of things educators and direct support providers (e.g., employment specialists, job coaches) and employers can do to promote self-determination. Keep these in mind as you support your child in his or her journey to post-school adult life.

- Discuss the concept of self-determination, including the freedom to make his or her own choices, determine support needs, post-school goals and resources needed to obtain those goals.
- Encourage and respect the decisions he or she has made, even when they differ from your recommendations.
- Share post-school ideas and suggestions (education, employment, living, etc.) but let your child make the final decision.
- Promote and support active participation in all phases of services, including career planning and assessment, direction of a job search, selection and training.
- Always ask what assistance is needed in achieving post-school goals and objectives.

There are many things families and friends can do while your child is still in school for support to encourage him or her to begin thinking about long-term success after high school. These include:

- Teaching the importance of work by assigning specific jobs around the home
- Encouraging your child to learn about jobs
- Teaching good personal hygiene, appearance and social skills
- Getting your child into training programs; he or she can work part-time before graduation

Legal Protections

There are many protections given to individuals with disabilities that allow them to find a job and work in their job without discrimination. One of the most important of these laws is the American with Disabilities Act that

was mentioned earlier in this chapter, which does not allow discrimination against people with disabilities and guarantees equal opportunities for individuals with disabilities in education, employment, transportation, public accommodations, state and local government services and telecommunications. You can find information on these and other laws at the U.S. Office of Disability Employment Policy website (<http://www.dol.gov/odep/pubs/fact/laws.htm>).

Some of the things an employer must do or provide are:

- Provide a non-discriminatory work environment
- Provide appropriate leave of absence benefits required by the Family Medical Leave Act
- Ensure that employees are working in a healthy and safe environment
- Provide a readily accessible workplace environment for job applicants and employees with disabilities
- Consider and provide a reasonable accommodation, if a job applicant or current employee requests one
- Provide a workplace that is non-discriminatory, non-threatening, non-hostile and non-retaliatory for all employees

Citations

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Brent, S., Jennings, E., Roush, M. (2013). *The Changing Face of Benefits: Knowledge for Successful Employment and Asset Development*. National Disability Institute.

Brugnaró, L. & Timmers, J. (2007). Self-determination: A Fundamental Ingredient of Employment Support. *Institute for Community Inclusion, Tools for Inclusion*, 22.

Camuso, A., & Baker, D. (2008). *Supported Employment: Participant Training Manual*. New Brunswick, NJ: The Elizabeth M. Boggs Center on Developmental Disabilities, University of Medicine and Dentistry of New Jersey-Robert Wood Johnson Medical School.

Easter Seals. (n.d.). *Easter Seals Living with Disabilities Study: Key Findings*

Resources

Transition

Florida's Transition Project (Part C to Part B)

(352) 372-2485

<http://www.floridatransitionproject.com>

Florida Inclusion Network

(850) 414-7593

<http://www.floridainclusionnetwork.com>

Training and Technical Assistance System (TATS) University of Central Florida

(407) 823-3058

tats@mail.ucf.edu

<http://www.floridatransitionproject.com>

Florida Diagnostic and Learning Resource System (FDLRS)

(386) 312-2265

<http://www.fdlrs.org>

National Technical Assistance Center on Transition

(704) 312-2265

www.transitionta.org

Project 10

(727) 873-4654

<http://project10.info/Contact.php>

<http://project10.info/>

http://project10.info/files/pro10-brochure2015_9.30.15.pdf

Florida Department of Education

Florida Department of Education Bureau of Exceptional Education and Student Services

(850) 245-0505

<http://www.fldoe.org/academics/exceptional-student-edu>

Florida Department of Education Division of Career and Adult Education

(850) 245-0446

<http://www.fldoe.org/academics/career-adult-edu>

Florida Department of Education State University System of Florida
(850) 245-9685
<http://www.flbog.edu>

Florida Department of Education Division of Colleges
(850) 245-0407
<http://www.fldoe.org/schools/higher-ed/fl-college-system>

Employment

Florida Department of Education Division of Vocational Rehabilitation
(850) 245-3399; (800) 451-4327 (V/TTY)
<http://www.rehabworks.org>
http://www.rehabworks.org/office_directory.shtml

**Florida Department of Education School-To-Work Transition Services
Division of Vocational Rehabilitation**
(850) 245-3360
<http://www.rehabworks.org/stw.shtml>

Florida Agency for Persons with Disabilities
(850) 488-4257; (866) 273-2273
APD.info@apdcares.org
<http://apd.myflorida.com>

Florida Association of Rehabilitation Facilities, Inc.
(850) 877-4816
info@floridaarf.org
<http://www.floridaarf.org>

Legal

U.S. Equal Employment Opportunity Commission
For publications: (202) 663-4191
For questions: (202) 663-4900 (V); (202) 663-494 (TTY)
<http://www.eeoc.gov>

U.S. Department of Labor Office of Disability Employment Policy
<http://www.dol.gov/odep/pubs/fact/laws.htm>



Chapter 17:

Planning for the Future

"I choose not to place "DIS" in my ability." - Robert M. Hensel, individual with Spina Bifida and world record holder for longest wheelie in a wheelchair

BEGINNING EARLY

Even though your child may still be quite young, you probably think about his or her future sometimes. What will the future hold? What will my child's life be like as an adult?

Actually, now is exactly the right time to begin making plans for your child's future. The way you think about and interact with your child now will have big implications for his or her future. It will affect the way others relate to him or her, and it will affect the way he or she thinks about himself or herself.

You may or may not be familiar with the story of Christy Brown, who was born in 1932 with cerebral palsy to a large Irish family in Dublin. At the time, no one knew that his physical limitations were due to cerebral palsy. Against doctor's recommendations, his mother took him home and treated him just like all of her other children. Eventually, with voluntary control over only one foot, Christy became a gifted author, painter and poet. In his 1954 book *My Left Foot*, which was also made into a 1989 movie, he gave credit to his mother and to his therapist for shaping his life with their unconditional love, support and belief in his potential.

Many other adults with disabilities have written and spoken about the profound effect their parents have had on their lives. Most often, they credit their ability to take part in the fullness of life to the fact that their parents expected them to be a part of the big, wide world, with all of its joy and all of its pain.

NORMALIZING YOU AND YOUR CHILD'S WORLD

Normalization does not mean "making your child more normal." It means normalizing environments, and it is everyone's responsibility. Schools are responsible for normalizing education settings for all students, employers are responsible for normalizing employment settings for all workers, and all of us are responsible for normalizing community settings for all citizens. Parents have a special responsibility for normalizing the early lives of their children with disabilities. As your child's advocate, you are in the best position to influence the way your child learns to see him or herself, abilities and disabilities. Your child will look to you to see how you react to his or her efforts and behaviors, just as we all learn about ourselves from the way others in our lives react to us. If your child sees only anxiety and protectiveness coming from you, he or she will soon learn that he or she is someone who needs protection and special treatment. In addition to a

physiological disability, your child may also develop a “hidden disability” of low self-esteem or overdependence on others.

The best thing any parent can give a child is a good, strong sense of self. Children with disabilities can be especially vulnerable to feelings of “being different,” and they may need the assistance of important adults in their lives to build their identity. By “normalizing” your child’s world, you can begin to help him or her develop good self-esteem at an early age.

What does that mean? Normalizing your child’s world means:

- Expecting behavior to be as normal as possible from birth onward
- Using discipline and managing your child’s behavior as you would for any other child
- Exposing your child to other children and encouraging him or her to socialize as normally as possible from infancy onward
- Considering your child’s mental health to be as important as his or her physical and intellectual development
- Treating your child as any other child in your family would be treated
- Exposing your child to all that life has to offer and the activities of the community in the same way you would any other child
- Exposing your child to inclusive environments where he or she will be challenged to develop typical language and behavioral patterns to the extent possible
- Encouraging your child to participate in typical community activities and programs as much as possible
- Expecting your child to accept personal responsibility for his or her own actions to the extent possible
- Encouraging your child to become as self-sufficient as possible at every age
- Encouraging your child to reach for the highest level of functioning possible
- Helping your child to recognize personal limitations, but not to use them as an excuse for every shortcoming

You may be thinking that interacting with your child in these ways would sometimes be difficult. Indeed, it is. Treating your child as any other child includes letting him or her try something new and accepting that he or she may fall down or scrape a knee. It includes allowing your child to approach a group of peers knowing that his or her feelings may get hurt. The truth is that self-esteem does not grow by doing things that are easy or routine. Think about the last time you did something that made you feel really good

about yourself. Most likely it happened when you tried something that was hard or scary for you and you succeeded. It doesn't matter how big or how small the task, the most important factor is the sense of accomplishment. Without the opportunity to try and fail, we never learn how to persist at a task and never get to savor success. It's hard, but next to your love, it's probably the best gift you can give to your child.

THE RIGHT TO SELF-DETERMINATION

When children are given the opportunity to be a part of their community and the chance to move towards increasing independence, they are already starting down the road to "self-determination." Self-determination refers to the right of people with disabilities to take charge of and take responsibility for their lives. With self-determination, it is the individual, not "the system," who decides where he or she will live, whom he or she will live with, what types of services the person requires and who will provide them, how he or she will spend time and how he or she will relate to his or her community.

Disability advocates often refer to five principles of self-determination:

1. **Freedom** – to live a meaningful life in the community
2. **Authority** – over dollars needed for support
3. **Support** – to organize resources in ways that are life-enhancing
4. **Responsibility** – for the wise use of public dollars
5. **Confirmation** – of the important leadership role that self-advocates have in this process

Viewing disability services in this way may require a change in thinking, and change rarely comes easily. In recent years, many states have begun to make changes in the way services are delivered, but there is still much to be done.

Even though your child may be very young right now, there are many things you can do to make sure he or she is ready for the opportunity to direct his or her own life later on. At the very center of self-determination is decision-making. If individuals are going to be able to make good choices as adults, they need to be exposed to making choices from infancy onward. How can you give choices to young children? Consider these examples:

- **Infancy.** Allow your child to decide when he or she has had enough to eat. If he or she turns away before the bowl is empty, respect his or her choice to stop eating.
- **Toddlerhood.** Give simple either/or choices. Do you want cereal or

oatmeal? Do you want to wear the red shirt or the blue shirt? Do you want to look at the book or play with blocks?

- **Preschool Age.** Continue offering choices throughout the day, expanding the activities over which your child is able to have control. Be careful, however, to only offer “real” choices. If bedtime is not really an option, do not ask your child, “Do you want to go to bed now?”

Offering children the opportunity to make choices about the things that happen to them builds many important qualities:

- **Self-Esteem** – I can do things myself!
- **Sense of Control** – I am powerful and I can make things happen!
- **Independence** – Look what I can do!

Self-determination is not all or nothing. Some individuals with disabilities will live completely independent lives in their own homes, with their own income and their own problem-solving skills. Others will not. The essence of self-determination, however, is being able to communicate your own preferences, something everyone has. **Every individual can move closer to directing some events in his or her life, even if he or she cannot become fully independent.**

THE IMPORTANCE OF HIGH EXPECTATIONS

The importance of high expectations, even when unplanned, like in Christy Brown’s *Story of My Left Foot* from the beginning of this chapter, cannot be overemphasized. Think of high expectations in relation to self-determination. A parent can allow self-determination regarding what ways and how much his or her child studies. The choices of that child will be partially determined by the expectations of academic success. If a parent fosters self-determination as described and sets high expectations of only A’s and B’s and (this is important), those grades are *within the capabilities* of that child, then self-determination is merged with high expectations, and the child will be responsible to himself or herself and the parents. If the child is capable of A’s and B’s but his or her parents are uncaring about grades, then how the child exercises self-determination may look quite different!

Yes, perhaps you will have to rethink expectations to match the capabilities of your child. A major victory for a child with a disability may be dressing himself or herself, while for a typically developing child, it may be walking across the stage to get a diploma. Indeed, that same child that had the victory of dressing may later also walk or ride across the stage for a diploma.

The stage, the diploma and the age may be different, but the success is as real. No matter what, the common factor is that **someone expected them to accomplish what they did.**

Across the United States, the government is investing in the development of Community Parent Resource Centers. One of the main objectives of such centers is to raise the expectations of parents, family and communities for those with disabilities. Finding the abilities of each person and helping every person reach their individual potential is emphasized. Throughout this chapter, this whole guide really, you see examples of setting high expectations for persons with disabilities and how that helps them to strive. Helping your child to reach his or her potential may include a diploma and employment. It may include a family of his or her own. For many parents, it may be simply surviving, relishing small victories and accepting a new definition of joy. The only difference is whether the child has reached as close to his or her potential as possible. This is like how many children play sports, have local success, learn to be good teammates, develop their skills to the degree they can and yet will never play professional sports. If they did their best, reaching the potential within their abilities and limitations, they were successful.

ADOLESCENCE AND SEXUALITY

When your child is very young, you can see frequent signs that he or she is growing and changing. You will notice increases in weight, mobility or efforts to talk. You will observe the development of his or her unique personality and temperament. You will realize that one day your little child will become a teenager and young adult.

What can you expect as your child matures? During adolescence, the developmental tasks for all young people include strengthening a sense of identity apart from the family, assuming the male or female sexual role and achieving some measure of independence.



Many parents have difficulty with the changing behaviors of their children during adolescence, particularly with regard to their child's developing sexuality. When a child has an intellectual or developmental disability, the challenge of dealing with sexual feelings and behavior may be more difficult and require different responses. It will help to remember that sexuality is a part of all human development and should be considered a normal part of growth.

Sometimes there is conflict between the rights and needs of parents and the rights and needs of children. As a parent, you may feel uncomfortable about your child's sexual interest or activity. However, your child has a right to express sexual feelings in both physical and emotional ways. You may want to protect your child from harm or criticism by the community. You may be worried about pregnancy, abuse or exploitation of your child, or you may believe that your child is not capable of managing a relationship that might include sex.

Your child may have concerns of his or her own as well, but learning to deal with his or her own sexuality is an important step in the developmental process. Obviously, there may be real problems to be faced as your child matures, and many times there are no easy solutions.

Fortunately, there is much more openness about sexuality today in our society. You can find organizations that offer assistance and information about sexuality, birth control, privacy rights, sex education, marriage, having children and parenting. As your child grows toward adulthood, you will gain a better sense of the nature of the issues you and your child will face together as he or she becomes a mature individual.

