First STEPS

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Welcome to Holland
BY EMILY PERL KINGSLEY

I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It’s like this ...

When you’re going to have a baby, it’s like planning a fabulous vacation trip - to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It’s all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, “Welcome to Holland.”

“Oh, Holland??” you say. “What do you mean Holland?? I signed up for Italy! I’m supposed to be in Italy. All my life I’ve dreamed of going to Italy.”

But there’s been a change in the flight plan. They’ve landed in Holland and there you must stay.

The important thing is that they haven’t taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It’s just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It’s just a different place. It’s slower-paced than Italy, less flashy than Italy. But after you’ve been there for a while and you catch your breath, you look around ... and you begin to notice that Holland has windmills ... and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy ... and they’re all bragging about what a wonderful time they had there. And for the rest of your life, you will say, “Yes, that’s where I was supposed to go. That’s what I had planned.”

And the pain of that will never, ever, ever, ever go away… because the loss of that dream is a very, very significant loss.

But … if you spend your life mourning the fact that you didn’t get to Italy, you may never be free to enjoy the very special, the very lovely things … about Holland.

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Do you remember how you felt when 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 a diagnosis of developmental delay or disability, you likely experienced a multitude of 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 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. In addition to 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.
GETTING A DIAGNOSIS

In one sense, the experience of receiving a diagnosis of a disability for your child is much the same for all parents. The feelings, thoughts, and reactions you have are easily understood by other parents who have gone before you. Yet the type and cause of 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-2 years)
- As a preschool-aged child (3-5 years)
- As a result of illness or injury at any age
- Upon adoption or foster placement

Identification of a disability at these various times will have many things in common, but some factors will differ; nevertheless, the diagnosis of a disability for a child at any age will have a profound emotional impact 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 the common term used in the medical field for physical abnormalities 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, ultrasound can detect many physical abnormalities of the fetus, such as spina bifida, before birth. Ultrasound can also accurately detect major abnormalities of the limbs and internal organs.

Amniocentesis and CVS (chorionic villus sampling) are other procedures used to detect prenatal defects by examining cells in the amniotic fluid that surrounds the developing fetus or cells from the placenta. Many chromosomal anomalies, such as Down syndrome, can be detected in this way. A variety of blood tests can also be used to reveal the presence of other medical conditions.

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 and to a sense of stress and urgency. Although it 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 abnormalities 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.

Even in cases when treatment is not given to the baby before birth, advance detection of the abnormality can lead to better preparation at the time of birth. As parents, you might be 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 that you faced. If you were given the option of terminating your pregnancy, you experienced the special dilemma involved in making that decision as well.
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.

**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 a result of the delivery itself, the news of a disability 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 new parents. If you have had a premature infant, a “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.

Parents who spend time with their newborn babies in the NICU experience many feelings of loss even though they know that their child is receiving the best possible care. You may have to make quick decisions about the need for one surgery or many surgeries, and you may feel like an outsider in your baby’s life. You may have wanted to breast-feed your baby and now find out that you can do so only 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 as involved in your baby’s care as possible, and allow yourself to lean on the understanding and expertise of the medical personnel in the NICU.

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 is in an incubator in the NICU, or you may be afraid to let yourself get too close to him because you are afraid he may not be with you for long. You may also experience difficulties managing all the other aspects of your life including your job, your responsibilities at home and your other children, when you feel you need to be at the hospital with your infant at all times. Today, medical staff are generally very aware of the importance of the relationship between newborn and parents and will help you work through the difficulties you are experiencing. Also, try to allow the people close to you to support you and hold you up during this difficult time.

Other non-life-threatening conditions may also be detected shortly after birth. 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 mental retardation. 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 infant hearing screening. Up to 3 or 4 in 1,000 newborns in the U.S. have significant hearing impairment. Without testing, most babies with hearing loss are not diagnosed until 2 or 3 years of age. By this time, they often have delayed speech and language development which will affect their social and academic skills as well. Detection of hearing loss in the neonatal period allows the baby to be fitted with hearing aids before 6 months of age and also receive evaluation to determine if he might be a candidate for cochlear implants. Other common screenings conducted on newborn babies include tests for sickle cell anemia and a number of disorders of metabolism.

