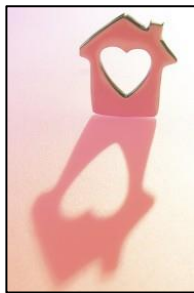


## The Unplanned Journey

### *When You Learn That Your Child Has a Disability*



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The birth of a child with a disability, or the discovery that a child has a disability, can have profound effects on the family. In “You are Not Alone,” Patricia McGill Smith offers the insights that she and others have gained through their own experience of having a child with a disability. In this article, we will provide additional information to support the life cycle, health, and well-being of the family when a member has a disability.

It is with a great deal of humility that we are even attempting to describe what the future may hold for you and your family. On the one hand, we want you to be as prepared as possible so you can negotiate the challenges that may await your family. On the other hand, we recognize that individual variation and differences are the rule when a child has a disability. Researchers often base their findings on group data—what happens to the majority of people in a circumstance. However, what might be “true” in a research sense may not be at all true for your family. Therefore, while we hope this article will guide you to sources that are helpful, take from our discussion only what you need.

### **The Journey**

*Growth is endless and our lives change and change us beyond anticipation. I do not forget the pain—it aches in a particular way when I look at Jessy’s friends (her paid companions), some of them just her age, and allow myself for a moment to think of all she cannot be. But we cannot sift experience and take only the part that does not hurt us. (1)*

No parent wants his or her child to be sick, disabled, or harmed in any way. It is not an experience anyone expects to have; rather, it is a journey that is unplanned. The terrain families must travel is often rough in places. And yet, the majority of families are able to find the strength within themselves and among their circles of support to adapt to and handle the stress and challenges that may accompany their child’s illness or disability.

Many parents have described the progression—and pendulum—of feelings they experienced upon learning that their child has an illness or a disability. Patty McGill Smith touched upon many of these emotions in her article—shock, denial, grief, guilt, anger, confusion. The type of emotions parents experience, as intense and overwhelming as they may be, are also normal and acceptable. Stability does return, both to the individual and to the family. Parents begin to search for needed information. Many report feelings of personal growth that are often, in retrospect, astounding to them. One mother, reflecting on life after the birth of a child with spina bifida and other disabilities, says:

*I have learned, and grown, more since Dylan’s birth than any other time in my life. You learn patience, and you get to witness miracles that you otherwise would have been too busy to have noticed...You learn acceptance, you realize you have been wrong to judge, and you learn that there is a thing called unconditional love. (2)*

Taken together, the many suggestions and insights offered by parents who have lived for years with the experience of disability in the family can provide parents who are new to the experience with much guidance and support. The remainder of this article will outline many of the ways that parents have helped themselves and those they love adjust to living with and caring for a child with special needs.

### **Access Information and Services**

One of the first things you can do that may prove enormously helpful, now and in the future, is to collect information—information about your child’s disability, about the services that are available, and about the specific

things you can do to help your child develop to the fullest extent possible. Collecting and using the information available on disability issues is a critical part of being a parent of a child with special needs. Fortunately, there is a great deal of information available on many disabilities and many disability issues.

### **Join a Group**

Much of the information that will be helpful to you is in the hands, heads, and hearts of other parents like yourself. For this reason, it is worthwhile to join a parent's group. Some groups are organized around one particular disability (e.g., cerebral palsy, Tourette syndrome, Down syndrome), while other groups draw together parents who, irrespective of the disabilities of their children, have similar concerns, such as daycare, transportation, coping, or finding out about and supporting special education in their community. Within each of these groups, information, emotional and practical support, and common concerns can be shared. The power of this mutual sharing to combat feelings of isolation, confusion, and stress is a consistent thread running throughout the literature written by and for parents.

*Our children had Down syndrome, seizure disorder, holes in the heart, premature birth, deafness, and cerebral palsy. I hated the repeat surgeries, but one mother wished her child had a condition that doctors could fix. I struggled with how to respond to strangers, but another mother wanted her child's condition to be visibly obvious so strangers would understand why she wasn't doing what other six-month-old babies did. It was powerful to simply congregate with other mothers whose babies had special needs, hear the variation in stories, see the experience refracted through the crystal of multiple identities. (3)*

Parent groups aren't only for mothers, though. Don Meyer writes of running "fathers-only" workshops where fathers came together to exchange insights and trade war stories.

*Often the din of the conversation was such that we were asked "to keep it down" by presenters in neighboring rooms. Fathers became so involved in talking to their peers that we sometimes needed to shoo them out of the room at the end of the meetings... All this from fathers who "don't say anything." Clearly these men have much to say, and much to offer one another. (4)*

There are many ways to identify a parent group in your area. The [state parent training and information \(PTI\) center](#) is also a good resource.

