

# When Your Child has a Disability

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Most parents-to-be have a vision of their new baby – what the child will be like – how life will be once the baby is born. Sometimes things don't work out as planned. When parents receive the news that their child has a disability, it generally comes as a shock. Some people are more or less prepared, like parents who know in advance that their child has Down Syndrome, or parents who are adopting special-needs children. But in general, having a disabled child was not part of the original vision of the family unit.

Parents' first reaction is often shock and dismay. There may even be denial: could the doctor have made a mistake? Some seek a second opinion, or even a third. After all, this is not how things were supposed to go!

Parents who have just been told that their child has a disability often say they feel like they've had the wind knocked out of them. The shock can produce a wide range of feelings:

- **grief** over the loss of the child they thought they had.
- **anger**: "How can this be happening to us?"
- **guilt**: "Did I do something during the pregnancy?"
- **hopelessness**: "What will life be like now?"

It is also normal to look for someone or something to blame; this sometimes causes great stress between the parents.

## With time comes acceptance

At some point, you will begin to feel acceptance. You will realize the disability is part of now part of your life, and that your child is still the same beloved son or daughter you've longed for and loved since birth. At this point, you can stop looking for blame and begin looking forward. Arriving at this stage can take a lot of hard work and introspection. Sometimes counseling for one or both partners is very helpful.

## Knowledge is power

Once you have accepted that your child has a disability, it is time to educate yourself! Concrete information can counteract the "what if" questions you may have. There are many ways a family can find information about most of childhood disabilities that exist today.



- Your pediatrician's office may have pamphlets and phone numbers to start you on your journey of education and discovery.
- Look in the local phone book or online to find the association or support group that applies to your child's disability.
- Search for resources at your local library or bookstore. Make sure you choose recently published books by reputable publishers. Information changes quickly, and it's important to stay up to date.
- The internet is a valuable tool, but be cautious. When selecting

internet resources, look for timely, accurate articles that back up opinions with facts you can check in other sources. Beware articles that express extreme opinions, or are full of grammar and spelling mistakes, a clue that the article may not contain accurate information. With some time and effort, you, too can become an expert.

## Find support locally

If there is a children's hospital in your area, they may sponsor classes or workshops about the specific disability you're dealing with. Nurses or social workers may be able to point you towards additional resources.

Parents of children who share your child's disability can be an invaluable resource. Often they have seen doctors, therapists, and other professionals in the area and can refer you to helpful professionals. Don't be afraid or embarrassed to lean heavily on experienced parents while you're getting your bearings.

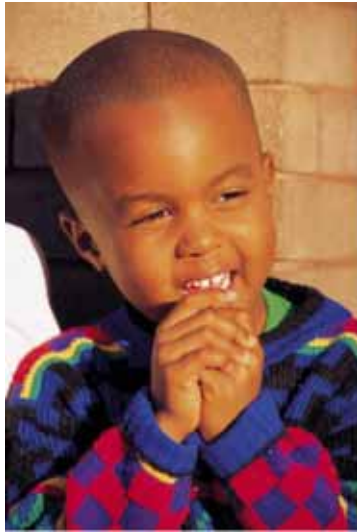
Many disabilities have national organizations with local chapters (for example there are organizations to help families of children with Down Syndrome, spina bifida, autism, blind or deaf children, children with cystic fibrosis, and so on). These organizations can be extremely helpful in determining your next steps to take.

When you find a local association that focuses on your child's disability, by all means call the contact person listed. Many times this is a parent has become an expert and is eager to help you.

Children with certain kinds of disabilities are eligible for special services through their school district. Help may be available through your school's psychologist or social worker.

### Get help for your child

Ask your pediatrician or family health care provider for referrals to specialists who deal specifically with your child's disability. In general, the earlier the intervention, the better the outcome for the child. You may be referred to a special clinic, occupational or physical therapist, or other specialist.



### Get support for the whole family

Having a child with a disability can affect the whole family unit. Siblings may resent the amount of time and energy the parents are dedicating to the disabled child. Local support groups and children's hospitals often have groups for siblings of disabled children. Here children can ask questions, share experiences, and vent their emotions in a safe environment.

It can be difficult for the parents, especially the primary caregiver, to find balance. It is normal to feel overwhelmed at times, but self-care

is important. A family counselor can help you work through the many stages of life with a disabled child. Far West has experienced counselors who can help you process your emotions, get information, and move forward into a healthy life with your disabled child.



*This information is provided for educational purposes only. It should not be used as a substitute for seeking professional care for the diagnosis and treatment of any medical condition.*

## 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."

"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 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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