Resources

- Sexuality Education for Children and Adolescents with Developmental Disabilities from the Florida Developmental Disabilities Council. https://www.autismspeaks.org/docs/family_services_docs/parentworkbook.pdf

ADULT LIVING ARRANGEMENTS

As children leave the high school years and transition to the adult world, many parents begin to think about the significance of living in the community in regards to their children. Some parents think of community-based living as an exciting step in their child's life that will widen his or her world. Other parents face this decision with great concern, anxiety or sadness. At

this time, it may be helpful to remember the principle of normalization. In our culture, it is “normal” or “typical” for young adults to move to alternate living arrangements sometime in their early-to-mid-20s. It is a part of the typical cycle of life. Although your family home is usually the best place for a young child to live, it may or may not be best for an adult child.

There is no “right time” for your child to move out of your family home. Depending on the resources available in the community, your child may find that the best living arrangement is in the family home, where he or she can receive needed services from the agencies that support him or her. The situation will be different for every individual. Sometimes the age of the parents will be a factor, as caring for a child can simply become too difficult for elderly caregivers. Sometimes, it will be the wish of the child to live in the community, and parents can move their child toward independence by helping him or her to make this a reality. It is important to remember that, with the right services and supports, every individual can live in the community. The range of living arrangements beyond the family home includes:

- ***Independent Living.*** The individual lives in the community and manages all activities on his or her own, with or without the informal support of friends or family.
- ***Supported Living.*** The individual receives an array of formal services and supports that allow him or her to establish and maintain his or her own household in the community. The intensity of the support can range from a few hours of drop-in assistance on a monthly, weekly or daily basis to arrangements in which paid personal assistants live in the home with the individual.
- ***Group Home Living.*** The individual lives in a residential home in the community with paid staff and other individuals with disabilities. The intensity of the support he or she receives there varies according to his or her needs.
- ***Residential Living.*** The individual lives in a facility with paid staff and other individuals with disabilities. The facility itself is not a personal residence and is likely to provide a home for a larger number of individuals than would typically be found in a family dwelling. Residential programs can be publicly or privately funded. Living in a large residential facility is not typically considered to be “community-based” living.

Resources

- Florida Association of Centers for Independent Living, Inc. Find

your local center at <http://www.floridacils.org/LocateYourLocalCIL.html>

ADULT RELATIONSHIPS AND FRIENDS

As your child grows into adulthood, the need for relationships with other adults outside of the family will also become increasingly important. Upon leaving high school, the opportunities your child has to interact with peers may become less frequent, and it will become important for new friendships and relationships to develop. If you started to include your child in community life early on, your child may already know how to seek out new relationships by the time he or she reaches adulthood. Employment and community living options will also provide opportunities to meet new people and develop new friendships. The more involved your child becomes in the mainstream of life in the early years, the more prepared he or she will be to participate with others later in life.

ADDRESSING FINANCIAL CONCERNS

The expenses associated with raising children can stretch a family's resources. When a child has a disability, particularly one that involves high-priced medical care, a family can quickly become financially overwhelmed. While it is often difficult to completely resolve financial concerns, there are a number of things parents can do that may help.

Often, so much attention is focused on the provision of health care that doctors and other medical staff may not mention available sources of financial aid. Many states have passed legislation intended to help families of children with a disability in addressing their financial concerns, but parents will need to be focused and persistent to get the answers they need.



Many children with disabilities are eligible to receive Supplemental Security Income (SSI) benefits, based upon their disability. If a child is found eligible for SSI, he or she is automatically eligible for Medicaid benefits, even if the family's income is higher than what is traditionally required for Medicaid in that state. This is very important for children with disabilities who may have many medical needs.

If your child qualifies, most early intervention services can be paid for by Medicaid. If your child qualifies for Medicaid, it is important to have him or her assessed by a provider qualified to perform the Early Periodic Screening, Diagnostic and Treatment (EPSDT) program. If an EPSDT program determines that your child has a condition that requires treatment due to a medical necessity, then it can be paid for by Medicaid. Furthermore, each state has a "Child Find" system, which is responsible for locating and assessing children with disabilities. This is required to be free by federal law. It is also important to know about what other resources can be used to get help for your child.

Private insurance benefits are one such resource. Nursing, physical therapy, psychological services and nutrition services can usually be reimbursed by private insurance. In some cases, occupational therapy and speech therapy are also reimbursable. However, educational expenses related to a child's disability are only rarely covered by insurance. It is still useful, though, to keep track of educational expenses, because these may be deductible on your federal income tax returns.

Some additional resources to look at in your search for financial assistance include the following, depending on your individual situation:

- Hospital social workers
- Public health departments
- Public health nurses
- Volunteer agencies
- Disability organizations
- State government agencies

Because searching for assistance may involve a lot of telephone calls, it is a good idea to have paper and a pen on hand to record the names and telephone numbers of all those you contact, as well as any referrals they give you. Whether or not you believe your income is too high for your family to qualify for financial aid, you should keep trying until you have a definitive answer. You should always revisit the issue if your income declines. As Charlotte Thompson, a leading researcher, notes in her book *Raising a*

Handicapped Child:

“The key is to keep trying - to get more information, to follow up leads and to continue applying for various types of financial assistance. This may seem like an endless paperwork maze to you, but with luck some of the paper at the end will be the green kind that can help you pay your child’s medical bills. Keep at it.” (Thompson, 1986, p. 103).

Resources

- Wrightslaw is a great resource for parents and has information on many topics related to disabilities from a legal perspective. As this is a website for parents, the information is written in an understandable way (www.wrightslaw.com/info/future.plan.index.htm).
- This website contains easy-to-understand articles on a number of legal issues related to developmental disabilities and is provided by Shepherd Financial Partners. (www.specialneedsplanning.com).
- Autism Speaks (2011). "Legal Matters to Consider: What is Long-term Planning?" <http://www.autismspeaks.org/family-services/tool-kits/transition-tool-kit/legal-matters>
- Addressing financial concerns: <http://www.kidsource.com/NICH-CY/parenting.disab.all.4.4.html#Addressing>

FUTURE PLANNING

It is not possible for parents to imagine all the stops and detours that they will make as their unexpected journey takes them into the future, but you will probably be thinking about what the future holds for your child at different times. Advocates believe it is important for parents to have expectations about what their child with a disability can achieve in the future and encourage their child to develop as much independence as possible, given the nature and severity of the disability.

What the future holds for your child when he or she leaves school is naturally of great concern to you as parents, disability advocates, disability organizations or persons with disabilities themselves. For far too long, students have exited the school years to an adult life that lacked opportunities for employment, further education or community participation (McLaughlin, 1993). Now, with the help of federal legislation and the advocacy of many concerned parties, adult life for individuals with disabilities holds increasing promise.

The Individuals with Disabilities Education Act (IDEA) now requires that school personnel, parents and each student with a disability (16 years of age or older, and, in many cases, younger) plan for the student's transition from school to post-school environments, including employment, additional education or training, independent living and community participation (Wandry & Repetto, 1993). This legislation is intended to prepare youth with disabilities for the adult world, as well as the roles they will encounter upon leaving high school, with the purpose of maximizing their participation in mainstream society. Furthermore, the Americans with Disabilities Act (ADA) has incorporated into law provisions that guarantee many of the principles of inclusion as individual rights. No longer may most child care centers refuse to serve children because they have a disability, and no longer may a qualified individual be denied employment because he or she has a disability. Public accommodations must now be accessible to all individuals. Many states have been working actively to establish community-based supports so that individuals with disabilities can lead their lives as independently as possible.

When you contemplate the future of your son or daughter with a disability, as well as develop goals for that child, it may be helpful to consider the following suggestions. These should all be considered within the abilities of the individual child:

- Ensure that your child has the opportunity to acquire skills now that will make him or her as independent as possible in the future.
- Ensure that your child has opportunities to develop social skills that can be used in a variety of settings. Regular classroom settings and exposure to many different environments are useful in this regard.
- Teach your child to be responsible for his or her own personal needs (e.g., self-care, household chores).
- Work with the school and other agencies to ensure that transition planning for your son or daughter takes place and addresses training for future employment, coordination with adult service providers, investigation of postsecondary education or training and participation in community activities.
- Help your child develop self-determination and self-advocacy skills.
- Explore different possibilities for living arrangements once your son or daughter is grown.

Resources

- Future planning: <http://www.kidsource.com/NICHCY/parenting>.

disab.all.4.4.html#Future

- Florida Developmental Disabilities Council, (2012). *Planning Ahead: A Guide for Parents, Family Members and Legal Representatives of Individuals with Developmental Disabilities*, 4th ed. http://www.fddc.org/sites/default/files/PA_Book_final_3-5-12-1.pdf

Estate Planning

All parents should plan for the future of their children. When a child has a disability, this responsibility becomes even more important. Although you know it's important, you may feel that you have plenty of time for planning as your child gets a little older, or you may want to begin planning, but you just can't seem to find the time or energy to do so. Add to that the reluctance we all have to think about our own death, and you may find yourself postponing your estate planning for far longer than you should. Although it may be difficult, it is important to plan for after you are gone, especially if there are specific things that need to be attended to for your child.

Resources

- Estate planning: <http://wrightslaw.com/info/estate.planning.nichcy.pdf>

Tax Deductions and Credits

There are many income tax deductions and credits available to parents of children with disabilities, and you will benefit from taking advantage of these special provisions. You will need to keep up-to-date with tax information each year and keep records that will support your deductions. If you need assistance in completing your taxes, you can contact your local Internal Revenue Service office or visit their website at www.irs.gov.

An ABLE United account offers Floridians with disabilities a tax-free way to save while maintaining government benefits. The account is available to Florida residents who at the time of application have a qualifying disability with onset of the disability before age 26. This is a way to save up to \$14,000 per year tax free for qualified disability expenses, individually or with the help of family or friends. As with many other government initiatives, it is important for you as a parent to understand the fine print before pursuing this benefit. <http://www.ableunited.com/>

Life Insurance

Make sure you are carrying enough life insurance. Although you are irreplaceable to your child, someone will need to take over for you in the event of your death. Even if it is your child's siblings or other relatives who step in, they will likely have to pay for at least some of the services that you currently provide. If your estate is not large enough to cover these costs, the number of available funds can be increased through life insurance proceeds. Premiums for “second-to-die” insurance (which pays only when the second of two parents passes away) often can be purchased at a reasonable cost.

Setting up a Trust

Any funds left for a child with a disability from an estate, or the proceeds of a life insurance policy, should be held in trust for the child. Leaving money directly to a child with a disability may place his or her ability to receive government funds (such as SSI) at risk in the future. Specialized trusts, such as “self-sufficiency trusts” or “special needs trusts,” allow parents to leave money to a child with a disability without disqualifying the child from government benefits. Because choosing the best type of trust fund for your child can be complex, it is recommended that you choose an attorney with experience in disability law to help you through this process.

There are different trust and savings plans that you will talk with your financial planner or attorney about. The most common one is an individual special needs trust that allows money to be put aside for your child without putting this child's benefits, such as SSI, at risk of being stopped. Plan ahead, because these can be expensive to set up. Another type of trust is what is called a pooled trust. This type of trust is maintained by a specialized nonprofit organization. In a pooled trust, many individuals' accounts are “pooled” together for investment, but the money in the account belongs to the individual the trust was set up for. The resource section has a list of



organizations in Florida that specialize in Pooled Trusts.

There is also an education savings plan that allows parents and family members to save for college expenses. This is called a 529A Plan. This is a tax deferred savings plan that does not affect the asset requirements for government programs and provides money for your child and his or her needs during college.

Resources

- PACER Center has resources and information on a number of topics related to disabilities. This article is specific to special needs trusts. <http://www.pacer.org/publications/possibilities/saving-for-your-childs-future-needs-part1.html>
- "Achieving A Better Life Experience Act: 113th Congress, Frequently Asked Questions." https://www.mda.org/sites/default/files/ABLE_Act_FAQs_113th_Congress.pdf

Wills and Guardianship

Choosing a guardian for your minor (under the age of 18) child in the event that you can no longer care for him or her is an important decision you must make. Sometimes, the choice is relatively simple, like when a sibling comes forward and asks to be given this role. Other times, the decision will be more difficult, but parents should devote time to this decision while they are able. When your decision is made, your attorney will include the naming of your child's guardian in your will. When your child reaches adulthood (18 years and older), you may need to petition for guardianship in court, if he or she is unable to make decisions about his or her future and cannot live alone. This is a very important decision you will have to make, and you should not assume that guardianship is always the best course of action for your child.

Resources

- Florida Developmental Disabilities Council, (2010). *Lighting the Way to Guardianship and Other Decision-Making Alternatives: A Manual for Individuals and Families*. <http://www.fddc.org/ltw/?Language=English>
- Thomas, K. & Hill, M., (2013). *Guarding, Advocating and Protecting Adults with Intellectual and Developmental Disabilities*. South Carolina Autism Society and South Carolina Developmental Disabilities Council. <http://frcdsn.org/wp-content/uploads/2014/07/SCAS-Guardian-Handbook-Final.pdf>

Care Plans and Letters of Intention

All parents of children with disabilities are advised to write down what their child's next guardian would need to know about their child and what their wishes are for him or her. Imagine if you went away for an evening and never came back. You have a picture of what you want your child's future life to look like, but his or her next caregiver may have a very different picture. By preparing a legal letter of intent, you will be able to communicate your wishes and desires for your child to those who will come after you. This document is usually a very personal letter in which you share the intimate details of your hopes for the best possible life for your child.

In the next resources section is a very detailed guide on how to write a letter of intent. This includes a general format that you may follow, as well as the different topic areas that you may want to include. These authors also note in the beginning of this guide that the creation of a letter of intent is a document that should be regularly reviewed and updated. The authors suggest reviewing it every year, as some of the details will change from year to year as your child grows.

Resources

- Russell, L. & Grant, A. (2005). "Letter of Intent Form: An 88 Item Checklist Showing Parents How to Communicate Their Wishes and Knowledge About Their Son or Daughter with a Disability to Future Caregivers." Planning for the Future, Inc. <http://specialneed-legalplanning.com>.

Coordinating with Family Members

Make sure you communicate the legal steps you have taken on behalf of your child to other members of your family, so that everyone is aware of your plans. This is important for many reasons. For example, a well-meaning relative may leave money directly to your child that would disqualify him or her from receiving benefits later on. If this relative had known that you established a trust for your child for this purpose, the damage could be avoided. In addition, by telling many people about your plans, it is less likely that any one person in your child's life would be inclined to work against your plans for the future.