### **Read Books Written By (and for) Parents**

You may also find it helpful to read many of the excellent resources—books, articles, Web sites—that are available on disability issues. Some are quoted in this publication. Worthwhile suggestions about what to read can come as well from talking to a local librarian, your child's teacher, or other involved professional; contacting a national, state, or local disability group; or talking to other parents of children with disabilities.

### **Find Out About Services**

The search for available services is a challenge for families and one that continues as the child's needs change. Most of these services are made available because of legislation at the federal and state levels.

Typically, there are many services available within communities, districts, and states to assist you in meeting the needs of your child with disabilities and your family. Families with a young child with disabilities (birth through the third birthday) should access *early intervention services*, which are designed to identify and treat developmental problems as early as possible. For school-aged children with disabilities, *special education* and *related services* can be important factors in addressing a child's educational needs.

**Early intervention services.** Early intervention services are designed to address the needs of infants and toddlers with disabilities as early as possible. These services can range from feeding support from a nutritionist in a hospital to developing a complete physical therapy program for an infant with cerebral palsy. However, these services are not just for the child with special needs. When framing the law describing early intervention services, Congress

recognized that families are central in a young child's life. Therefore, the family's priorities, concerns, and resources are a major consideration when planning services for infants and toddlers with disabilities. The plan that is developed through this process is called an Individualized Family Service Plan (IFSP).

Parents, too, can benefit from early intervention services. As full members of the team developing the program for their child, they can learn skills that may be useful for a long time—skills in helping their child learn and develop, as well as skills in decision-making, planning, being of support to others, and influencing policy-making in their community.

The services themselves are offered through a public or private agency and are provided in different settings, such as your home, a clinic, a neighborhood daycare center or Head Start program, a hospital, or the local health department. Initial evaluation and assessment of your child will be provided free of charge. Services may also be provided at no cost, although this may vary from state to state. Some states charge a “sliding-scale” fee for services.

**Special education and related services.** Through the mandates of two federal laws—the Individuals with Disabilities Education Act (IDEA) and Section 504 of the Rehabilitation Act of 1973—each eligible child with special needs is guaranteed a free appropriate public education designed to address his or her unique needs. This education is planned by a team, including the parents of the child.

Thus, as parents, you are key participants in the team that determines what type of special education your child will receive. Together, the members of your child's team develop an Individualized Education Program (IEP), which states in writing the educational program that is planned for your son or daughter.

There are many books and websites that are particularly useful if you are seeking to understand and access special education services.

## **Supporting and Empowering Family**

### **You're the heart of the family**

Many factors can influence the well-being of a family. One factor is certainly the emotional and physical health of the parents. You, as parents, are definitely the heart of the family. You are the ones who deal with the issues associated with your child's disability—doctors, child care providers, family members, your child's school, the professionals who work with your child. You also maintain the household — working to pay the bills, shopping, cooking, cleaning up, taking care of other children. Is it any wonder that many parents of children with disabilities report times of feeling overwhelmed?

Therefore, it is very important for you, as parents, to take some time to care for yourselves as individuals: getting enough sleep, eating regular meals, taking a short walk, and doing the things that you really enjoy, even if you can only squeeze them in occasionally. As one mother relates:

*I would sometimes retreat to my “tower” and pretend that I had no responsibilities other than to amuse myself with a good book or a soothing tape. The respite usually didn't last more than a half hour, and it was never enough, but it helped me break the “martyr” pattern of thinking I was required to live and breathe only for my children.*

*In those brief moments of quiet reflection I could renew my sense of self and remember that I was important, too; that I was Kate, a person, with lots of abilities and interests that did not all coincide with my role as Mommy. I came to realize that a little selfishness is not a bad thing. If I could enjoy myself more, I could enjoy my children more. (5)*

Many families will be single-parent families, but for those who are not, the relationship between the parents is a factor that can influence the family's well-being. When the parents' relationship is a strong and supportive one, it enriches family life for all members. Conversely, when there are problems in the relationship, the tension affects the rest of the family as well. This is stating what most of us already know—that marriages undergo change with the

birth of a child, any child. But when a child in the family has special needs, this change may be even more profound. As Kelly Harland puts it, “How unexpectedly it all unfolds. One moment, you and your lover are singing along in bad Italian with Venetians in a crowded bar...red wine pouring out of nowhere. And the next minute, the two of you are filling out disability forms for your tiny son.” (6)

