

Diagnosis: Finding Out Your Child Has Special Needs

Something's just not right. You know it in your head, your heart, and the pit of your stomach. Your child isn't developing like other children. But you're afraid that giving a name to your fears and putting a label on your child will make things real that you'd love to believe are imaginary. How do you find the strength to move from suspicion to certainty? And even after a diagnosis is given, how can you accept that this is your child's fate?

Seeking a diagnosis for a child is one of the hardest things that parents can do. It means putting aside dreams of one kind of life for your child and setting off down another path, but fear and denial don't help your child. Getting the proper diagnosis and treatment does. A diagnosis doesn't change your child, it explains your child. It may be scary or hard to accept, but the right diagnosis can lead you to information, therapy, technology, and services that can greatly improve the quality of life for your child and your family. As you set out to help your child, keep these five things in mind:

Your Child is Still Your Child

The things you love about your child will still remain the same. There will still be moments of joy, calm, stillness, and general family life. You may learn to treasure those moments more. Every kind of special need brings with it its own particular stresses, tragedies, struggles, and frustrations, but rarely is it every minute of every day and every bit of your child's being. Your child is still your child.

Labels Are Not the Enemy

None of us like to think of our precious child as just another bowl of alphabet soup. Labels can seem scary or limiting, defining our loved one by their dis- and not their ability, but a label can also help you to get services for your child, therapy, insurance coverage, the right school placement, tolerance for behaviors, understanding, and support. A label does not define your child, it's just another tool for getting your child the help he or she needs.

You Are Not Alone

Finding out that your child has special needs can be overwhelming, and it's easy to feel alone. Here at Partners in Learning, we're here for you and to remind you that you're not alone. We offer support groups, workshops, and parent classes. Check out our calendar for more details! Also, the internet has made it possible to network with parents and organizations across the country and around the world. Online you can find support groups, forums where experts will answer your questions, sites filled with information about your child's diagnosis, announcements of gatherings and conferences, and other resources that can help you become part of a community of people who know just what you're going through.

Every Child is Different

Children develop at their own pace. They respond uniquely to therapies or medications or treatments. They follow their own path. Don't assume that because you've heard sad stories about children like yours, your family's story will be sad, too, and don't assume that because one thing doesn't work, nothing will. Your child is a unique individual, and, although a diagnosis may provide a useful template, it's not the whole picture.

There's Always Hope

Life for people with disabilities has improved enormously over the last century, and there's no reason to believe that progress won't continue. Medical breakthroughs are made every day. New therapies are constantly being developed. Different educational techniques bring undreamed of results. Tests are becoming more sensitive and medications more targeted, and sometimes love and a strong will can perform miracles.

After the Diagnosis

Consider Getting a Second Opinion

If you have any doubts about the diagnosis or about the doctor who gave it to you, seek out a second opinion. Some disabilities are diagnosed on the basis of tests that are definitive, but others rely on a large degree of interpretation and professional judgment. Different doctors can make those interpretations differently. The gut instinct of a parent who lives with a child day in and day out is often at least as accurate as the opinion of a doctor who sees the child for a short period of time in an examining room. It's important to accept reality and not endlessly defer the help your child needs, but it's also important to get a proper diagnosis.

Let Yourself Mourn

Once you've accepted a diagnosis, it's natural to go through a period of mourning for the "perfect" child you've dreamt of and the life that your child and your family will not have. This doesn't mean you've given up or don't think your child will have a valuable and fulfilling life. It just means you have to close one chapter before you can start the next one. Recognize, too, that family members, even extended family members, may be going through a similar period of grieving, and respect that the reactions you encounter during this time may not be true to the help and support you will receive from them in the future.

Read Everything You Can Find

Partners In Learning has a Family Resource Room where parents can check out books, videos, and even use computers. If there are books on your child's disability, find them and read them. Become an expert not only on your child but on your child's condition. Ask the doctor to recommend some good books on the subject. Comb the Special Needs shelves of bookstores and libraries. Search the virtual shelves of online booksellers. You may not find any single book that truly explains or encapsulates your child, but over a number of different sources you may be able to gather useful tips and information that will help you assemble your own picture. In addition to making you better informed, reading can help you feel like you're doing something even if you're not emotionally ready to do much else.

Share With Family and Friends

You may fear the judgments and reactions of others when you tell them the news of your child's special needs, and indeed you may not get the response you hope for from everyone you love. Yet support from a close circle of family and friends is one of the most important resources parents of children with special needs can have, and people can't support you if you don't give them a chance. There may be surprises, as you find friends and relatives you thought you could count on slipping away and others you

never expected much from stepping up and pitching in. Not everyone is equipped to be a special friend to an exceptional child. But the ones who are, are worth their weight in gold.

Find a Support Group

Partners in Learning offers Autism and Down Syndrome Support Groups. Friends and family can help in many essential ways, but they may never be able to understand what parenting your child is really like. That's where support groups come in. You may be able to find a live support group in your area through organizations dedicated to your child's particular disability; or through your early intervention service provider. You may prefer to start with an e-mail group that you can access at your convenience and with a greater degree of anonymity. Message boards can also be a great place to link up with parents who can sympathize directly with your experience and provide support and advice.

Start Lining Up Services

If your child will need early intervention or special education services, don't wait to make the first phone calls to set that in motion. It can take months to get the first appointments and evaluations scheduled and completed, and you won't want to add more time to that by dragging your feet. Contact your state's early intervention office or your school district as soon as those services are recommended, and start gathering the reports and information you're going to need once the process begins.

Here are Rowan County contacts:

Ages Birth – 3: Concord Children's Developmental Services Agency, 1065 Vinehaven Drive, Concord, NC 28025: 704-786-9181

Ages 3 – 5: Rowan Salisbury School Exceptional Children's Department: 704-216-7353