"The greatest glory in living lies not in never falling, but in rising every time we fall."
- Nelson Mandela

Chapter 18:

Resources



Florida State Agencies and Organizations

Programs for Infants and Toddlers with Disabilities: Ages Birth through Two

Florida Department of Health Child's Medical Services Early Steps

(800) 218-0001

EarlyStepsDirectory@flhealth.gov

Directory for Early Childhood

Disability Resources: [http://www.](http://www.floridahealth.gov/AlternateSites/CMS-Kids/early_steps_directory/index.html)

[floridahealth.gov/AlternateSites/CMS-Kids/early_steps_directory/index.html](http://www.floridahealth.gov/AlternateSites/CMS-Kids/early_steps_directory/index.html)

Local Early Steps Contact

Information: [http://www.](http://www.floridahealth.gov/AlternateSites/CMS-Kids/home/contact/earlysteps.pdf)

[floridahealth.gov/AlternateSites/CMS-Kids/home/contact/](http://www.floridahealth.gov/AlternateSites/CMS-Kids/home/contact/earlysteps.pdf)

[earlysteps.pdf](http://www.floridahealth.gov/AlternateSites/CMS-Kids/home/contact/earlysteps.pdf)

Department of Health Children's Medical Services

(850) 245-4200; (800) 654-4440

[CMS_Central_Office@doh.state.](mailto:CMS_Central_Office@doh.state.fl.us)

[fl.us](mailto:CMS_Central_Office@doh.state.fl.us)

<http://www.floridahealth.gov/AlternateSites/CMS-Kids/families/families.html>

Florida Association of Healthy Start Coalitions, Inc.

(850) 270-9246

<http://www.floridahealth.gov/%5C/programs-and-services/childrens-health/healthy-start/index.html>

To find your local Healthy Start

Coalition: <http://healthystartflorida.com/find-a-coalition/>

Programs for Children with Disabilities: Ages Three through Five

Florida Department of Education Bureau of Exceptional Education and Student Services

(850) 245-0478

<http://www.fldoe.org/academics/exceptional-student-edu/early-education>

Office of Early Learning Programs

Office of Early Learning Florida Department of Education

(866) 357-3239;

Dial 711 Toll Free Family Line

<http://www.floridaearlylearning.com/>

State Vocational Rehabilitation Agency

Florida Department of Education Division of Vocational Rehabilitation

(850) 245-3399;

(800) 451-4327 (V/TTY)

<http://www.rehabworks.org>

Link for Area Office Directory:

<http://www.rehabworks.org/office-directory.shtml>

Vocational Rehabilitation School-To-Work Transition Services

(850) 245-3360

<http://www.rehabworks.org/stw.shtml>

Career and Technical Education for Students with Disabilities

Florida Department of Education Division of Career and Adult Education

(850) 245-0446

Information for career and technical education and adult education programs: <http://www.fldoe.org/academics/career-adult-edu>

State Medicaid Office

Florida Agency for Health Care Administration

(850) 488-3560

<http://ahca.myflorida.com/Medicaid>

Local Medicaid Office Locator:

<http://ahca.myflorida.com/Medicaid/Areas/index.shtml>

Florida Department of Children and Families ACCESS Centers

ACCESS Centers Locator:

<http://www.dcf.state.fl.us/programs/access/map.shtml>

Community Partners That Provide ACCESS Assistance:

<http://www.dcf.state.fl.us/access/CPSLookup/search.aspx>

Florida Department of Children and Families Medicaid

<http://www.myflfamilies.com/service-programs/access-florida-food-medical-assistance-cash-medicaid>

Medicaid Online Application:

<http://www.myflorida.com/accessflorida/>

SSI Medicaid Fact Sheet:

<http://www.dcf.state.fl.us/programs/access/docs/ssifactsheet.pdf>

State Child Abuse Hotline

Florida Child Abuse Hotline

(800) 962-2873;

(800) 453-5145 (TTY)

State Mental Health Agency

Florida Department of Children and Families Mental Health Program Office

(866) 762-2237;

(800) 955-8771 (TTY)

<http://www.myflfamilies.com/service-programs/mental-health>

Link for regional offices:

<http://www.myflfamilies.com/contact-us>

State Mental Health Services for Children and Youth

Florida Department of Children and Families Mental Health Programs Office

(866) 762-2237;

(800) 955-8771 (TTY)

<http://www.myflfamilies.com/service-programs/mental-health/childrens-mental-health-services>

State Developmental Services

Florida Agency for Persons with Disabilities

(850) 488-4257; (866) 273-2293

apd.info@apdcares.org

<http://apd.myflorida.com/>

Resource Directory

<http://resourcedirectory.apd.myflorida.com/resourcedirectory/>

Bill of Rights:

<http://apd.myflorida.com/training/docs/bill-of-rights-2008.pdf>

2015 Waiver Guidebook:

http://apd.myflorida.com/ibudget/docs/DD_iBudget_Rule%2059G-13.070Adoption.pdf

Finding a Florida iBudget Waiver Provider:

<http://apd.myflorida.com/ibudget/>

Nancy E. Wright, Disability Lawyer and Information Blog

<http://newrightlaw.com/practice-areas/developmental-disabilities-medicaid-waiver>

Florida Developmental Disabilities Council, Inc.

(850) 488-4180; (800) 580-7801

<http://www.fddc.org>

Protection and Advocacy Agency

Disability Rights Florida

(850) 488-9071 (V);

(800) 346-4127 (TTY)

<http://www.disabilityrightsflorida.org/>

Client Assistance Programs: Programs for Children with Special Health Care Needs

Florida Agency on Health Care Administration: Managed Medical Assistance Plan FAQ

[https://ahca.myflorida.com/](https://ahca.myflorida.com/Medicaid/statewide_mc/pdf/mma/SMMC_MMA_Snapshot.pdf)

[Medicaid/statewide_mc/pdf/mma/SMMC_MMA_Snapshot.pdf](https://ahca.myflorida.com/Medicaid/statewide_mc/pdf/mma/SMMC_MMA_Snapshot.pdf)

Florida Department of Health Children's Medical Services

(850) 245-4200; (800) 654-4440

CMS_Central_Office@doh.state.fl.us

<http://www.floridahealth.gov/AlternateSites/CMS-Kids/>

Florida Healthy Kids

(888) 540-5437

<https://www.healthykids.org/healthykids/what/>

Florida KidCare Application:
<https://www.healthykids.org/application/>

Florida Agency for Health Care Administration: State Children's Health Insurance Program (CHIP)

(888) 540-5437;

(877) 316-8748 (TTY)

<http://www.floridakidcare.org>

Programs for Children and Youth who are Blind or Visually Impaired

**Florida Department of Education
Division of Blind Services**

(850) 245-0300;

(800) 342-1828 (in FL)

<http://dbs.myflorida.com/>

District Office Locator:

<http://dbs.myflorida.com/>

[About%20Blind%20Services/](http://dbs.myflorida.com/About%20Blind%20Services/)

[contact-blind-services.html#county](http://dbs.myflorida.com/contact-blind-services.html#county)

**Florida School for the Deaf and the Blind Outreach Services/
Parent Infant Program**

(904) 827-2232; (904) 827-2437;

(904) 201-4581 (VP)

Outreach Services:

[http://www.fsdb.k12.fl.us/index.](http://www.fsdb.k12.fl.us/index.php/outreach/)

[php/outreach/](http://www.fsdb.k12.fl.us/index.php/outreach/)

Parent-Infant Program:

[http://www.fsdb.k12.fl.us/index.](http://www.fsdb.k12.fl.us/index.php/parent-services/parent-infant-programs/)

[php/parent-services/parent-infant-programs/](http://www.fsdb.k12.fl.us/index.php/parent-services/parent-infant-programs/)

Programs for Children and Youth who are Deaf or Hard of Hearing

**Florida Department of
Education Division of Vocational
Rehabilitation Deaf and Hard of
Hearing Services**

(850) 245-3399; (800) 451-4327

[http://www.rehabworks.org/deaf.](http://www.rehabworks.org/deaf.shtml)
[shtml](http://www.rehabworks.org/deaf.shtml)

**Telecommunications Relay
for People who are Deaf,
Hard of Hearing, Deaf/Blind,
or Speech Impaired: Florida
Telecommunications Relay, Inc.**

(800) 222-3448; (888) 447-5620

(TTY); (850) 270-2641 (VP)

<http://www.ftri.org>

***Regional ADA and
Information Technology
Technical Assistance Center***

**Southeast Disability and Business
Technical Assistance Center
for Assistive Technology and
Environmental Access Georgia
Technological Institute**

(800) 949-4232 (V/TTY)

<http://www.sedbtac.org>

Technology-Related Assistance

**Florida Alliance for Assistive
Service and Technology (FAAST),
Inc.**

(850) 487-3278; (888) 788-9216;

(877) 506-2723 (TDD)

faast@faast.org

<http://www.faast.org>

State Mediation System

**Florida Department of Education
Bureau of Exceptional Education
and Student Services ESE Program
Administration and Quality
Assurance**

(850) 245-0478

[http://www.fldoe.org/academics/
exceptional-student-edu/dispute-
resolution](http://www.fldoe.org/academics/exceptional-student-edu/dispute-resolution)

Special Format Library

**Florida Department of Education
Division of Blind Services Bureau
of Braille and Talking Book**

Library Services

(386) 239-6000; (800) 226-6075

[http://dbs.myflorida.com/](http://dbs.myflorida.com/Talking%20Books%20Library/)

[Talking%20Books%20Library/](http://dbs.myflorida.com/Talking%20Books%20Library/)

Disability-Specific Organizations

Attention Deficit Disorder

**Attention Deficit Disorder
Association**

(484) 945-2101

<http://www.add.org>

**Children and Adults with
Attention Deficit/Hyperactivity
Disorder**

(301) 306-7070; (800) 233-4050

(Voice mail to request information
packet)

<http://www.chadd.org>

Autism

Autism Navigator

<http://autismnavigator.com/>

Autism Recovery Network

info@autismrecovert.sg

<http://autismrecovery.sg/>

Autism Speaks Florida

[http://communities.autismspeaks.](http://communities.autismspeaks.org/site/c.ihLPK1PDLof/b.7501065/k.66E4/Autism_Speaks_in_Florida.htm)

[org/site/c.ihLPK1PDLof/](http://communities.autismspeaks.org/site/c.ihLPK1PDLof/b.7501065/k.66E4/Autism_Speaks_in_Florida.htm)

[b.7501065/k.66E4/Autism Speaks](http://communities.autismspeaks.org/site/c.ihLPK1PDLof/b.7501065/k.66E4/Autism_Speaks_in_Florida.htm)

[in Florida.htm](http://communities.autismspeaks.org/site/c.ihLPK1PDLof/b.7501065/k.66E4/Autism_Speaks_in_Florida.htm)

Autism Society of Florida, Inc.

(407) 207-3388; (855) 529-6807

email@autismfl.com

<http://www.autismfl.com>

Autism Web

<http://autismweb.com/>

**Centers for Disease Control and
Prevention: Facts about Autism**

[http://www.cdc.gov/ncbddd/autism/](http://www.cdc.gov/ncbddd/autism/facts.html)
[facts.html](http://www.cdc.gov/ncbddd/autism/facts.html)

**Centers for Disease Control and
Prevention: Signs and Symptoms
of ASD**

[http://www.cdc.gov/ncbddd/autism/](http://www.cdc.gov/ncbddd/autism/signs.html)
[signs.html](http://www.cdc.gov/ncbddd/autism/signs.html)

**Children's Therapy and Resource
Center**

<http://www.kamloopschildrens>

[therapy.org/autism-red-flags-](http://www.kamloopschildrens)

[preschool](http://www.kamloopschildrens)

**Florida Centers for Autism and
Related Disabilities (CARD)**

Local CARD of Florida locator:

[http://card.ufl.edu/about-card/find-](http://card.ufl.edu/about-card/find-your-card/)
[your-card/](http://card.ufl.edu/about-card/find-your-card/)

**Mayo Clinic Autism Tests and
Diagnosis**

[http://www.mayoclinic.org/](http://www.mayoclinic.org/diseases-conditions/autism-spectrum-disorder/basics/tests-diagnosis/con-20021148)

[diseases-conditions/autism-](http://www.mayoclinic.org/diseases-conditions/autism-spectrum-disorder/basics/tests-diagnosis/con-20021148)

[spectrum-disorder/basics/tests-](http://www.mayoclinic.org/diseases-conditions/autism-spectrum-disorder/basics/tests-diagnosis/con-20021148)

[diagnosis/con-20021148](http://www.mayoclinic.org/diseases-conditions/autism-spectrum-disorder/basics/tests-diagnosis/con-20021148)

Blindness/Visual Impairments

American Foundation for the Blind

(212) 502-7600 (headquarters)
Family Connect Program Email:

familyconnect@afb.net

<http://www.afb.org>

Family Connect Program Website:

<http://www.familyconnect.org/parentsitewhome.aspx>

Florida Association for Agencies Serving the Blind

<http://faasb.com/resources/>

<http://faasb.com/members/>

Brain Injury

Brain Injury Association of Florida

(850) 410-0103; (800) 992-3442

<http://www.biaf.org>

Cerebral Palsy

CP Family Network

<http://cpfamilynetwork.org/>

The Friendship Circle

Resources to Know About:

<http://www.friendshipcircle.org/blog/2013/11/06/20-cerebral-palsy-resources-you-should-know-about/>

[blog/2013/11/06/20-cerebral-palsy-resources-you-should-know-about/](http://www.friendshipcircle.org/blog/2013/11/06/20-cerebral-palsy-resources-you-should-know-about/)

My Child at Cerebral Palsy

<http://www.cerebralpalsy.org/>

United Cerebral Palsy

Search for Local Affiliate:

<http://ucp.org/findaffiliate/>

Challenging Behaviors

Positive Behavioral Interventions and Supports

University of South Florida
Department of Child and Family
Studies Florida Mental Health
Institute

(813) 974-6440

<http://flpbs.fmhi.usf.edu/>

Down Syndrome

Global Down Syndrome Foundation

<http://www.globaldownsyndrome.org/about-down-syndrome/resources/local-organizations/florida-down-syndrome-organizations/>

[org/about-down-syndrome/resources/local-organizations/florida-down-syndrome-organizations/](http://www.globaldownsyndrome.org/about-down-syndrome/resources/local-organizations/florida-down-syndrome-organizations/)

Epilepsy

Epilepsy Foundation Florida

(305) 670-4949; (877) 553-7456

<http://www.efof.org>

Florida Department of Health Epilepsy Services Program

(850) 245-4330

cdprevention@fhealth.gov

Contact information for regional
Epilepsy Associations in Florida:

<http://www.floridahealth.gov/diseases-and-conditions/epilepsy/service-providers.html>

Learning Disabilities

Learning Disabilities Association of Florida

(561) 247-0221; (561) 361-7495

<http://www.lda-florida.org/>

Mental Health

NAMI Florida Center for Child and Adolescent Resources

(850) 671-4445

info@namiflorida.org

<http://www.namiflorida.org/children-and-families.php>

Florida Association for Infant Mental Health

<http://faimh.org/>

Intellectual Disabilities and Related Developmental Disabilities

The Arc of Florida

(850) 226-1155

<http://www.arcflorida.org>

Prader-Willi

Florida Chapter of the Prader-Willi Syndrome Association

(850) 245-6484

www.pwfa.org

Speech and Hearing

Florida Association of Speech-Language Pathologists and Audiologists

(800) 243-3574

flasha@flasha.org

<http://www.flasha.org>

Spina Bifida

Spina Bifida Association of Central Florida

(407) 248-9210

<http://www.sbacentralflorida.org/>

Spina Bifida Association of Florida of Jacksonville, Inc.