The March of Dimes has taken the lead in advocating for newborn screening for all babies in all states. Currently, technology is available to screen for approximately 55 disorders. The March of Dimes would like to see all babies screened for 29 specific disorders for which effective treatment is available. At this time, each state sets its own standards for newborn screening tests.
With the addition of cystic fibrosis screening in July 2006, the Florida Newborn Screening Program now includes screening for all 29 disorders recommended by the March of Dimes.

**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, and most infants with even 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 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 she doesn’t seem to hear your voice, or perhaps doesn’t seem to look for your face. Perhaps your child was babbling and using words, and now, at 20 months, she stops talking.

All parents observe their children and delight in the new skills they demonstrate. When skills don’t emerge when you expect them, though, you may become worried or suspicious. Typically, you become aware of a behavior or an inability of your child that doesn’t seem quite right. *Shouldn’t he be sitting up by now? Why isn’t she 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.
You may want to start by sharing your concerns with your spouse or other family members. If they try to brush off your concerns, 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, take the next step and seek an evaluation for your child. 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 take the first step.

For other parents, it may not be you who first sees the signs of a developmental delay in your child. Your pediatrician, your friend or family member, or your child care provider may be the one who brings it to your attention. In this case, you may resist what they are telling you. You may want to deny that anything is wrong, and you may try to avoid the person 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.

Sometimes, when you finally make contact with a physician or an early childhood specialist, they will tell you that “every child is different,” and even though your child has a mild delay, that 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. 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 overconcerned. This way, if a problem is found, intervention can begin earlier.

**DIAGNOSIS AS A PRESCHOOL-AGED CHILD (3-5 YEARS)**

Most severe disabilities and special health care needs will be diagnosed before your child reaches age 3; therefore, those that are identified between the ages of 3 and 5
will tend to be more subtle. During the preschool years, referrals are generally made on the basis of cognitive delays or difficulties, learning disabilities, behavioral issues, or speech and language disorders.

You may suspect delays in your 3- to 5-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 3 or 4, but now notice that he seems to be having difficulty in some specific areas. Or a child care provider or preschool teacher may tell you that your child is not demonstrating 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 disorders of attention (inability to pay attention) make their appearance at this time. Referrals may also be made later in the elementary school years.

**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 time. Extended hospital stays and medical appointments can take precedence over all other life activities and can place a severe strain on family functioning and finances.

When a young child acquires 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.

If, for example, your child contracted viral encephalitis, he may have spent extended time in the hospital, followed by ongoing recuperation at home, with 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 recovery but also mourn the developmental delays he is experiencing. While your family is readjusting 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 are likely to run high.

A serious accident or injury to your child may also bring life-altering events into your life. 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 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.

DIAGNOSIS UPON ADOPTION OR FOSTER PLACEMENT

Many parents who adopt children are aware that the child they are about to receive 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 integrate 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 their adopted child. Perhaps you had arranged to adopt a newborn as soon as she was born, or you have sought an international adoption in which you are matched with a child without first meeting him. When you meet that newborn or young child for the first time, you will 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,” and in addition, you may feel a sense of betrayal because “this is not what I signed up for.” Just as the biological parent must give up the image of the “perfect baby,” 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 feel the same joy and positive feelings as well when your child shows progress and achievements on her own schedule.
Facing the Future
BY MATTIE STEPANEK

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.

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

Although he lived with a rare form of muscular dystrophy in his brief 13 years, Mattie Stepanek wrote hundreds of poems he called Heartsongs. His book of poems, titled Heartsongs, has become a national bestseller.
In 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 “ideal child” and readjust your plans to fit your 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 these questions is a normal reaction, and they are the type of questions we all ask ourselves when something unexpected happens in our lives. Gradually, as you begin to understand your child’s diagnosis, you will experience a wide range of emotions as you ask more and more questions and seek new information.

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, no matter how extreme they may seem. One of the first reactions is that of denial. You may say, “This cannot be happening to our family.” “I do not accept this.” “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 toward 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 or even 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. “What does this diagnosis mean?” “Will my child learn to walk? Or talk?” “Will she 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. If you have other children, you may worry about how they will be affected. “Will he be a burden for his siblings after we are gone?” If you don’t have other children, you may wonder if it’s safe to have another child. You will also worry about society’s reaction to your child. “What will people think of him? Will they be accepting?”

Guilt is another normal emotion. Mothers may think they did something wrong during pregnancy or while taking care of the child. Fathers may blame the child’s mother for doing something wrong. You may even wonder if you are being punished for something you did earlier in your life that was wrong in God’s eyes or in society’s eyes, or you may begin to question your faith.