Much of the literature written by parents discusses ways for parents to protect their relationship. One point emerges again and again, and that is the importance of making time for each other: meeting for lunch, getting away for a few hours together, sharing an activity. Talking to each other and really listening are also important—and conversations do not always have to revolve around the children in the family. Finding other topics to discuss can do much to revitalize parents and preserve intimacy between them. It is also important to recognize that there are times when one partner needs to have space. As one parent puts it, “Realize that you do not deal with this stress in the same way your spouse does. Let your spouse deal with it in their own way, and try to come to an understanding of your differences.” (7) Another parent shares, “At these lonely moments, the greatest gift was simply to let the other be.” (8)

Sharing the duties of providing care is also necessary, although couples report that they often have to work hard at communicating in order to achieve the “we-ness” that goes behind teamwork. Many parents have found it is necessary and helpful to seek joint counseling. Through this process, they grew to understand each other’s needs and concerns more fully and found ways of discussing and resolving their differences. As one parent says, “We steer a rocky ship, my husband and I...We have had to check in with the therapist, sometimes once a year, sometimes once a week. We’ve experienced a hard distance between one another from time to time, as Will in all his complexity takes over every spare second of our lives. We have hung on, though. Our hearts are bonded by something that goes even deeper than love.” (9)

### **Brothers and Sisters**

We know from the experiences of families and the findings of research that having a child with a disability powerfully affects everyone in the family. This includes that child’s brothers and sisters. Many authors and researchers have written with eloquence about how the presence of a disability affects each sibling individually, as well as the relationships between siblings.

The impact, according to the siblings themselves, varies considerably from person to person. Yet there are common threads that run through their stories. (10) For many, the experience is a positive, enriching one that teaches them to accept other people as they are. Some become deeply involved in helping parents care for the child with a disability. It is not uncommon for siblings to become ardent protectors and supporters of their brother or sister with special needs or to experience feelings of great joy in watching him or her achieve even the smallest gain in learning or development. Megan, age 17, says of her life with her brother who has Down syndrome:

*Every day Andy teaches me to never give up. He knows he is different, but he doesn’t focus on that. He doesn’t give up, and every time I see him having a hard time, I make myself work that much harder...I don’t know what I would do without Andy. He changed my life...If I had not grown up with him, I would have less understanding, patience, and compassion for people. He shows us that anyone can do anything. (11)*

In contrast, many siblings experience feelings of bitterness and resentment towards their parents or the brother or sister with a disability. They may feel jealous, neglected, or rejected as they watch most of their parents’ energy, attention, money, and psychological support flow to the child with special needs. (12) As Angela, age 8, puts it, “[T]here are times when I sit down and think, ‘It’s not fair!’” (13)

And many, many siblings swing back and forth between positive and negative emotions. Helen, age 10, whose sister has severe intellectual disabilities and seizures, begins by saying that she’s glad to have a sister with special needs. “It has opened my eyes to a world of people I never would have known about.” (14) But she also says, “Sometimes I wish I had special needs. I think that a lot when Martha gets oohed and aahed over and nobody even thinks about me.” (15) And then in the next breath, Helen says, “Another thing is that it really makes me mad when kids slap their chest with their hands and go, ‘I’m a retard!’ It made me so mad!” (16)

The reaction and adjustment of siblings to a brother or sister with a disability may also vary depending upon their ages and developmental levels. The younger the nondisabled sibling is, the more difficult it may be for him or her to understand the situation and to interpret events realistically. Younger children may be confused about the nature of the disability, including what caused it. They may feel that they themselves are to blame or may worry about “catching” the disability. As siblings mature, their understanding of the disability matures as well, but new concerns may emerge. They may worry about the future of their brother or sister, about how their peers will react to their sibling, or about whether or not they themselves can pass the disability along to their own children. (17)

Clearly, it is important for you to take time to talk openly about your child’s disability with your other children, explaining it as best you can in terms that are appropriate to each child’s developmental level. As Robert Naseef remarks, “Just as parents need information, so do siblings, on their level.” (18)

### **Your Child with Special Needs**

Much of how you raise your child with a disability will depend on your family’s personal beliefs about childrearing, your child’s age, and the nature of his or her disability. An important point to remember is that most of the regular child-raising issues will apply—children with disabilities will go through the usual childhood stages. They may not go through stages at the same age, at the same rate, or use the same words as children without disabilities, but they are children and kids are kids.

We, as parents, may believe that all children should be treated the same, but in practice that is usually not the case. Why? Because anyone who has been around children, even infants, knows they have different personalities and react differently to similar situations. We encourage and coax the shy child and set limits for the rambunctious one. We tell the loud ones to be quiet and the quiet ones to speak up. We offer different activities to the child who loves to paint than to the one who wants to play ball. Children just are not the same—but they should have the same opportunities.

