



When Something Is Not Quite Right

It's a scenario every parent fears: the heart-stopping moment when a doctor says, "I'm afraid there's something wrong."

Sometimes it's gradual, as it was in our family. We didn't have a firm diagnosis of high-functioning autism until age 5, even though some signs were evident from age 2. And sometimes right from birth, or even before, a diagnosis like Down's syndrome is already in place. No matter when you get the news, it's a life-changing moment. But while you're embarking on a journey no parent chooses to take, you don't have to travel alone.

The Emotional Issues

Dealing with your baby's disability brings, first, a tidal wave of emotions. Most parents run the gamut—grief, denial, anger, guilt—in any order and often all at once. Your child's doctor will probably hand you a list of resources, among them one or more support groups. Instead of tossing that list with the idea that you're not a support group "type," file it away. Eventually, you may find that in a world where few people understand what you're going through, other parents will become your greatest resource and strength.

At the very least, try to find someone who will listen, won't judge you, and—very important—won't deny the problem. This is the time to ascertain who among your circle will be your assets and which ones will only pull you downriver. You don't have to cut yourself off from, say, your aunt who's always been there for you. But do understand that this is new territory, and not everyone will be able to help with this particular issue.

If talking directly is daunting, go online. Google "[name of disability] + forums" or "+ parent support." You'll find lots of parents sharing advice and resources. In addition, when calling the organizations below, ask about parent support networks, even if you think you'll never use them.

Finding Resources

Your child's doctor should give you information when asked, "Where do we go from here?" But it's important to note that you are your child's best advocate. The challenge is not a lack of help, but rather sorting out what's most useful in an ocean of available information.

Families have a couple of options. First of all, the state is required to provide special education for disabled children from birth through age 21. This includes early intervention provided through a birth-to-age three program. Services

funded by the state include physical, occupational and behavioral therapies; assistive technology; speech therapy; special education; and assistance to families in finding additional resources. Services can be provided in the home or at a doctor's office. Contact your local agency to begin the process:

Infant Toddler Services of Johnson County:

6400 Glenwood, Overland Park, KS 66202;
913.432.2900; ITSJC.org

Wyandotte County Infant-Toddler Services:

4911 State Ave., Kansas City, KS 66102; 913.287.8851;
ChildrensTLC.org/WyCoITS.html

First Steps (Missouri side, greater KC area):

4230 Phelps Rd., Independence, MO 64055;
816.363.1078; DESE.mo.gov/divspeced/FirstSteps/

To secure services not provided by such a program, contact your local CDDO (Community Developmental Disability Organization). Meant to be a "single point of entry"—a one-stop shop—your CDDO can help direct you to service providers, respite care, agencies and funding. Because you may be put on a waiting list, contact the CDDO as soon as possible, and investigate if any services could be provided by a birth-to-three program as described above. Here's the con-

tact info for the Kansas City area:

Johnson County Developmental Supports:

10501 Lackman Rd., Lenexa, KS 66219;
913.826.2626; JCDS.org

Wyandotte County Developmental Disabilities

Organization: 701 N. 7th St., Kansas City, KS 66101;
913.573.5460; TinyURL.com/lqkuza

Missouri Department of Mental Health, Division of Developmental Disabilities:

821 E. Admiral Blvd., Kansas City, MO 64106;
816.889.3400; DMH.mo.gov/mrdd

In addition, parents can contact Families Together, a nonprofit organization dedicated to helping kids with disabilities and their parents. While geared toward Kansas families, the organization provides a great list of resources for everyone on the website. The Parent to Parent program connects families of newly diagnosed children with those who already know the ropes and can serve as a resource and source of support in a bewildering situation. Call 913.287.1970 or visit FamiliesTogetherInc.org.

Claire M. Caterer is a Shawnee mom of a child with special needs. She writes frequently about parenting children with disabilities.

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