Many parents experience confusion and anxiety in the initial stages of grief and loss. 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 might
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, and you may feel shut out, sad or disappointed in your situation. Some parents speak of depression and rejection of their child, including having a “death wish” for the child in their moments of deepest despair.

All these emotions are normal reactions to a child’s disability and, as a parent, you should feel safe in recognizing and accepting all your thoughts and feelings. These reactions all serve a purpose and you can allow yourself to experience all these feelings without remorse. You are not going “crazy,” although you may feel out of control for a time. Eventually these emotions will begin to move you toward an acceptance of your child as a unique individual with strengths and weaknesses, likes and dislikes, abilities and disabilities.

Many mental health professionals refer to acceptance as the final phase of the “grief process,” and many parents of children with disabilities can relate to the stages of shock, grief, denial, anger, and acceptance that appear in many well-known books. Other parents feel that this way of looking at grief only stresses loss and doesn’t recognize the positive aspects of having a child with special needs, whether through birth, the onset of a serious illness or condition, or a traumatic accident. Certainly these events are life-altering in their impact, but loss and sorrow are only part of what parents 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, and sometimes it’s orderly and sometimes it’s messy. For them, their feelings sometimes follow the “five stages of grief” in the textbooks and sometimes they don’t. What is important to know is that you are not alone in your feelings and, even though you may not move step-by-step through a series of stages, 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, disabled or in need of special services. When it happens, an unplanned journey begins. Like any
MANAGING YOUR FEELINGS

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.

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 family doctor or pediatrician, use the telephone directory, or conduct a computer search. In Chapter 10, you will find a list of 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 (e.g., Down Syndrome or Attention Deficit Disorder), while others do not make this distinction. A list of statewide organizations can also be found in Chapter 10.

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 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 lines 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.

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 and 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).

If you feel you need 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.

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. Nevertheless, you owe it to yourself to take care of your own health and well-being in order 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. Remember that it’s still okay to laugh and enjoy pleasurable moments in your life without feeling guilty. Remember to take 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 to 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. Fortunately, there is a wealth of information available on disabilities and disability issues. Unfortunately, there is so much information to be found that you may not know where to begin.

One place 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. On one hand, it is their responsibility to explain their terminology to you. On the other hand, though, it is important for you to learn this new language so you come to feel comfortable and capable of participating in all conversations about your child. A dictionary of terms is found in Appendix C 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 those topics in local libraries, bookstores, and through computer searches. Worthwhile suggestions for good sources of information can also come from professionals such as physicians, service coordinators, therapists, teachers, disability associations, other parents of children with disabilities, and the National Dissemination Center for Children with Disabilities (NICHCY).

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) research the problem on your own through books, articles and computer
searches; (d) trust your intuition and observations to offer up your own interpretations of your child’s disability; and (e) seek out second (and third, and fourth) 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 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, all the time nodding your head and saying “Yes! That’s just like me.” While you are gaining valuable new information, you will also be soothing your emotions. There are also a number of magazines and journals available by subscription for parents of children with disabilities, with Exceptional Parent being one of the most popular.
UNDERSTANDING DEVELOPMENTAL DISABILITIES
UNDERSTANDING DEVELOPMENTAL DISABILITIES

THE PURPOSE OF LEGAL DEFINITIONS
In order to make consistent decisions on behalf of persons with disabilities, it is necessary to have formal definitions of the categories to be used for their identification. Although most people are opposed 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 or making rules about the annual income cutoff needed to qualify for federal monetary assistance. In other words, there must be “decision rules” in place to determine whether a particular individual should be included in or excluded from any particular category. Without rules, there would be chaos, and the system could not operate.

You will note that the federal definition makes a subtle difference between children aged birth to 5 years and children 5 years and older. Children from birth to 5 years are often given a diagnosis of “developmental delay” in place of “developmental disability.”

The term “developmental disability” implies the presence of a lifelong disability. The term “developmental delay,” on the other hand, is used to refer to children who are not reaching developmental milestones at the expected times. Giving a diagnosis of developmental delay recognizes that a child has a substantial delay in the process of development, but it does not mean that the delay will necessarily be lifelong or will lead to a disability.