(904) 697-3686; (904) 697-3914

<http://www.spinabifidajax.org/>

Spina Bifida of South Florida

info@sbofsf.org

<http://www.sbofsf.org>

Transition

Florida's Transition Project - For Transition from Part C to Part B Services

(352) 372-2485

<http://www.floridatransitionproject.com>

Project 10

(727) 873-4654

project10@stpete.usf.edu

<http://project10.info/>

Contact information for Project10 regional representatives:

<http://project10.info/Contact.php>

Program brochure:

http://project10.info/files/pro10-brochure2015_9.30.15.pdf

University of Central Florida Technical Assistance and Training System (TATS)

(407) 823-3058

tats@mail.ucf.edu

<http://www.tats.ucf.edu/>

State Parent Organizations

Family Café

(850) 224-4670

<http://www.familycafe.net/>

Family Care Council Florida

(800) 470-8101

<http://www.fccflorida.org>

Family Network on Disabilities

(727) 523-1130; (800) 825-5736

<http://www.fndusa.org>

Parent to Parent of Miami, Inc.

(305) 271-9797

info@ptopmiami.org

<http://www.ptopmiami.org>

Florida Parent Teacher**Association (PTA)**

(407) 855-7604; (800) 373-5782

info@floridapta.org

<http://www.floridapta.org/>

Area and local PTAs Locator:

<http://www.floridapta.org/contact-us/area-pta-links>

Independent Living**Florida Association for Centers of Independent Living, Inc.**

<http://www.floridacils.org/>

Center for Independent Living

locator: [http://www.floridacils.org/](http://www.floridacils.org/LocateYourLocalCIL.html)

[LocateYourLocalCIL.html](http://www.floridacils.org/LocateYourLocalCIL.html)

Florida Independent Living Council

(877) 822-1993;

(850) 488-5624 (V/ TTY)

<http://ilcflorida.org/>

Independent Living Research Utilization Program

(713) 520-0232 (V/TTY)

ilru@ilru.org

<http://www.ilru.org>

Research and Training Center on Independent Living

(785) 864-4095 (V);

(785) 864-0706 (TTY)

RTCIL@ku.edu

<http://www rtcil.org>

National Council on Independent Living

(877) 525-3400 (V);

(202) 207-0340 (TDD)

ncil@ncil.org

<http://www.ncil.org>

Legal Assistance**Advocacy Center for Persons with Disabilities, Inc.**

(800) 342-0823 (V);

(800) 346-4127 (TTD)

http://www.flspedlaw.com/Advocacy_Cntr.html

The Florida Bar

(850) 561-5600

<http://www.floridabar.org>

Pro Bono Directory of Low-Cost and Free Legal Assistance:

<http://www.floridabar.org/tfb/>

[TFBConsum.nsf/840090C16EEDAF0085256B61000928DC/](http://www.floridabar.org/tfb/TFBConsum.nsf/840090C16EEDAF0085256B61000928DC/A99E4C9F07844AC385256FF90073D012)

[A99E4C9F07844AC](http://www.floridabar.org/tfb/TFBConsum.nsf/840090C16EEDAF0085256B61000928DC/A99E4C9F07844AC385256FF90073D012)

[385256FF90073D012](http://www.floridabar.org/tfb/TFBConsum.nsf/840090C16EEDAF0085256B61000928DC/A99E4C9F07844AC385256FF90073D012)

Florida Statewide Advocacy Council

(800) 342-0825

Page with Council Information:

<http://apd.myflorida.com/selfadvocacy/>

Other Organizations and Resources

Best Buddies Florida

<https://bestbuddies.org/find-programs/florida/>

Care.com

Local caregiver search:

<http://www.care.com/specialneeds-care-p1087-q18890605.html?null&qs=1>

Child Care Provider Search

<http://www.myflfamilies.com/service-programs/child-care/parent-resources>

Florida Department of Children and Families Child Care Website

<http://www.myflfamilies.com/service-programs/child-care>

Easter Seals Florida

(407) 306-9766

<http://www.fl.easterseals.com>

Regional Florida Easter Seals contact information:

<http://www.easterseals.com/connect-locally/?state=FL>

Florida Association of Rehabilitation Facilities, Inc.

(850) 877-4816

info@floridaarf.org

<http://www.floridaarf.org>

Family Café - Florida Youth Council

The Florida Youth Council is a group of youth (age 15-17) and emerging leaders (age 18-30) with disabilities or special health care needs that live in Florida.

http://www.familycafe.net/index.php?option=com_content&view=category&id=44&Itemid=55

Sexuality Education for Children and Adolescents with Developmental Disabilities: A Manual for Parents and Caregivers

https://www.autismspeaks.org/docs/family_services_docs/parentworkbook.pdf

Florida Head Start State Collaboration Office

Local Early Head Start and Preschool Head Start directory:

<http://www.floridaheadstart.org>

Florida State University Florida Inclusion Network (FIN)

<http://www.floridainclusionnetwork.com/>

Regional FIN contact information:

<http://www.floridainclusionnetwork.com/meet-the-fin/>

Humana Military (Florida TRICARE Service Provider)

(800) 444-5445

www.HumanaMilitary.com

South Florida Parent Center

<http://www.sfptic.org/>

Transportation Safety Administration (TSA)
<https://www.tsa.gov/travel/special-procedures>

Advocacy

U.S. Department of Justice Civil Rights Division Americans with Disabilities Act (ADA)
(800) 514-0301 (V);
(800) 514-0383 (TTY)
<http://www.ada.gov>

The Arc: ACA - What Disability Advocates Need to Know
<http://blog.thearc.org/2012/09/06/the-affordable-care-act-what-disability-advocates-need-to-know/>

Center for Parent Information and Resources - Parent Advocacy
<http://www.parentcenterhub.org/repository/priority-selfadvocacy/>

Disability Rights Education and Defense Fund
(510) 644-2555 (V);
(510) 841-8645 (TTY)
info@dredf.org
<http://www.dredf.org>

Florida Developmental Disabilities Council, Inc.
Building Self-Determination and Advocacy page:
<http://www.fddc.org/about/building-self-determination-and-advocacy>

National Disability Rights Network
<http://www.ndrn.org/index.php>

TASH (formerly the Association for Persons with Severe Handicaps)
(202) 540-9020
info@tash.org
<http://www.tash.org>

U.S. Equal Employment Opportunity Commission
Publications: (202) 663-4191
Questions: (202) 663-4900 (V);
(202) 663-494 (TTY)
<http://www.eeoc.gov>

Wrightslaw
<http://www.wrightslaw.com>
Parent Rights:
<http://www.wrightslaw.com/info/protections.index.htm>

Assistive Technology/Devices
Rehabilitation Engineering and Assistive Technology Society of North America (RESNA)
(703) 524-6686 (V);
(703) 524-6639 (TTY)
<http://www.resna.org>

Alliance for Technology Access (ATA)
(800) 914-3017;
(731) 554-5282 (V);
(731) 554-5284 (TTY)
atainfo@atacces.org
<http://www.icdri.org/community/ata.htm>

AbleNet, Inc.
(800) 322-0956 (V)
<http://www.ablenetinc.com>

**United States Society for
Augmentative and Alternative
Communication**
(215) 631-1877
info@ussaac.org
<http://www.ussaac.org>

Blindness/Visual Impairments

Learning Ally
(800) 221-4792
<https://www.learningally.org>

American Council of the Blind
(800) 424-8666; (202) 467-5081
info@acb.org
<http://www.acb.org>

**American Printing House for the
Blind, Inc.**
(800) 223-1839 (V)
info@aph.org
<http://www.aph.org>

Lighthouse International
(800) 284-4422
info@lighthouseguild.org
<http://www.lighthouse.org>

**National Association of Parents
of the Visually Impaired -
Lighthouse International**
(212) 769-7819
napvi@lighthouseguild.org
<http://www.napvi.org>

National Federation of the Blind
(410) 659-9314 (V)
<http://www.nfb.org>

Prevent Blindness America
(800) 331-2020 (V)
<http://www.preventblindness.org>

Challenging Behaviors

**Autism Speaks Challenging
Behavior Toolkit**
<https://www.autismspeaks.org/family-services/tool-kits/challenging-behaviors-tool-kit>

**U.S. Office of Special Education
Programs National Technical
Assistance Center on Positive
Behavioral Intervention and
Supports (PBIS)**
<http://www.pbis.org>

Child Abuse

Florida Child Abuse Hotline
(800) 962-2873; (800) 453-5145
(TTY)

National Child Abuse Hotline
Hotline: (800) 422-4453
(800 4-A-CHILD)
<http://www.childhelp.org/hotline/>

Parents Anonymous, Inc.
(909) 621-6184
<http://www.parentsanonymous.org>

Prevent Child Abuse America
(312) 663-3520; (800) 244-5373
(information and referral)
<http://www.preventchildabuse.org>

Cognitive Disabilities

American Association on Intellectual and Developmental Disabilities

(202) 387-1968
<http://aaidd.org/>

The Arc of the United States

(800) 433-5255 (V)
<http://www.thearc.org>

The Arc of Florida

(800) 226-1155
<http://www.arcflorida.org>
Map of ARC locations:
<http://www.arcflorida.org/arc-locations>

Communication Disorders

National Institutes of Health National Institute on Deafness and Other Communication Disorders

(800) 241-1044;
(800) 241-1055 (TTY)
nidcdinfo@nidcd.nih.gov
<http://www.nidcd.nih.gov>

Stuttering Foundation of America

(800) 992-9392
info@stutteringhelp.org
<http://www.stuttersfa.org>

Deafness/Hearing Impairments

ADARA (American Deafness and Rehabilitation Association)

<http://www.adara.org>

American Society for Deaf Children

(800) 942-2732
<http://www.deafchildren.org>

Better Hearing Institute

(800) 327-9355
<http://www.betterhearing.org>

Hearing Health Foundation

(212) 257-6140; (866) 454-3924
info@hhf.org
<http://hearinghealthfoundation.org/>

Gallaudet University Laurent Clerc National Deaf Education Center

(202) 651-5855 (V/TTY)
<http://clerccenter.gallaudet.edu>

John Tracy Clinic

(213) 748-5481
<http://www.jtc.org>

Listening and Spoken Language Knowledge Center

(202) 337-5220 (V)
info@agbell.org
<http://www.agbell.org/>

National Association of the Deaf (NAD)

(301) 587-1788 (V);
(301) 587-1789 (TTY)
<http://www.nad.org>

Special Education

Florida Department of Education Bureau of Exceptional Education and Student Services (BEES)

(850) 245-0475

[http://www.fldoe.org/academics/
exceptional-student-edu](http://www.fldoe.org/academics/exceptional-student-edu)

BEES contacts page:

<http://app4.fldoe.org/EESSContacts/>

BEES publications and

presentations:

[http://www.fldoe.org/academics/
exceptional-student-edu/bees-
resources/presentations-pubs/index.
stml](http://www.fldoe.org/academics/exceptional-student-edu/bees-resources/presentations-pubs/index.stml)

Florida Consortium on Inclusive Higher Education

(727) 873-4654

<http://fltpsid.info/>

Florida Diagnostic and Learning Resources System (FDLRS)

Contact information and an
extensive resource listing of
available services:

<http://www.fdlrs.org/>

Child Find:

[http://www.fdlrs.org/child-find.
html](http://www.fdlrs.org/child-find.html)

National Youth Transition Center

Information for Students and
Families Transitioning to
Postsecondary Education:

<http://heath.gwu.edu/>

U.S. Department of Health and Human Services Administration on Children, Youth and Families Office of Head Start

[http://www.acf.hhs.gov/programs/
ohs](http://www.acf.hhs.gov/programs/ohs)

U.S. Department of Education Office of Special Education Programs (OSEP)

(800) 872-5327

[http://www2.ed.gov/about/offices/
list/osep/index.html](http://www2.ed.gov/about/offices/list/osep/index.html)

Special Education Guide

[http://www.specialeducationguide.
com/](http://www.specialeducationguide.com/)

Employment

Job Accommodation Network

(800) 526-7234 (V);

(877) 781-9403 (TTY)

<http://askjan.org/>

U.S. Equal Employment Opportunity Commission

Publications: (202) 663-4191

Questions: (202) 663-4900 (V);

(202) 663-494 (TTY)

<http://www.eeoc.gov>

Financial Planning

NICHCY: Addressing Financial Concerns

[http://www.kidsource.com/
NICHCY/parenting.disab.
all.4.4.html#Addressing](http://www.kidsource.com/NICHCY/parenting.disab.all.4.4.html#Addressing)

PACER Center: Special Needs Trust

<http://www.pacer.org/publications/possibilities/saving-for-your-childs-future-needs-part1.html>

Possibilities: A Financial Resource

<http://www.pacer.org/publications/possibilities/table-of-contents.html>

Russel and Grant: Letter of Intent

<http://specialneedslegalplanning.com>

Special Needs Financial Planning

www.specialneedsplanning.com

Wrightslaw

Estate Planning:

http://wrightslaw.com/info/estate_planning.nichcy.pdf

Future Planning:

<http://www.wrightslaw.com/info/future.plan.index.htm>

Healthcare

The Catalyst Center: Information on the Affordable Care Act

<http://www.hdwg.org/catalyst/publications/aca>

CHAMPSVA

(800) 733-8387

<http://www.va.gov/health/>

Information on benefits for spouse and children:

http://www.va.gov/healthbenefits/apply/family_members.asp

Information on ACA and VA

benefits: <http://www.va.gov/health/aca/FamilyMembers.asp>

Federal Health Insurance Marketplace

<https://www.healthcare.gov/>

Search tool for local navigators:

<https://localhelp.healthcare.gov/#intro>

Information on Florida Managed Medical Assistance Plans

<http://www.flmedicaidmanagedcare.com/MMA/ProgramInformation.aspx>

Managed Medical Assistance Plans:

<http://www.flmedicaidmanagedcare.com/SelectCounty.aspx>

Medicare

<https://www.medicare.gov/>

Medicare Information: Social Security Administration

<http://www.ssa.gov/pubs/EN-05-10043.pdf>

U.S. Veterans Administration

Survivors and Dependents

Educational Assistance Program

(888) 442-4551

http://www.benefits.va.gov/gibill/survivor_dependent_assistance.asp

TRICARE

<http://www.tricare.mil/>

Hospice

Children's Hospice

International

(703) 684-0330

info@CHOnline.org

<http://www.chionline.org>

Hospicelink (Hospice Education Institute)

(207) 255-8800;
(800) 331-1620 (Hospicelink)
hospiceall@aol.com
<http://www.hospiceworld.org>

Inclusion

The Early Childhood Technical Assistance Center (ECTAC)

(919) 962-2001
ectacenter@unc.edu
<http://ectacenter.org/>
Inclusion information
<http://www.nectac.org/topics/inclusion/default.asp>

Learning Disabilities

Help Guide: Learning Disabilities

<http://www.helpguide.org/articles/learning-disabilities/helping-children-with-learning-disabilities.htm>

International Dyslexia Association

(800) 222-3123
<http://www.interdys.org>
Florida branch contact information
<http://www.idafla.org/contactus.htm>

Learning Disabilities Association of America (LDA)

(412) 341-1515
info@LDAAmerica.org
<http://www.ldanatl.org>

National Center for Learning Disabilities (NCLD)

(888) 575-7373
info@ncid.org
<http://www.ncld.org>

PBS Parents: Learning Disabilities

<http://www.pbs.org/parents/education/learning-disabilities/>

Medical Organizations

March of Dimes Birth Defects Foundation

Florida Chapter
(914) 997-4488; (407) 599-5077
<http://www.modimes.org>

Muscular Dystrophy Association (MDA)

(800) 572-1717
<http://www.mdausa.org>

National Easter Seal Society

(800) 221-6827
<http://www.easter-seals.org>

Shriners of North America: Shriners Hospitals for Children

(813) 972-2250
<http://www.shrinershq.org>
Tampa hospital which specializes in orthopedics: <http://www.shrinershospitalsforchildren.org/Locations/tampa>

Mental Health

Mental Health America

(703) 684-7722; (800) 969-6642
<http://www.nmha.org>

**National Alliance on Mental
Illness (NAMI) Florida**
(850) 671-4445
<http://www.namiflorida.org/>

***Parent and Family
Organizations and Support
Groups***

**Florida Alliance of Information
and Referral Services (FLAIRS)**
(866) 728-8445
<http://www.flairs.org>

2-1-1 Resources

Local agency search by category
of services and map of local 2-1-1
centers:
<http://www.my211florida.org/>

The Arc's National Sibling Council
(800) 433-5255
<http://www.thearc.org/siblings>

Beach Center on Disability
(785) 864-7600; (866) 783-3378
beachcenter@ku.edu
<http://www.beachcenter.org>

**Brain Child, Books for Parenting
Children with Disabilities**
[http://www.brainchildmag.
com/2015/01/top-ten-books-
for-parenting-children-with-
disabilities/](http://www.brainchildmag.com/2015/01/top-ten-books-for-parenting-children-with-disabilities/)

Bright Feats Directory
(407) 620-9355
<http://www.brightfeats.com/>

**Center for Parent Information and
Resources**
<http://www.parentcenterhub.org/>

**Center for Parent Information and
Resources (CPIR): Parent Groups**
Find local groups
[http://www.parentcenterhub.org/
repository/parentgroups/](http://www.parentcenterhub.org/repository/parentgroups/)

The Circle of Security
<http://www.circleofsecurity.net/>

Delete Stress
[http://www.deletestress.com/
stresschecklist.html](http://www.deletestress.com/stresschecklist.html)

Exceptional Parent Magazine
<http://www.eparent.com/>

Extension Parenting Resources
www.extension.org/parenting

Family Connect
Parents of children with visual
impairments:
[http://www.familyconnect.org/
parentsitehome.aspx](http://www.familyconnect.org/parentsitehome.aspx)

**Family Resource Center on
Disabilities**
(312) 939-3513
info@frcd.org
<http://frcd.org/>

Family Voices
(888) 835-5669; (505) 872-4774
<http://www.familyvoices.org>

FAST Family Support
(888) 248-0822
<http://www.fastfamilysupport.org/>

Federation of Families for Children's Mental Health

(240) 403-1901

ffcmh@ffcmh.org

<http://www.ffcmh.org>

F.R.I.E.N.D.S. (Families Raising, Inspiring, Educating and Networking for Down Syndrome)

<http://www.friendssupport.org/>

My Child Without Limits

<http://www.mychildwithoutlimits.org/?page=home>

NAEYC for Families

(202) 232-8777; (800) 424-2460

<http://families.naeyc.org/>

National Association of Parents with Children in Special Education

(800) 754-4421

contact@napcse.org

<http://www.napcse.org/>

Parents Helping Parents

(408) 727-5775

<http://www.php.com>

Parenting Special Needs Magazine

<http://parentingspecialneeds.org/>

Parent to Parent

<http://www.p2pusa.org/p2pusa/sitepages/p2p-home.aspx>

Sibling Support Project

(206) 297-6368

info@siblingsupport.org

<https://www.siblingsupport.org/>

Special Needs Book Review

<http://www.specialneedsbookreview.com/2013/01/02/top-20-books-on-parenting-or-teaching-children-with-special-needs-reviewed-by-special-needs-book-review/>

Support for Families of Children with Disabilities

(415) 282-7494; (415) 920-5040

<https://www.supportforfamilies.org/index.html>

Technical Assistance Alliance for Parent Centers

(952) 838-9000 (V);

(952) 838-0190 (TTY)

alliance@taalliance.org

<http://www.taalliance.org>

University of Delaware, Books on the Disability Experience

<http://www.nlcdd.org/resources-books-movies-disability.html>

Your Life, Your Voice

<http://www.yourlifeyourvoice.org/Pages/home.aspx>

Physical Disabilities

Centers for Disease Control and Prevention

Living with Spina Bifida - Infants:

<http://www.cdc.gov/ncbddd/spinabifida/infant.html>

Living with Spina Bifida - Toddlers:

<http://www.cdc.gov/ncbddd/spinabifida/toddler.html>

Living with Spina Bifida - School

Age: <http://www.cdc.gov/ncbddd/spinabifida/school-age.html>

Center for Parent Information and Resources: Spina Bifida

[http://www.parentcenterhub.org/
repository/spinabifida/](http://www.parentcenterhub.org/repository/spinabifida/)

National Scoliosis Foundation

(800) 673-6922

NSF@scoliosis.org

<http://www.scoliosis.org>

Spina Bifida Association

(202) 944-3285

sbaa@sbaa.org

[http://www.spinabifidaassociation.
org](http://www.spinabifidaassociation.org)

Spina Bifida Resource Center

<http://www.spinabifida.net/>

United Spinal Association

(800) 404-2898; (718) 803-3782

info@unitedspinal.org

<http://www.spinalcord.org>

Rare Disorders

Genetic Alliance, Inc.

(202) 966-5557

fo@geneticalliance.org

<http://www.geneticalliance.org>

National Organization for Rare Disorders (NORD)

(203) 744-0100

<https://www.rarediseases.org/>

Recreation

American Therapeutic Recreation Association

(601) 450-2872

<https://www.atra-online.com/>

Deliver the Dream

(954) 564-3512; (888) 687-3732

contact@deliverthedream.org

<http://www.deliverthedream.org/>

PATH (Professional Association of Therapeutic Horsemanship) International

(800) 369-7433; (303) 452-1212

<http://www.pathintl.org/>

Songs of Love Foundation

Personalized, uplifting songs, free of charge, for children and teens currently facing tough medical, physical or emotional challenges

<https://www.songslove.org/>

Special Olympics Florida

(352) 243-9356

<https://specialolympicsflorida.org>

Local program contacts:

[https://specialolympicsflorida.org/
local-programs](https://specialolympicsflorida.org/local-programs)

Special Olympics International

(202) 628-3630

info@specialolympics.org

<http://www.specialolympics.org>

Respite Care

Access to Respite Care and Help (ARCH)

(919) 490-5577

<http://www.archrespite.org>

Respite locator:

<http://archrespite.org/respitelocator>

Nathaniel's Hope - Respite and Support

<http://www.nathanielshope.org/>

Social Security Income (SSI)

Social Security Administration

(800) 772-1213;

(800) 325-0778 (TTY)

<http://www.ssa.gov>

Benefits application:

<https://www.ssa.gov/disabilityssi/>

Local office locator:

<https://secure.ssa.gov/ICON/main.jsp>

SSI Child Disability Starter Kit:

http://www.ssa.gov/disability/disability_starter_kits_child_eng.htm

Specific Disabilities and Special Health Care Needs

Alliance of Genetic Support Groups

(202) 966-5557

info@geneticalliance.org

<http://www.geneticalliance.org>

Angelman Syndrome Foundation

(800) 432-6435

<http://www.angelman.org>

Autism Speaks

(888) 288-4762

familyservices@autismspeaks.org

<http://www.autismspeaks.org>

Children and Adults with Attention-Deficit/Hyperactivity Disorder (CHADD)

(301) 306-7070; (800) 233-4050

(voicemail to request information packet)

<http://www.chadd.org>

Children's Craniofacial Association

(800) 535-3643

contactCCA@ccakids.com

<http://www.ccakids.com>

Cleft Palate Foundation

(800) 242-5338

info@cleftline.org

<http://www.cleftline.org>

Cornelia de Lange Syndrome Foundation, Inc.

(860) 676-8166; (800) 223-8355 (support line)

info@cdlsusa.org

<http://www.cdlsusa.org>

Epilepsy Foundation of America

(800) 332-1000; (866) 748-8008

(Spanish speakers)

contactus@efa.org

<http://www.epilepsyfoundation.org>

Hydrocephalus Association

(888) 598-3789; (301) 202-381

info@hydroassoc.org

<http://www.hydroassoc.org>

International Prader-Willi Syndrome Organization

<http://www.ipwso.org/>

International Rett Syndrome Association

(800) 818-7388

admin@rettsyndrome.org

<http://www.rettsyndrome.org>

National Ataxia Foundation

(763) 553-0020

naf@ataxia.org

<http://www.ataxia.org>

**National Attention Deficit
Disorder Association (ADDA)**

(484) 945-2101

<http://www.add.org>

**National Autism Center - National
Standards Project**

<http://www.nationalautismcenter.org/resources/>

**National Down Syndrome
Congress**

(800) 232-6372

info@ndsccenter.org

<http://www.ndsccenter.org>

**National Down Syndrome
Society**

(800) 221-4602 (helpline)

info@ndss.org

<http://www.ndss.org>

**National Fragile X
Foundation**

(800) 688-8765

natlfx@fragilex.org

<http://www.fragilex.org>

**National Multiple Sclerosis
Society**

(800) 344-4867

<http://www.nmss.org>

Contact Florida Chapter:

<http://www.nationalmssociety.org/Chapters?chapters=6518,6519,6520>

**National Organization on Fetal
Alcohol Syndrome (NOFAS)**

(800) 666-6327; (202) 785-4586

information@nofas.org

<http://www.nofas.org>

**National Reye's Syndrome
Foundation**

(800) 233-7393 (V)

nrsf@reyessyndrome.org

www.reyessyndrome.org

**Prader-Willi Syndrome
Association**

(800) 926-4797

info@pwsausa.org

<http://www.pwsausa.org>

**Sensory Processing Disorder
Resource Center**

<http://www.sensory-processing-disorder.com/>

**Sensory Processing
Foundation**

(303) 794-1182

<http://www.spdfoundation.net/>

**Bright Tots - Sensory Integration/
Sensory Process Disorder**

<http://www.brighttots.com/sensory-integration.html>

**Brain Balance Centers - Signs and
Symptoms of Sensory Processing
Disorder**

<http://www.brainbalancecenters.com/blog/2012/04/signs-and-symptoms-of-sensory-processing-disorder/>

**Technical Center for Social-
Emotional Intervention for Young
Children**

http://challengingbehavior.fmhi.usf.edu/do/resources/teaching_tools/ttyc.htm

Tourette Syndrome Association

(718) 224-2999

<http://www.tsa-usa.org>

Tuberous Sclerosis Alliance

(800) 225-6872; (301) 562-9890

info@tsalliance.org

<http://www.tsalliance.org/>

Therapies

**American Occupational Therapy
Association (AOTA)**

(301) 652-6611;

(800) 377-8555 (TDD)

<http://www.aota.org>

**American Physical Therapy
Association (APTA)**

(800) 999-2782 (V);

(703) 683-6748 (TDD)

<http://www.apta.org>

**American Speech-Language-
Hearing Association (ASHA)**

(800) 638-8255 (V/TTY)

<http://www.asha.org>

CECO Therapy

(407) 671-4687

info@ceco.org

<http://www.cecfl.org/>

Trauma

American Trauma Society

(800) 556-7890

info@amtrauma.org

<http://www.amtrauma.org>

Brain Injury Association

(800) 444-6443; (703) 761-0750

(information center)

<http://www.biausa.org>

***Clearinghouses and General
Resources***

Center on Human Policy

(800) 894-0826; (315) 443-3851

thechp@syr.edu

<http://thechp.syr.edu>

Child Welfare Information Center

(800) 394-3366

info@childwelfare.gov

www.childwelfare.gov

**U.S. Department of Education
Clearinghouse on Disability
Information**

(202) 245-7307;

(202) 205-5637 (TTD)