Among their opportunities should be the chance to assume increasingly greater degrees of responsibility and independence. There may be many ways in which your child can help himself or herself or other members of the family, including doing chores around the house. You will need to consider what these activities might be, given your son or daughter’s disabilities and capabilities. As you expect and encourage your child to assume responsibility, his or her sense of pride and competence will also increase.

Conversely, to not expect or encourage your child to contribute to self-care or household matters may send the message that he or she is not capable of helping. Dependence is fostered instead. As one mother insists, “Let him do things for himself. Don’t baby him. My father-in-law noticed how Chrissy can manipulate people very well...[His] comment was, ‘Boy, he wouldn’t walk anywhere if he could find someone to carry him all over.’ Yup. That’s why we don’t carry him!” (20)

Of course, the nature and severity of your child’s disability may affect how much he or she is able to participate in household duties and so on. Peggy Finston remarks:

*The issue, then, for each of us is what is a “realistic” amount of normality to expect from our child? If we expect too much, we run the risk of rejecting him as he is. If we expect too little, we will fail to encourage him to do the most he can with himself. There is no one answer for all of us, or even for all of us dealing with the same condition. The best we can do is to realize that this is an ongoing question that we need to consider. (21)*

Another issue that may concern you is what (or whether) to tell your child about his or her disability. As with siblings, the child with special needs may also have a need for information and perspective about what makes him or her different.

*Now my hug becomes tighter, closer. I feel my breath in his tousled hair. “Will, do you ever wonder why you get so scared when something comes out of the blue, why it upsets you so much?” He snuffles. “Yeah.” I hesitate. I’m*

*feeling terribly warm. I never wanted to introduce my child to the label someone else created for him. And yet an instinct tells me it may help him....(22)*

This is how Kelly Harland describes the conversation she had with her son when she told him about his disability, autism.

*And now he's still. He has calmed down. He's listening.*

*...And silence, as I try to imagine where to go next. Maybe I'm all wrong. Maybe I should never have used that word. But an odd rush comes over me. It feels like, with this tentative back-and-forth, we've suddenly crashed through some floodgate....Has Will known for awhile that he has a problem; has he been waiting for his mom to explain it to him? There is in all this talk something for both of us to hold onto, maybe in this one moment a way to quell the terror, or even rise above it. (23)*

As your child grows and matures and especially as he or she edges into young adulthood, it may be very helpful for him or her to be able to discuss the nature of the disability. This includes what special accommodations he or she needs in order to succeed in school and other settings. You may wish to involve your child in his or her own IEP meeting, which can teach your child useful skills like self-advocacy, expressing personal interests and goals, and being involved in making decisions that affect his or her life. In fact, by law, whenever your child's transition to life after high school is going to be discussed at an IEP meeting, your child must be invited to attend the meeting.

### **Grandparents (and the Rest of the Family)**

Grandparents are often greatly affected by the birth of a child with a disability. "They face the double grief of their grandchild's disability and their own child's pain."(24) It is important to remember that they will need support and information, too. (This is true for other members of the family as well.)

Therefore, your parents and other members of the extended family need to be given opportunities to get to know your child as a person and not just a person with disabilities. Help them to understand your child's strengths and needs, help them to accept him or her as part of the family. Allowing family members to become involved with your child may also allow you some much-needed time away from the responsibilities associated with caring for a child with special needs.

### **Care Givers**

All parents, at some time, will probably seek child care. For families with a child who needs more supervision or specialized assistance, child care may be difficult to find—or feel comfortable with. However, even if you do not work outside the home and do not need regular child care, you may benefit greatly from having child care on a periodic or even an ongoing basis. This will give you time to take care of personal matters, enjoy some leisure activity, or be relieved of the constant need to care for a child with a disability or chronic illness.

You may also benefit from respite care, a system of temporary child care provided by people familiar with the needs of children with disabilities. "Temporary" can range from an hour to several months, depending on the respite care provider and the needs and desires of the family. Many respite care providers have undergone specialized training and can knowledgeably care for children whose needs may range from close supervision to medical care. Respite care can be provided to infants, teenagers, or adults with special needs. In some cases, the respite provider may be able to provide care only for the child with the disability; in other cases, care may be available for siblings as well. Respite care generally differs from daycare in that it is not available on a daily basis to allow a parent to return to the work force.

To find out more about respite services, contact the ARCH National Respite Network and Resource Center. ARCH operates the National Respite Locator Service whose mission is to help parents locate respite care services in their area.

Although many parents initially may feel reluctant to leave their child with special needs in the care of someone else, those who have tried it give ample testimony to its value in restoring their energy, sense of humor, and perspective.