The distinction between the two terms is made in recognition of the fact that the development of very young children is highly changeable, treatable, and difficult to measure. For example, an impoverished, underfed, understimulated infant may show
signs of significant developmental delay at 12 months, but with proper early intervention, may “catch up” and erase the signs of delay by the time he enters kindergarten at age 5; therefore, it would be improper to diagnose him as having a developmental disability. Other children may have identifiable conditions at birth that are so severe as to leave little doubt that their delays will lead to a long-term disability; nevertheless, care should be taken by medical personnel, educational staff, and family members to not make any predictions about any one child’s potential for progress. No one has the right to make predictions on the prognosis of a very young child. We probably all know children who were never supposed

In the long run, men hit only what they aim at. Therefore, they had better aim at something high. HENRY DAVID THOREAU

FEDERAL DEFINITION OF DEVELOPMENTAL DISABILITIES

With regard to developmental disabilities, the federal government has enacted a series of legislative definitions 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):

The term developmental disability means a severe, chronic disability of an individual 5 years of age or older that:

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;
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 life-long 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.
to walk, or talk, or read, or even live, and when they do these things, they are said to be miracles. Belief in miracles aside, their progress is more likely due to our lack of good “crystal balls” 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

In Florida, Chapter 393 of the Florida Statutes 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.

The Statute continues by providing a definition of each of the conditions referenced in section (10):

**Spina bifida** means 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 characterized by impairment in social interactions and communication abilities and unusual or restricted ranges of play and interest. Autism results in social isolation and varying degrees of unusual behaviors.

*Retardation* refers to significant limitations in functioning related to below-average intelligence. People who have mental retardation learn more slowly than others and may need assistance in areas like communication, self-care, self-direction, health and safety, leisure, work, and functional academics. While the term is still clinically correct, “intellectual disability” is becoming the preferred nomenclature.

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

**Prader-Willi syndrome** is an inherited condition. A lack of muscle tone and 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 as well as mild intellectual disabilities.

**Note:** The definitions listed here are adapted from section 393.063, Florida Statutes. There are, of course, many other types of disabilities. The categories of disability recognized in the Individuals with Disabilities Education Act (IDEA) are presented in Appendix B.

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

In Florida, infants and toddlers from birth to 36 months who meet the definition of “established conditions” and/or developmental delays under the IDEA may be served through Early Steps. Early Steps is administered 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 Chapter 7. An explanation of the definitions found in the IDEA is found in Appendix B.

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

In Florida, children from 3 to 5 years can receive special education services under “Part B” of the IDEA according to categories of disabilities, including a category of developmental delay, as presented in Appendix B. Services for children with disabilities from 3 to 5 years, as well as through age 21, are administered by the Florida Department of Education and are described in greater detail in Chapter 7.

In addition, the Florida Statutes, like the federal law, also make a special provision for children from 3 to 5 years under the category of “high-risk child.” Children determined to be at “high-risk” may be eligible for certain services through the Florida Agency for Persons with Disabilities and through the school readiness services of the Office of Early Learning in the Florida Agency for Workforce Innovation.
Legal definitions serve the purpose of determining which individuals 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. 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 a frustration for many parents in the early stages of their child’s diagnosis. You may feel that it is highly important to learn the cause of the problem so you can better understand it, or so you can “fix” it. You may continue to seek a cause for many years. You may 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, 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 will allow yourself to stop.

In the end, though, 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 weaknesses 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 on your child’s present skills and abilities and what you have all agreed 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 isn’t holding the spoon. What matters are the steps and adapted tools that will be needed to help him 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. Just as children without disabilities are different from one another, it is true that each child with a disability is unique as well.

OTHER DEFINITIONS OF 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 legislation that governs their operations. For example, a disability under the Americans with Disabilities Act of 1990 (U.S. Department of Justice) differs from the definition of disability in use by the Social Security Administration. As a parent, you will need to be aware of these multiple definitions and 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 departments go more smoothly. You will also want to become familiar with the definitions in use in different agencies in Florida as well as in the county school district in which you live. Florida is one of the states that recognizes the eligibility category of “developmental delay” for children ages 3 to 5.

TYPES OF DEVELOPMENTAL DISABILITIES
A list of categories of developmental disabilities with brief descriptions can be found in Appendix B.
When the Trees Sing

BY MATTIE STE PANEK

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. Stepanek. Reprinted with permission from Journey Through Heartsongs (Hyperion/VSP, 2002).
MAKING INDIVIDUAL AND FAMILY ADJUSTMENTS
BONDING, ATTACHMENT, AND ACCEPTANCE

The strength of the relationships that parents have with their children is extremely important to the development of children. The sense of trust and intimacy that develops in the first few years of life will have long-term implications for the development of self-worth and self-esteem as children grow.