[http://www.ed.gov/about/offices/
list/osers/codi.html](http://www.ed.gov/about/offices/list/osers/codi.html)

**DOIT: National Resources for
Parents of Children and Youth
with Disabilities**

<http://www.washington.edu/>

[doit/national-resources-parents-
children-and-youth-disabilities](http://www.washington.edu/doit/national-resources-parents-children-and-youth-disabilities)

**Early Childhood Technical
Assistance Center (ECTAC)**

(919) 962-2001

ectacenter@unc.edu

<http://ectacenter.org/>

**HEATH Resource Center at the
National Youth Transitions Center**

(800) 544-3284 (V/TTY)

askHEALTH@gwu.edu

<https://heath.gwu.edu/>

**National Center on Deaf-
Blindness**

(503) 838-8754

info@nationaldb.org

www.nationaldb.org

**National Institute on Deafness and
Other Communication Disorders**

(800) 241-1044;

(800) 241-1055 (TTY)

nidcdinfo@nidcd.nih.gov

<http://www.nidcd.nih.gov>

**National Prevention Information
Network**

(800) 232-4636;

(800) 232-6348 (TTY)

NPIN-info@cdc.gov

<http://www.cdcnpin.org>

**National Rehabilitation
Information Center (NARIC)**

(800) 346-2742;

(301) 459-5984 (TTY)

naricinfo@heitechservices.com

<http://www.naric.com>

PACER Center

(952) 838-9000

<http://www.pacer.org/>

Programs page:

[http://www.pacer.org/pandr/
proglist.asp](http://www.pacer.org/pandr/proglist.asp)

**University of Kansas Department
of Special Education**

(785) 864-0685

specialduad@ku.edu

[http://specialedu.soe.ku.edu/
research](http://specialedu.soe.ku.edu/research)

Zero to Three

(202) 638-1144

www.zerotothree.org

Parent resources:

[http://www.zerotothree.org/
parenting-resources/](http://www.zerotothree.org/parenting-resources/)



Appendix A: Definitions

Definitions of the IDEA Disability categories: The IDEA provides definitions of the existing disability categories. The actual names of the categories may vary from state to state. This section includes disabilities not described elsewhere in this guide. The descriptions of the categories may differ in Florida from the federal descriptions listed here:

1. Deaf-Blindness. Deaf-blindness means simultaneous (“at the same time”) hearing and visual impairments. The combination results in communicational and educational needs that cannot be met in special education programs solely for children with deafness or for children with blindness alone.

2. Emotional Disturbance. Emotional disturbance means a condition exhibiting one or more of the following characteristics over a long period of time and to a marked degree that adversely affects a child’s educational performance:

- (a) An inability to learn that cannot be explained by intellectual, sensory or health factors
- (b) An inability to build or maintain satisfactory interpersonal relationships with peers and teachers
- (c) Inappropriate types of behavior or feelings under normal circumstances
- (d) A general pervasive mood of unhappiness or depression
- (e) A tendency to develop physical symptoms or fears associated with personal or school problems

The term “emotional disturbance” includes schizophrenia, but it does not apply to children who are socially maladjusted, unless it is determined that they have an emotional disturbance.

3. Hearing Impairment, including Deafness. Deafness means a hearing impairment so severe that a child is impaired in processing linguistic information through hearing, with or without amplification, and that adversely affects a child’s educational performance.

Hearing impairment means impairment in hearing, whether permanent or fluctuating, that adversely affects a child’s educational performance but is not included under the definition of “deafness.”

4. Multiple Disabilities. Multiple disabilities means impairments that

occur together (such as intellectual disability-blindness, intellectual disability-orthopedic impairment, etc.) so that the combination results in educational needs that cannot be met in a special education program solely for one of the impairments. The term does not include deaf-blindness.

***Note:** Florida does not recognize a category of “multiple disabilities.” Instead, Florida school districts may designate primary and secondary categories of eligibility.*

5. Orthopedic Impairment. Orthopedic impairment means a physical impairment that adversely affects a child’s educational performance. The term includes impairments caused by a congenital anomaly (e.g., clubfoot, absence of a limb, etc.), impairments caused by disease (e.g., poliomyelitis, bone tuberculosis, etc.) and impairments from other causes (e.g., cerebral palsy, amputations and fractures or burns that cause contractures).

6. Other Health Impairment. Other health impairment means having limited strength, vitality or alertness, including a heightened alertness to environmental stimuli, that results in limited alertness with respect to the educational environment, that -

- (a) is due to chronic or acute health problems such as asthma, attention deficit disorder or attention deficit hyperactivity disorder, diabetes, epilepsy, a heart condition, hemophilia, lead poisoning, leukemia, nephritis, rheumatic fever, and sickle cell anemia; and
- (b) adversely affects a child’s educational performance.

7. Specific Learning Disability. Specific learning disability means a disorder in one or more of the basic psychological processes involved in understanding or in using language, spoken or written, that may manifest itself in an impaired ability to listen, think, speak, read, write, spell or to do mathematical calculations. The term includes such conditions as perceptual disabilities, brain injury, minimal brain dysfunction, dyslexia and developmental aphasia. The term does not include learning problems that are primarily the result of visual, hearing or motor disabilities; of intellectual disability; of emotional disturbance; or of environmental, cultural or economic disadvantage.

8. Speech or Language Impairment. Speech or language impairment means a communication disorder such as stuttering, impaired articulation, a language impairment or a voice impairment that adversely affects a child’s educational performance.

9. Traumatic Brain Injury. Traumatic brain injury means an acquired injury to the brain caused by an external physical force, resulting in total or partial functional disability or psychosocial impairment, or both, that adversely affects a child's educational performance. The term applies to open or closed head injuries resulting in impairments in one or more areas, such as cognition; language; memory; attention; reasoning; abstract thinking; judgment; problem-solving; sensory, perceptual and motor abilities; psychosocial behavior; physical functions; information processing; and speech. The term does not include brain injuries that are congenital or degenerative, or brain injuries induced by birth trauma.

10. Visual Impairment Including Blindness. Visual impairment means impairment in vision that, even with correction, adversely affects a child's educational performance. The term includes both partial sight and blindness.



Appendix B:

Dictionary of Terms

A

Accommodation: A change made in teaching methods or materials to assist a child in fully taking part in the life and activities of the classroom.

Activities of Daily Living (ADL): Basic life activities such as bathing, toileting, dressing, eating, socializing, communication, mobility and so on.

Acute: Intense and of short duration, usually said of a disease or health condition. Marked by sudden onset, sharp rise and lasting a short time, demanding prompt attention.

Adaptive Equipment: Devices or additions to equipment that allow an individual to access his or her environment. Examples include wheelchairs, adaptive seating and specialized desks and tables.

Adjusted Age: Age in weeks from conception. Computed by subtracting the amount of prematurity from the infant's actual age since birth. Used with premature infants.

Advocacy: The process of actively speaking out, writing in favor of, supporting and/or acting on behalf of oneself, another person or a cause.

Advocacy can be any action to assure the best possible services for or intervention in the service system on behalf of an individual or group.

Advocate: 1. Anyone who speaks or acts on behalf of oneself, another person or a cause. 2. In relation to estate planning, a person or institution that will serve as a friend and look out for the best interests of an individual with a disability.

Age Appropriate: Activities, materials, curriculum and environment consistent with the chronological age of the child being served.

Ambulatory: Being able to move from place to place with or without assistive devices.

Amendment: A change, revision or addition made to a law.

Americans with Disabilities Act (ADA): Federal legislation that gives civil rights protections to individuals with disabilities. Enacted into law July 1990.

Amniocentesis: A prenatal assessment of a fetus which involves analysis of amniotic fluid.

Amnioscopy: A prenatal diagnostic procedure in which the fetus is seen by use of a fibro optic light.

Amniotic Fluid: Fluid that surrounds and protects the developing fetus. This fluid is sampled through amniocentesis.

APGAR Score: An evaluation of a newborn's physical condition after birth that enables professionals to quickly identify an infant at risk. It is the sum

of ratings (0, 1 and 2) on five criteria: appearance or coloring, pulse (heart rate), grimace (responsiveness to stimuli), activity (muscle tone) and respiration. The first letter in each word combines to make the acronym APGAR. Ratings are taken at one minute and again at five minutes after birth.

Appropriate: 1. Able to meet a need; suitable or fitting. 2. In special education, often refers to as the “most normal” setting possible. An “appropriate education” refers to an individualized educational program specially designed to meet the unique needs of a child with a disability.

Articulation: The ability to make specific speech sounds: e.g., the “g” in gum, the “b” in bear, the “s” in snake.

Articulation Disorders: Difficulties with the way sounds are formed and strung together, usually characterized by substituting one sound for another (*wabbit* for rabbit), omitting a sound (han for hand), adding a sound (*galue* for glue) or distorting a sound (*shlip* for sip).

Assessment: 1. A collecting and bringing together of information about a child’s educational needs which includes the use of social, psychological and educational measurements and is designed to plan the child’s educational program. 2. The ongoing observations and monitoring of progress at various levels by qualified personnel to track the child’s unique needs, the family’s strengths and needs related to development of the child and the nature and extent of the services needed by the child and the child’s family to best support the development of the child.

Assistive Device: Any item, piece of equipment or product system, whether acquired commercially, modified or customized, that is used to increase, maintain or improve functional capabilities of a person with a disability. Examples include visual alerting systems for a person with a hearing impairment or a Braille printer for a person who is blind.

Assistive Technology: The systematic application of technology, engineering methodologies or scientific principles to meet the needs of, and address the barriers confronted by persons with disabilities in areas including education, employment, supported employment, transportation, independent living and other aspects of daily life. The term includes assistive technology devices and assistive technology services.

At Risk: A term used with children who have or could have intellectual or developmental disorders that may affect later learning.

Attending Behavior: The ability to pay attention to a task. Attending behavior includes alertness, stimulus selection, focusing and vigilance.

Attention: The ability to focus on relevant information, screen out distractions or stay on task.

Audiogram: A graph on which the results of a person’s hearing test are recorded. Usually performed by an audiologist using an instrument called an audiometer.

Audiologist: A professional educated in the study of normal and impaired hearing. The audiologist determines if a person has a hearing impairment, what type of impairment it is and how the individual can make the best use of remaining hearing. If a person will benefit from using a hearing aid or other listening device, the audiologist can assist with the selection, fitting and purchase of the most appropriate aid and with training the individual to use the aid effectively.

Audiology: 1. The science or study of hearing. 2. Detection and management of aural (hearing) factors associated with communication.

Audiometer: An electric device used to detect a person's response to sound stimuli.

Auditory Brainstem Response (ABR): A highly reliable test used when more information is needed to complete an in-depth evaluation of hearing or the auditory system, or when other methods of evaluation have not given reliable results. Most commonly used with infants and other individuals who are hard to test and can be performed while they are sleeping. Also referred to as "auditory evoked potentials measurement" or "brainstem evoked response audiometry."

Augmentative/Alternative Communication: Any approach designed to support, enhance or supplement the communication of individuals who cannot communicate verbally and independently in all situations. Use of a communication board is an example.

B

Barrier-Free Facility/Environment: A building or other structure or setting that is designed and constructed so that people with mobility disabilities (such as those using wheelchairs) can move freely throughout and access all areas and features without encountering architectural obstructions.

Behavior Management: To develop, strengthen, maintain, decrease or eliminate behaviors in a planned or systematic way. May include a behavior management plan.

Behavior Modification: A technique of changing behavior based on the theory of reinforcement. Careful observation of events preceding and following the behavior in question is made, and the environment is changed to reinforce the desired responses, thereby bringing about the desired change in behavior.

Behavioral Intervention: Making accommodations in the child's environment that include positive behavioral supports or a behavior management system. May include use of predictable routines, clear rules, consistent enforcement and regular consultation and review.

C

Caregivers: Any persons who have input into the care of the child, such as a babysitter, extended family, child care personnel or hospital personnel (nurses, aides, etc.).

Career and Technical Education: Organized instruction which is designed to prepare individuals for employment in a specific occupation or group of closely related jobs in an occupational field, and which is especially and particularly suited to the needs of those individuals. Also referred to as “vocational education”.

Case History: Information gathered, typically from a care provider or parent, regarding a child’s developmental, medical and family history.

Case Management: 1. A service that assists persons to obtain and coordinate community resources such as income assistance, education, housing, medical care, treatment, vocational preparation and recreation. 2. The planning, implementation and monitoring of a person’s program from diagnosis through treatment. 3. Also referred to as “service coordination.”

Case Management Activities: 1. The activities carried out by a service coordinator to assist and enable a child and family to receive the rights, procedural safeguards and services that are authorized to be provided. 2. Activities to establish a long-term process for coordinating the range of assistance needed by persons with disabilities and their families that are designed to ensure accessibility, continuity of supports and services and the ability of persons with disabilities to achieve maximum independence, productivity and inclusion in the community.

Case Manager: An individual who assists and coordinates the evaluation and treatment services for individuals and families. Also referred to as a “service coordinator.”

Child Development Associate (CDA): A competency-based training and certification program for child care personnel.

Child Find: A publicly-funded program under the Individuals with Disabilities Education Act of 1990 (IDEA) designed to locate, identify and evaluate young children with potential developmental delays or disabilities. Directed by the Department of Education in each state. May include public education about the importance of child development and parenting techniques.

Child Protective Services (CPS): State or county agency responsible for addressing issues of child abuse and neglect. In Florida, the Department of Children and Families is responsible for Protective Services for children.

Chorionic Villus Sampling (CVS): A prenatal assessment of a fetus which involves analysis of a small sample of the placenta.

Chromosomal Abnormalities: Defects or damage in the chromosomes of an individual.

Chromosomes: Threadlike materials within each cell that carry the genes of that individual. These play a central role in tissue development and inherited characteristics.

Chronic: Marked by long duration or frequent recurrence of a disease or health condition.

Chronological Age: Age of a child in years, months and days since birth.

Civil Rights: With regard to education, the rights of a citizen of the United States that deal with protections related to due process, informed consent, appeal, petition for change, equal protection under the law, educational services, equal opportunity and opportunities in the least restrictive setting.

Cognitive: A term that describes mental processes such as remembering, reasoning, understanding, problem-solving, evaluating and using judgment.

Cognitive development: The development of skills necessary for understanding and organizing the world, including such perceptual and conceptual skills such as discrimination, memory, sequencing, concept formation, generalization, reasoning and problem-solving.