### **Working with Professionals**

Over 20 years ago, parent Cory Moore, speaking directly to professionals, wrote:

*We need respect, we need to have our contribution valued. We need to participate, not merely be involved. It is, after all, the parent who knew the child first and who knows the child best. Our relationship with our sons and daughters is personal and spans a lifetime. (25)*

This sentiment echoes throughout the parent literature and in the hearts of parents everywhere. Not surprisingly, many of the materials written by parents for other parents offer insight into how you might work together with professionals for the benefit of your child and family. The best relationships are characterized by mutual respect, trust, and openness, where both you and the professional exchange information and ideas about the best care, medical intervention, or educational program for your child. Both you and the professional need to speak clearly about issues and listen carefully. Indeed, both of you have important expertise to share.

You, for example, have intimate knowledge of your child with special needs. You live with and observe your son or daughter on a daily basis and can contribute invaluable information about his or her routine, development, history, strengths, needs, and so on.

The professional, too, has specialized knowledge to contribute—that of his or her discipline. Often you must rely upon the professional's judgment in matters that are critical to the well-being of your child.

Thus, there should be a mutuality in the parent/professional relationship. This can take time to develop and may require effort from both parties. To that end, many parent writers suggest:

- If you are looking for a specialist with whom you can work well, ask other parents of children with disabilities. Often, they can recommend a good speech or physical therapist, doctor, dentist, or surgeon.
- If you don't understand the terminology a professional uses, ask questions. Say, "What do you mean by that? We don't understand."
- If necessary, write down the professional's answers. This is particularly useful in medical situations when a medication or therapy is to be administered.
- Learn as much as you can about your child's disability. This will assist you with your child, and it can help you participate most 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 information concerning your special needs child. This can include your child's medical history, test results, observations about behavior or symptoms that will help the professional do his or her job, and so on. (A loose-leaf notebook is easy to maintain and add information to.)
- If you don't agree with a professional's recommendations, say so. Be as specific as you can about why you don't agree.
- Do whatever informed "shopping around" is necessary to find a doctor who understands your child's needs, is willing to work collaboratively with other medical professionals, and with whom you feel comfortable.
- Measure a professional's recommendations for home treatment programs or other interventions against your own schedule, finances, and other commitments. You may not be able to follow all advice or take on one more thing, feeling as Helen Featherstone did when she wrote, "What am I supposed to give

up?...There is no time in my life that hasn't been spoken for, and for every fifteen-minute activity that has been added, one has to be taken away." (26) Peggy Finston points out that "most professionals won't be familiar with the sum total of our obligations and will not take it upon themselves to give us permission to quit. This is up to us. It's in our power to make the decision." (27)

In conclusion, it is important that the parent/professional relationship empower the parent to be a full participant in information-gathering, information-sharing, and in decision-making. However, it is ultimately up to you to decide what role(s) you want to take in this process and what role(s) you need help with. It is helpful to know that families do, indeed, choose different roles in relationship to professionals. Some parents want to allow professionals to make most decisions about their child, others want to serve as an informant to the professional, some want veto power, and some parents want a shared role in the intervention with their child. (28)

You are also free to change your mind about the role or level of involvement you may want or be able to assume regarding your child's services. You may find that you choose different roles at different times for different purposes. Be as direct as possible about what you want or don't want to take on in this regard.

### Summary

In this article, we have looked at many of the issues facing you as parents of a child with a disability. Learning that your child has a disability or illness is just the beginning of the journey. At times, you may feel overwhelmed by the challenges associated with disability and by the strength of your own emotions. And while you may feel alone and isolated, there are many supports available. Other parents can be invaluable sources of help and information. Services are also available through public agencies that can assist your entire family—early intervention services for infants and toddlers and educational services for preschoolers and school-aged children. Having access to information and supports may be critical in maintaining a stable and healthy family life.

We urge you to read, to talk to other parents who have a child with a disability, to talk with each other and with other family members, and to reach out for assistance when you need it. We conclude with the words of Clare Claiborne Park, as she reflects upon the experience and emotions of being a parent of a child with disabilities.

*This experience we did not choose, which we would have given anything to avoid, has made us different, has made us better. Through it we have learned the lesson of Sophocles and Shakespeare—that one grows by suffering. And that too is Jessy's gift. I write now what fifteen years past I would still not have thought possible to write; that if today I was given the choice, to accept the experience, with everything that it entails, or to refuse the bitter largesse, I would have to stretch out my hands—because out of it has come, for all of us, an unimagined life. And I will not change the last word of the story. It is still love. (29)*

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