Some professionals make a distinction between the terms “bonding” and “attachment.” When this distinction is made, “bonding” is usually described as the bond of affection and responsibility the parent makes with the infant that usually has its roots in pregnancy. In general terms, it refers to the parent’s early feelings for the new child. “Attachment,” by contrast, refers to the specific relationship that a child develops with a primary caregiver, which is usually a parent but may be another caregiver with whom the child spends considerable quality time. For our purposes here, let’s use the term “bonding” in a general way to refer to the mutual emotional attachment between parent and child.

The bonding process needs special consideration when your relationship is with a child who has a disability. You may have difficulty if your child requires extended separation from you or if you were not fully prepared for your role as a parent of a child with a disability. Behavioral characteristics of your child may also interfere. For example, many parents find it difficult to bond with an infant who is often jittery and inconsolable. As you try to pat and bounce and jiggle the baby, she may become more and more upset, leading you to feel like you don’t know how to take care of her or that the baby is rejecting you, and a vicious cycle is set in motion.
“Over-bonding” can also occur. You may feel so invested in your child or feel that he is so dependent on you that you become overly concerned for him and begin to put his needs before the needs of yourself and the other members of your family. Or you may feel guilt over your child’s disability and overindulge him in order to relieve these feelings. As your child grows, you may be afraid to provide appropriate discipline for him because you don’t want to tell him “no” or deny him anything.

If you feel you are having difficulty in establishing a close, secure bond with your child, consult with someone you trust. Medical personnel and early childhood specialists are attuned to the importance of parent-child bonding and can offer assistance to you.

SUPPORTING THE NEEDS OF YOUR FAMILY

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 such as holding down a job, shopping, cooking, cleaning up, and taking care of other children and aging parents. 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. This may sound like a cliché, but truly, 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 the child arrives with a disability, however, the 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 regard to your adjustment.

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 an activity 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 pressure of your child’s needs and routines. With nearly one of every two marriages resulting in divorce in the United States, we already know that families fall apart or choose to split up for many reasons, including money struggles, addictions, abuse, health, or just plain unhappiness. It is no surprise then to think that having a child with a disability can also cause families to separate or move into a state of chronic stress or crisis, but there is no clear information on the rate of divorce for families who have a child with a disability. 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. Families, like individuals, are unique, and no one can predict in advance what might happen in any given family.

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 they are unique individuals as well, each one will react differently to their new sibling. Numerous books have been written by now-adult 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 feelings of bitterness and resentment toward their parents or the brother or sister with a disability, 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 can 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, no matter how difficult that may be. It is also important to talk openly with them about their sibling’s disability, explaining it to them according to each one’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 resolving 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.

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, so they can come to think of him as a child, and not just a child with a disability. Understand that they are going to have some of the same feelings of loss and grief that you are experiencing. As you share your feelings, you can be supportive to each other. Also, 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 caretaking routines. As such, it is an essential part of the overall support you may need from time to time.

For many parents it 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 outside of your home, in a separate facility, 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) that your child may not get the same quality of care you can give, (b) that some things, such as medications, may be forgotten, or (c) that 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 report it to be a liberating experience.

Another reason to consider using respite care is to have an established system in place in case an emergency arises. If an emergency causes you to have to be away from your child and 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 ARC agencies, Easter Seals, or United Cerebral Palsy. It can be provided by local organizations such as churches, 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. Often in Florida, there is not enough care available to meet the demand for services.

Services are furnished in many ways, depending on the provider, 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 the family’s 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 disabilities. Family income may also be considered.

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. The Florida Respite Coalition (with headquarters in Winter Park, FL) maintains a directory of registered respite care providers in the state. You can contact this agency to locate providers in your community. Contact informa-
tion for the Coalition can be found in Chapter 10 (“State of Florida Resources, Other Organizations”). 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 health and safety standards.

**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 family well. Too often, children with special health care needs see many 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 services you can expect from a Medical Home include these:

- Your child’s primary care doctor and office are available and accessible.
- The staff members in the office 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 Home at the website of the American Academy of Pediatrics at www.aap.org.
KNOWING THE RIGHTS AND RESPONSIBILITIES OF PARENTS AND OF CHILDREN WITH DISABILITIES
KNOWING THE RIGHTS AND RESPONSIBILITIES OF PARENTS AND OF CHILDREN WITH DISABILITIES

THE RIGHTS OF ALL CHILDREN
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.