Communication: The process of transmitting or receiving thoughts or messages from one person to another in a way that both understand, using facial expressions, body language, gestures, sign language, speech pictures, written words, etc.

Communication Disorders: Difficulties of speech, language or hearing that interfere with effective communication.

Community Supports: Providing activities, services and other assistance to persons with disabilities, their families and their communities which are designed to: (a) assist neighborhoods and communities to be more responsive to the needs of persons with disabilities, (b) develop local networks which can provide informal support and (c) make communities accessible and enable communities to offer their resources and opportunities to persons with disabilities and their families. Community supports include community education, personal assistance services, vehicular and home modifications, support at work and transportation services.

Comprehensive Transition Program (CTP): Federal financial aid available to students with intellectual disabilities, including Pell, work study and SEOG (Supplemental Education Opportunity Grant), for postsecondary institutions that have been approved by the U.S. Department of Education.

Confidentiality: The process of protecting private information and notifying involved persons for permission prior to the sharing of information.

Congenital: Present at birth. A condition or disease existing at birth.

Continuum of Placements: A range of educational settings available, as appropriate, for children with disabilities, including such options as regular

classrooms, regular classrooms with itinerant or resource teachers, special classes, home instruction and instruction in hospital or residential institutions.

Crisis: A turning point in the course of one's life; a decisive or crucial time; a difficult stage or event.

Crisis intervention: Short-term therapy or counseling with individuals, families, groups, communities and/or organizations that have experienced a substantial loss or change.

D

Delayed Language: A language disorder in which there is a noticeable slowness in the development of the vocabulary and grammar necessary for expressing and understanding thoughts and ideas.

Delayed Speech: Failure of speech to develop at the expected age. A deficit in the use of speech so that the child performs below age-level expectations, as a younger child would be expected to perform.

Development: Growing both physically and mentally. Having to do with the steps or stages in growth and development before the age of 18.

Developmental Age (DA): The age score a child receives based on actual performance within a specific developmental area as compared to the chronological age.

Developmental Assessment: Standardized tests that are intended to document the emergence of a sequence of behaviors, skills or abilities over a period of time.

Developmental Delay: When a child's development progresses at a slower rate than the development of most children.

Developmental Disability (DD): 1. A physical or mental impairment originating before the age of 18 which may be expected to continue indefinitely and to result in substantial limitations to major life activities (see Chapter 3). 2. When applied to children birth to age five inclusive, it refers to substantial developmental delays or specific congenital or acquired conditions with a high probability of resulting in developmental disabilities if services are not provided.

Developmental Domains: Areas of child development that refer to different types of skills, such as gross motor development, fine motor development, social development, language development and so on.

Developmental History: The developmental progress of a child over time with regard to such skills as sitting, walking and talking during the period from birth to 18 years.

Developmental Milestones: Specific skills or tasks that most children can do within a certain age range, such as sitting up, crawling, walking, saying a

first word, etc. Stages of growth that are sequential in order and expected to occur by a certain age as a sign of typical maturation.

Developmental Period: The time between conception and 18 years of age, during which physical and mental growth occur.

Developmental Screening: The process used to determine if a child may have a developmental delay and be in need of further evaluation.

Developmental Tests: Standardized tests that measure a child's development as it compares to the development of all other children at that age.

Developmentally Appropriate Practice (DAP): Instructional practices that are appropriate for the age of the children within the group and is implemented with attention to the different needs and developmental levels of those individual children.

Diagnosis: 1. Identifying the nature or cause of a physical or mental disorder by looking at its symptoms. 2. The process of identifying specific mental or physical disorders.

Disability: A physical or mental impairment which substantially limits one or more major life activities. The preferred term instead of "handicap" when referring to a physical or mental impairment of an individual. A "disability" refers to the actual impairment of the body. A "disability" only becomes a "handicap" when it prevents the individual from performing certain skills or tasks or when others assume that the individual cannot perform these skills because of the disability.

Discrimination: Any action which limits or denies a person or a group of persons opportunities, privileges, roles or rewards on the basis of their sex, age, race, disability, sexual orientation, national origin, religious affiliation, or other protected class under federal, state or local law.

DOE: Department of Education.

Due Process: A legal term referring to actions that protect a person's rights under the law; in special education, this applies to actions taken to protect the educational rights of children with disabilities.

Due Process Hearing: A formal legal proceeding presided over by an impartial public official who listens to both sides of the dispute and renders a decision based upon the law.

E

Early Childhood Specialist: An individual who specializes in early childhood development, usually having a Master's degree or Ph.D. in an area related to early childhood education or child development.

Early Childhood Teacher: An individual trained in child development

Early Childhood Special Education Teacher: An individual trained in child development and the education of young children with disabilities.

Early Interventionist: An individual who provides early intervention services to young children (birth-two years) with disabilities and their families with the intent of enhancing the developmental outcomes of children.

Early Intervention Programs or Services: Programs or services designed to meet the developmental needs of eligible infants and toddlers and their families under Part C of the IDEA and also to meet the needs of the family as they relate to the child's development.

Early and Periodic Screening, Diagnosis and Treatment Program (EPS-DT): A program within the Medicaid Program for children under 21 years of age which promotes prevention and/or early detection and treatment of special health care needs and conditions through periodic health screening.

Echolalia: The repetition or imitation of words or phrases spoken by others that tends to be ongoing and persistent and is used without any apparent communication value.

Educationally Relevant: Generally applies to physical and occupational therapy; even though therapy may be medically necessary, school-based therapy services may not be considered educationally necessary unless needed to help the child benefit from his or her educational program.

Empowerment: The interaction of professionals with families in such a way that families maintain or acquire a sense of control over their lives and attribute positive changes that result from early intervention to their own strengths, abilities and actions.

Environment: The world around an individual.

Environmentally at Risk: Early life events associated with less than optimal development outcomes (e.g., poor nutrition, low social support or high levels of family/parental stress).

Equal Access: 1. The elimination of barriers that prohibit a child with a disability from participating in activities typically engaged in by other children. 2. In general, providing the same opportunities for persons with disabilities to have the same access to schools, work environments and community facilities as the general population.

Established Condition: A physical or mental condition of a child that has a high probability of resulting in a disability or developmental delay.

Evaluation: A way of collecting information about a child's learning needs, strengths and abilities which includes testing, observations and parental input and is designed to determine the child's eligibility for early intervention or special education programs and services.

Exceptional Student Education: The term used in Florida to refer to special education programs and services for children with disabilities or children who are gifted and/or talented.

Expressive Language: The ideas, concepts and feelings a child is able to

share through speech, signing, gestures, etc.

Expressive Language Skills: Skills required to produce language for communication with other individuals. Speaking, signing and writing are expressive language skills.

Extended School Year (ESY): Refers to school programs for children with disabilities that extend beyond 180 days. The IEP team must consider every child's need for extended school year services (during the summer months) as part of the IEP process.

Eye Contact: Looking someone "in the eye" while talking to this person. Generally a natural, although not a constant, interaction of the speaker's eyes with those of the listener. May vary according to a person's cultural background.

F

Facilitate: 1. To make easy or easier. 2. To assist someone in a task or process.

Family Centered/Focused Model: Providing intervention services for children with special needs within the context of the family for the purpose of enhancing the child's developmental outcomes. Recognizes that the family is the foundation of a child's life and that service systems and personnel must support, respect, encourage and enhance the strength and competence of the family.

Family Counseling: Support to families in responding to the impact of a family member with special needs on the family's activities and ability to function.

Family Needs: Refers to various family necessities, such as basic resources, specialized child care, personal and family concerns, financial and medical resources, education, meal preparation, financial budgeting and household support.

Family Resources: 1. Refers to family wealth, assets, available money or property 2. Also refers to the family's strengths, knowledge, contacts, abilities, etc. (things without intrinsic/market value).

Family Strengths: Characteristics that family members identify as contributing to the growth and development of the child and family, such as good coping strategies, nurturing relationships, open communication, religious or personal beliefs, family competence and family/community interconnectedness.

Family Support Programs/Services: Services, supports and other assistance to families in providing care for their children or adult members with developmental disabilities so they can remain in the home. These services are designed to (a) strengthen the family's role as primary caregiver, (b)

prevent inappropriate out-of-home placement and maintain family unity and/or (c) reunite families with members who have been placed out of the home. Services may include respite care, assistive technology, personal assistance, parent training and counseling, support for elderly parents, vehicular and home modifications and assistance with extraordinary expenses associated with the needs of the person with a disability.

Family Support Plan: see “Individualized Family Service Plan.”

Family Systems: The family as a unique, interactive social system whose characteristics reflect the region, economic status, ethnicity and individual features of its members.

Family Therapy: A therapeutic technique in which family members participate together in order to improve family communication and create more satisfying interactions and relationships.

Fine Motor: The use of small muscle groups for controlled movements, particularly in object manipulation. Includes movements of the hands, how we hold onto things, movement of the fingers for reaching and grasping, etc.

Florida Center for Students with Unique Abilities (FCSUA): A center at the University of Central Florida intended to provide financial support so that students with intellectual disabilities have opportunities for inclusive on-campus experiences and employment opportunities through degree, certificate, or non-degree programs. Support includes scholarships for students and startup and enhancement grants for programs. Center also responsible for establishing statewide coordination of dissemination of information regarding programs and services for students with disabilities.

Florida Postsecondary Comprehensive Transition Program (FPCTP): A designation by the Florida Center for Students with Unique Abilities for postsecondary programs designed to meet the needs of students with intellectual disabilities as provided for by Florida law. This designation enables students attending these programs to apply for state scholarships to attend these programs.

Free Appropriate Public Education (FAPE): A key requirement of federal legislation (Public Law 94-142 and its amendments) which requires that special education and related services are provided to all eligible children and meet the following requirements: (a) provided at public expense, under public supervision and direction and without charge; (b) meet the standards of the state board of education and the laws pertaining thereto; (c) include preschool, kindergarten, elementary school and secondary school education; and (d) provided in conformity with an individual educational program (IEP) designed to address the unique needs of each child and each child’s need for interaction with typical peers.

Functional: Represents a skill that is necessary for success in daily activities, now or in the future. See also “activities of daily living.”

Functional Academic Curriculum: Curriculum that teaches academic material (reading, math, etc.) with content that is most relevant and necessary for a child’s daily living activities. See also “functional life/compensatory curriculum.”

Functional Age: An individual’s level of ability to perform various tasks relative to the average age of others who can perform the same tasks.

G

Generalization: The ability to apply a set of skills or knowledge learned under one set of conditions to other conditions or environments.

Genes: The parts of the chromosome that direct the way in which body tissue develops, from the formation of all body parts to the color of the hair.

Genetic Counseling: A process of giving parents the information they need to make decisions regarding the medical treatment of their children and the possibility of having additional children with disabilities. Often done when there is reason to believe a genetic abnormality may be present.

Genetic Screening: Testing of a group of people to identify those at risk for a specific genetic disorder or at risk for transmitting a disorder to their children.

Gestational Age: The estimated age of a fetus expressed in weeks, calculated from the first day of the last normal menstrual period.

Gross Motor: Movement that involves balance, coordination and large muscle activity as required in rolling over, sitting, walking, running, skipping, climbing, jumping and other physical activities.

H

Handicap: A limitation imposed on an individual by the environment or by society and the person’s capacity to manage that limitation. See also “disability.”

Home-Based Services: When a teacher, early interventionist or therapist goes to individual homes (or other comfortable settings, e.g., child care center) on a regular basis to provide a needed service to children or their family members.

Human Rights: Rights of a citizen of a country that deal with the life activities such as choice, freedom of movement, freedom of religion, access to humane living conditions, medical care, pursuit of happiness, etc.

I J K

IDEA: See “Individuals with Disabilities Education Act.”

IEP: See “Individual Educational Plan.”

IFSP: See “Individualized Family Service Plan.”

Inclusion: With regard to education, the practice of providing a child’s educational program in a regular education classroom, with the supports and accommodations needed by that child and ideally takes place at the child’s neighborhood school. “Full inclusion” occurs when children receive their entire education in the regular education setting. “Partial inclusion” occurs when children with disabilities spend part of their day in regular education while they receive instruction in special education classrooms or resource rooms for other portions of their school day.

Individual Supports: Services, supports and other assistance that enable persons with developmental disabilities to be independent, productive and integrated into their communities and that are designed to: (a) enable people to control their environment, permitting the most independent life possible, (b) prevent placement into a more restrictive living arrangement than is necessary and (c) enable people to live, learn, work and enjoy life in the community. Individual supports may include personal assistance services, assistive technology, vehicular and home modifications, support at work and transportation.

Individual Educational Plan (IEP): A written plan to identify the annual goals, objectives and special education and related services needed to meet the individual needs of a child age three through 21 with a disability. Developed by teachers, parents, the child and others as appropriate. Reviewed annually.

Individualized Family Service Plan (IFSP): A plan of intervention for a child age birth through 2 with a disability or developmental delay and his or her family, similar in content to the IEP and developed by a team of individuals involved with the child, including the family. Contains statements regarding the child’s present development level, strengths and needs; the family’s strengths and needs; major goals of the plan; a description of specific interventions and delivery systems to accomplish outcomes, statement of natural environments, dates of initiation and duration of services, dates for evaluation of the plan and a transition plan. The IFSP is known as a Family Support Plan (FSP) in Florida.

Individuals with Disabilities Education Act (IDEA): The Individuals with Disabilities Education Act, which provides grants to states and local jurisdictions to support the planning of service systems and the delivery of services to children who have or are at risk of developmental delays or disabilities. Funds are provided for infants and toddlers (birth through two years) through Part C of the IDEA, and for children three through 21 years of age through Part B.

Integration: For persons with disabilities, integration means living, learn-

ing, working and enjoying life in regular contact with citizens without disabilities in their home communities. More commonly referred to today as “inclusion.”

Intellectual Disability: Significantly sub-average general intellectual functioning existing concurrently with deficits in adaptive behavior which manifests before the age of 18 and can reasonably be expected to continue indefinitely. “Adaptive behavior” means the effectiveness or degree with which an individual meets the standards of personal independence and social responsibility expected of his or her age, cultural group, and community; and “significantly sub-average general intellectual functioning” means performance that is two or more standard deviations from the mean score on a standardized intelligence test specified in the rules of the agency (Florida law definition).

Intelligence Quotient (IQ): A score obtained from an intelligence test that provides a measure of mental ability in relation to age.

