

PARENT CONNECTIONS

A Newsletter for First Steps Families ♦ Winter 2009

Choosing to Take Charge: How to Gain Control Over Your Life

Parenting a child with special needs is not an easy job. It involves giving care full time, and it can be a source of overwhelming stress. It is important to view yourself as an advocate for your child and to get connected. This can serve as a positive way to gain some control over your situation (and hopefully help with your stress level). The following steps will assist you along the way:

- **Gain knowledge**

Knowledge is power. The more you learn about your child's diagnosis, the clearer you can get your message across to professionals involved in your child's life. Searching the Web is a great way to quickly access a lot of information. If you do not have the Internet available in your home, your local library will probably have access.

- **Become organized**

Information can pile up quickly; figure out a way to keep your records organized. Whether you use an accordion file or a three-ring binder, find a method that works for you. Keep notes of all phone calls, doctor visits and other records. Take notes during meetings; it is easy to go into overload and forget what is being said.

- **Stay strong**

Remain firm in the belief that you are your child's best and strongest advocate. You are in this for the long term, not the short term (as many who move in and out of your child's life will be). Be prepared to tell your story again and again as people come and go.

- **Network with others**

Try to form partnerships with the people involved in your child's life. Your expertise about your child and your focus on family-centered care can help change the way professionals view you.

- **Accept assistance**

You must take care of yourself. Asking for help is a sign of strength, not weakness. Why is it so hard to ask for help? Despite the fact that you might be drowning in responsibility, the response is often "no thanks" when help is offered. Try to change that to a heartfelt "yes."

Finding out that you are not alone – and talking to someone who can immediately identify with no sleep, an uncertain future and fear about what could happen to your child – will change your life. You do not have to wander through this alone. Get connected!

“A hundred years from now, it will not matter what kind of car I drove, what kind of house I lived in, how much money I had in the bank...but the world may be a better place because I made a difference in the life of a child.”

— Forest Witcraft



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Thoughts From a Parent on Networking and Finding Support

By Stephanie Anderson, St. Joseph

When our daughter was born with Down syndrome, my husband and I were overwhelmed with emotion. We immediately began to worry about how we were going to raise our daughter and meet all of her needs. We also worried about how the news would affect our extended family. Little did we know there are organizations, support groups and resources that exist to help families like ours.

A few hours after our daughter's birth, the nurses provided us with a packet that contained information about the Down Syndrome Guild of Greater Kansas City (DSG). They asked if we wanted someone from DSG to get in touch with us, and within 24 hours we had a meeting scheduled with the DSG director. We also contacted our local Down syndrome group and have since attended and participated in many events.

Networking with other families has helped us understand what to expect and what not to expect. Most importantly, it has provided us with hope. So many families have made the unknown seem bearable simply by sharing their stories. They have given recommendations on therapies, which training sessions to attend, which doctors to see and other specific issues regarding development. It is comforting to know that others have traveled on the same path.

Networking is important in all aspects of life, especially when you need reassurance that you are not alone and that you are doing the right thing. There are people and groups waiting to help and answer questions regardless of your child's diagnosis. We had no idea that so many people would be so supportive, and we are very appreciative to everyone for their generosity.

RESOURCES

- ★ **The Arc of the U.S. – MO Chapter**
Phone: (816) 632-7664
Online: <http://www.arcusmo.com>
- ★ **Family Voices**
Phone: (888) 835-5669
Online: <http://www.familyvoices.org>
- ★ **Missouri Department of Elementary and Secondary Education**
Phone: (573) 751-4212
Online: <http://dese.mo.gov>
- ★ **Missouri Dept. of Mental Health: Division of Developmental Disabilities**
Phone: (800) 364-9687
Online: <http://www.dmh.missouri.gov/mrdd/mrddindex.htm>
- ★ **Network of Care**
Online: <http://missouri.networkofcare.org>
- ★ **Missouri Families for Effective Autism Treatment (MO-FEAT)**
Phone: (877) 275-8988
Online: <http://www.mo-feat.org>
- ★ **MPACT**
Phone: (800) 743-7634
Online: <http://www.ptimpact.com>
- ★ **National Down Syndrome Society**
Phone: (800) 221-4602
Online: <http://www.ndss.org>
- ★ **National Family Caregivers Association**
Phone: (800) 896-3650
Online: <http://www.nfcacares.org>
- ★ **Sharing Our Strengths (SOS)**
Phone: (800) 773-8652
Online: <http://sharingourstrengths.com>



Missouri Department of Elementary and Secondary Education
 Division of Special Education Phone: (866) 583-2392
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 Jefferson City, MO 65102-0480 (click on First Steps)

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