On one level, we can read this list of children’s rights 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 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. Whether you are rich or poor, you know that it may not always be easy to guarantee that your child will receive an appropriate education, be allowed to make his own decisions, or be free from discrimination and societal attitudes that may stand in the way of your goals for him.

A THOUGHT TO REMEMBER
What is important to remember is that your child has the same rights and the same needs as every other child. In addition, your child may also have some “special needs” as a result of her disability. Just as your child has the same rights as other children, she will also have some “special rights” that are just as important.
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.

Section 393.13 of the Florida Statutes is designated as the “Bill of Rights of Persons Who are Developmentally Disabled,” and it ensures that the rights listed here cannot be denied to your child on the basis of her disability.

Any time you feel that your child’s basic human rights or his 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

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, 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, and
- the right to vote in public elections.
Knowing the rights and responsibilities of parents and of children with disabilities

All human beings are born free and equal in dignity and rights.

UNIVERSAL DECLARATION OF HUMAN RIGHTS OF THE UNITED NATIONS GENERAL ASSEMBLY (1948)

the professionals who are working with you. Human rights belong to all children, and all children means ALL children.

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 like they have lost their rights as parents. You may now feel that you must 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 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 parent rights with regard to children’s disabilities, they are talking about 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 in 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. They were written by parents for parents, and they come out of the real-life experiences of parents who are living what the textbooks can only describe. 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 may not 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 might help your child, look into it. Times change, and so do treatments. But do not 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 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, it is you who has to live with the decisions you make, and you deserve the time you need to make those decisions.

3. **The right to privacy.** In the same way that you may not want to share other 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 a family’s privacy when suddenly new people are brought into the family circle who examine, give advice, and sometimes seem judgmental. Some aspects of your life may not be anyone else’s business. If you do not want to discuss something or if you do not want your child’s picture taken, for example, it is your right to say “no,” or “not right now,” or “I’ll think about this and get back to you,” or “I just can’t handle this right now.”

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 well-meaning people tell you that there are some goals they think your child will never be able to reach or 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 for learning 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, it is you who will live with the consequences of your decisions, and 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, in 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 that 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 can be lost that would otherwise be shared by you and your child. You are the one being asked to do “one more thing.” If 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 for your family’s life, but don’t fall into this trap. You have limits and your child has limits. 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 mommy or daddy or grandma or papa. Therapy and educational activities done at home can certainly be beneficial, but you and your child need time to just fool around, 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 be “turned on” all the time to addressing the disability of your child. Sometimes you feel sad
or you are worried about money or your other children, or you are sick. If other people take that as a sign that you’re “not adjusting” or you’re “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 could 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, and 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, 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 time off.** As a parent, you need time to yourself with your spouse, partner, or other family members or friends 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 though 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 her. Teachers and therapists come and go, but you are the expert with the most experience and first-hand knowledge about your child.

As the expert, you have the right to be in charge of your child’s educa-
tional, medical and social decisions, at least until your child is able to do this for himself. Professionals do not have to live with the consequences of their decisions, so while you will value their knowledge and opinions, remember that these are “informed” opinions but 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 as an equal 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 exploring some part of your child’s body. If the reason is not explained to you, you should 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, and sometimes 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 a 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 are meant with good intentions. It is your decision what to do with them.

THE RESPONSIBILITIES OF PARENTS
Taking Action
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 so you can take good care of your child. That makes caring for 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 feel 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 and 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:

• **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 and sometimes 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 reasons they do what they do!

The best relationships between parents and professionals are characterized by mutual respect, trust and openness. In this situa-

• **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.
tion, 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.

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

The professional has specialized knowledge to contribute – that is, the knowledge of her discipline. Often, you will need to rely on 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 she relates to your child, and how openly she responds to your concerns will determine whether you continue to work with that person or decide to seek the services of another person. If your relationship is not a good fit, do not feel bad about seeking other services.

Overall, the parent-professional relationship should be reciprocal. Both you and the professional need to trust and feel trusted, both need to admit when you are wrong or when you do not know something, and both need to negotiate with each other. This relationship can take time to develop and may require effort on both sides.

Many 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 and so on.

- If you don’t understand the terminology a professional is using, ask questions. Say, “What do you mean by that? I don’t understand.”
• 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.

• 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.

• If you don’t agree with the professional’s recommendations, say so. 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.