Interdisciplinary Team: Individuals involved in assessment and recommendations for persons with disabilities. Team consists of persons from a wide variety of disciplines including, but not limited to, medical experts, educators, speech-language pathologists, occupational therapists, rehabilitation engineers, care providers, psychologist, counselors and social workers. Team members may not necessarily work together.

Intervention: Action taken to correct, remediate or prevent identified or potential medical or developmental delays or disorders.

L

Language Delay: A term used when a child’s rate of language development is proceeding more slowly than expected for his or her age.

Language Development: Growth of expressive and receptive communication. Also includes the development of skills related to understanding and production of language.

Language Disorder: A term used when the quality and sequence of language development is significantly disrupted.

Least Restrictive Environment (LRE): 1. An educational setting or program that provides a child with disabilities with the chance to learn and progress to the best of his or her ability. Also provides the child with as much interaction as possible with children without disabilities, while meeting all the child’s learning needs and physical requirements. 2. As defined in special education legislation: A learning environment for a child in need of special education and/or related services that includes to the maximum extent appropriate children who are not in need of special education or special education and related services, as determined through the child’s

individual educational program.

Legal Rights: Rights which are given to citizens of a country because of specific laws which have been passed so that their human and civil rights can be protected.

Limited English Proficiency: Refers to individuals for whom English is their second language and, as a result, who have sufficient difficulty speaking, reading, writing or understanding the English language as to deny them the opportunity to learn successfully in classrooms where the language of instruction is English or to participate fully in everyday life.

Local Education Agency (LEA): A school district, board of education or other public authority under the supervision of a state educational agency having administrative control and direction of public elementary or secondary schools in a city, county, township, school district or political subdivision in a state.

M

Mainstream: The regular education setting, where children without disabilities receive their education. To “mainstream” a child is to place him or her in a regular education class rather than in a self-contained special class. See also “mainstreaming.”

Mainstreaming: The process of including children with disabilities in regular educational or other community programs. Term has largely been replaced by the term “inclusion.”

Major Life Activities: Functions such as caring for one’s self, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning and working.

Manipulation: How a person uses his or her hands with objects, such as writing or drawing with a crayon.

Manipulatives: Toys that children play with using their hands.

Manual Communication: Use of sign language and fingerspelling as the primary mode of communication, with or without use of oral/aural communication, by deaf and hearing impaired individuals.

Medically Necessary: The frequency, extent and types of services or supplies that represent appropriate medical care and are generally accepted by qualified professionals as reasonable and adequate for the diagnosis and treatment of illness, injury or maternity and well-baby care.

Mental Age: A child’s age equivalent score on tests of mental ability. See also “developmental age.”

Motor: Movement of muscles and joints.

Motor Development/Skills: The skills and performance of patterns related to the development and use of muscles or limbs.

Multidisciplinary Evaluation/Assessment (MDE): An evaluation of a child's strengths and weaknesses from a variety of professional points of view using a number of different sources of information and involving the child's parents.

Multidisciplinary: A team approach in which specialists from more than one discipline (such as educators, psychologists, physicians, therapists and others) work together and share information in order to evaluate, assess and develop educational plans for children who are referred for evaluation. Team members work together, usually on an ongoing basis.

N

Natural Environment: An environment where individuals with disabilities would live, work and play if they did not have a disability.

Natural Learning: Places where children experience everyday, typically occurring learning opportunities that promote behavioral and developmental growth.

Neonatal Intensive Care Unit (NICU): A special unit of a hospital providing advanced technology and trained healthcare professionals for infants in distress.

Noncompliant/Noncompliance: Not following directions or rules. Refers to children who exhibit troublesome or challenging behaviors.

Normal: A general term applied to behavior or abilities that fall within the average or typical range of human development.

Normalization Principle: 1. Making an individual's life and surroundings as culturally normal as possible. 2. The principle that children and families should have access to services provided in as usual a fashion and environment as possible, to help children and families become or remain part of their community.

O

Objectives: Small steps taken to meet goals.

Occupational Therapist (OT): A person who practices occupational therapy and who may be licensed, registered, certified or otherwise regulated by law.

Occupational Therapy (OT): Therapy designed to develop adaptive or physical skills to aid in daily living and improve interactions with a person's physical and social world. Focuses on developing functional skills related to sensory-motor integration, coordination of movement, fine motor skills, self-help skills (dressing, self-feeding, etc.), adaptive devices/equipment, computer keyboarding, body positioning for school or work and potential work-related activities.

Orientation: Awareness of where one is in relation to time, place and person.

Orientation and Mobility (O and M): Refers to training for persons who are blind/visually impaired that helps to familiarize them with their surroundings and enables them to travel safely and independently throughout the environment.

Orientation and Mobility Specialist: An individual trained to teach travel concepts and techniques to persons who are blind or visually impaired.

Orthosis/Orthotics: An orthopedic appliance used to support, align, prevent or correct deformities or to improve the functioning of movable parts of the body. Common orthoses for children are “AFOs,” or ankle-foot orthoses.

P Q

Peer Buddy/Tutor: A peer who helps a child with a disability learn or perform activities or move about through the learning environment.

People-First Language: A respectful way of talking or writing about persons with disabilities that identifies and emphasizes the “person first” and the disability as a secondary characteristic. Requires that all references about a person’s needs, disabling condition, use of specialized equipment, etc., are stated following the reference to the person. Example: instead of saying, “A crippled boy confined to a wheelchair,” say, “A boy with cerebral palsy who uses a wheelchair.”

Perception: A person’s ability to consciously recognize and interpret what is seen, heard or felt. More specifically, the process of organizing or interpreting information obtained through the senses.

Perceptual Disorders: The inability to interpret information received through one or more of the senses (despite adequate vision, hearing and other sensory processes) and to perform appropriate actions in response to that information.

Perseveration: 1. The tendency to continue an activity once it has been started and to be unable to modify or stop the activity even though it has become inappropriate. 2. Persistent repetition of words, ideas or subjects so that, once an individual begins speaking about a particular subject or uses a particular word, it continues to occur.

Physical Therapist (PT): A person who is licensed to assist in the examination, testing and treatment of persons who have physical disabilities through the use of massage, exercise, manipulation, application of heat or cold, use of sonar waves and other specialized techniques.

Physical Therapy (PT): Instructional support and treatment of physical disabilities provided by a trained physical therapist, under a doctor’s

prescription, to help a person improve the use of bones, muscles, joints and nerves. Assists in maximizing a person's general fitness, sensorimotor development, muscular and skeletal function and ability to perform daily life activities.

Pincer Grasp: Bringing together the thumb and the tip of the index finger so that a small object can be held skillfully.

Positive Behavioral Supports: A comprehensive approach to addressing challenging behaviors using a "proactive" or preventative approach based on several assumptions about the nature and function of the behaviors.

Prematurity: Underdevelopment, as in the condition of an infant born too soon. Refers to infants delivered before 37 weeks from the first day of the mother's last normal menstrual period.

Prenatal: The time before birth, when a baby is developing during pregnancy. The period of time between the conception and birth of an infant.

Present Levels of Performance: Statements in an IEP that describe what a child can do or what he or she knows.

Procedural Safeguards: 1. Laws that protect the rights of children with disabilities and their families. 2. The requirements of a law with regard to such issues as evaluation policies, parental consent, placement, due process, mediation, notification of meetings, etc.

Prognosis: A forecast or prediction as to the course or outcome of a condition or disease.

Pull-Out: A term applied to interventions (such as therapies) that remove a child with a disability from the assigned classroom to a separate area for the delivery of services for part of the school day.

R

Receptive Language Disorders: Difficulties in comprehending what others say.

Regular Classroom: The classroom and school a child with a disability would attend if he or she did not have a disability, along with the typical peers from his or her neighborhood.

Related Services: Services that are necessary for a child to benefit from special education services. May include transportation and supportive services such as speech pathology, audiology, psychological services, physical and occupational therapy, recreation, early identification and assessment, counseling, interpreters for persons with hearing impairments, medical services for diagnostic or evaluation purposes, school health services, social work services in schools and parent counseling and training.

Residential School Program: An approved, specialized educational program provided in a facility that a child attends 24 hours a day.

Residential Treatment: Live-in facilities that provide treatment and care for children with emotional/behavioral disabilities who require continuous medication and/or supervision or relief from environmental stress.

Resilience: The tendency for a child, adult or family to rebound from stressful circumstances or events and be able to resume usual activity. The power of recovery.

Resource Room: A room separate from the regular classroom in which children with disabilities can receive specialized assistance during a portion of their school day to reinforce and supplement regular classroom instruction.

Resource Teacher: A specialist who works with children with disabilities and acts as a consultant to other teachers, providing materials and methods to help children who are having difficulty within the regular classroom. May work from a centralized resource room within a school where appropriate materials are housed.

Respite: Temporary care given to an individual for the purpose of providing a period of relief to the primary caregivers. Used to decrease stress in the homes of persons with disabilities, thereby increasing caregivers' overall effectiveness, or to provide care in emergency situations.

S

Section 504: A part of the Rehabilitation Act of 1973 which states that no program or activity receiving federal funds can exclude, deny benefit to or discriminate against any person on the basis of a disability. Also requires access for persons with disabilities to all public buildings. Also known as "504."

Section 504 Plan: An individualized plan for a student with a disability who may not meet the eligibility criteria for exceptional student education (ESE) programs but who requires accommodations under Section 504 of the Rehabilitation Act of 1973 and thereby receives identification, evaluation, provision of services, parental notification and procedural safeguards.

Segregated Educational Facilities: Educational facilities that are separate from the typical placements of peers without disabilities, often termed "special schools."

Self-Esteem: A person's feelings of self-worth and value.

Self-Advocacy: Having the opportunity to know one's rights and responsibilities, stand up for them and make choices about one's own life.

Self-Care Skills/Self-Help Skills: Abilities related to personal hygiene, eating, dressing and generally taking care of oneself.

Self-Contained Special Education Classroom: A separate classroom where children with disabilities receive the majority of their school instruc-

tion, often with some opportunity to interact with their non-disabled peers during nonacademic activities and/or on the playground.

Self-Determination: The extent to which persons with developmental disabilities exert control and choice over their own lives.

Self-Fulfilling Prophecy: The philosophy that a person will tend to behave on the basis of the expectations demonstrated by those around him or her. The idea of a person becoming what he or she is labeled to be based on other people's expectations.

Sensorimotor Skills: An individual's ability to interpret information received through the senses (vision, hearing, touch) and then perform appropriate movements or motor actions in response to that information.

Sensory: Relating to the various sensory systems: tactile (touch), kinesthetic (movement), olfactory (smell), visual (sight), auditory (hearing), gustatory (taste), vestibular (balance).

Sensory Integration: Neurological processes which enable one to effectively interpret and use sensory input. Organization of the brain to make "sense" out of environmental information and coordinate it with information from the body and past experiences to produce an adequate adaptive response.

Sensory Modality: Sensory modality refers to any one of the five sensory avenues for receiving information: seeing, hearing, touching, tasting and smelling.

Shared Responsibility: Concept that regular education and special education systems both have responsibilities, as partners, for the best education of children with disabilities.

Short Attention Span: Inability to focus attention on a task for a sustained period of time, meaning more than a few seconds or minutes, depending upon the age of the child.

Sign Language: A form of manual communication in which words and concepts are represented by hand positions, finger spelling, body language and facial expressions.

Special Education Classroom: See "self-contained classroom."

Special Education: Refers to instruction specifically designed to meet the needs of children with disabilities and may include classroom instruction, home instruction and instruction in hospitals and residential facilities.

Special Education Programs/Services: Programs, services or specially designed instruction offered at no cost to families for children ages three through 21 years with special educational needs who are found eligible for these services.

Speech Therapist/Speech Pathologist: See "speech-language pathologist."

Speech-Language Pathologist (SLP): A specialist in the field of human communication, its development and its disorders, including articulation

errors; language deficits; vocabulary, pitch or voice problems; and swallowing disorders. These also devise alternative communication methods for individuals who are nonverbal.

Speech/Language Therapy: Treatment of speech, language and communication difficulties and disorders to enhance the communication ability of the individual.

Stress: Internal and external factors that interfere with a person's emotional, cognitive and social functioning.

Supported Employment (SE): Vocational training and ongoing support provided to an individual with a disability who is working competitively at a job site in the community.

Syndrome: A combination of symptoms which occur together and define a disease or disorder.

T

Telecommunication Device for the Deaf (TDD): An electronic keyboard device that sends, receives and prints typed messages over telephone lines, so that individuals with hearing and/or speech impairments can communicate over the telephone. Used interchangeably with "TTY."

Teletypewriter (TTY): A typewriter that converts typed letters into electric signals which are then sent through telephone lines and printed on another typewriter connected to a phone on the other end so that individuals with hearing and/or speech impairments can communicate over the telephone. Used interchangeably with "TDD."

Transition: The process of bridging the time and environments between two settings, programs or life situations (e.g., from home to school, school to school or from school/home to employment/independent living) to ensure a smooth change-over to the new setting.

Transition Plan: A designed program outlining the transition activities required to identify the services needed by the individual, the steps that must occur prior to the change to the new setting and the timelines and responsibilities for completion of these activities.

Transition Programs for Students with Intellectual Disabilities (TP-SID): Provides federal grants to institutions or consortia of institutions of higher education to enable them to create or expand high quality inclusive model comprehensive transition and postsecondary programs for students with intellectual disabilities. In Florida, administered by the Florida Consortium of Inclusive Higher Education at the University of Central Florida.

Typical peers: The same-aged peers of a child with a disability who are not identified as having a disability.

U V W X Y Z

Ultrasound: A prenatal evaluation procedure which employs high-frequency sound waves that are bounced through the mother's abdomen to reveal certain characteristics of the developing fetus.

Visual Acuity: The sharpness or clearness of vision.

Visual Perception: The capacity to identify, organize and interpret or give meaning to what is seen.

Vocational Education/Instruction: This term has been replaced by 'career and technical education'.

Vocational Rehabilitation Specialist: A professional who specializes in designing and implementing programs to assist persons with disabilities to obtain and hold employment.

Vocational Rehabilitation (VR): The service of providing diagnoses, guidance, training, physical restoration and placement to persons with disabilities for the purpose of preparing them for and involving them in employment that helps them to live with greater independence. Also known as "rehabilitation services."

Well-Baby Care/Well Child Care: Preventive and routine care to protect and assess the general health of children, including immunizations.

