

Parenting a Child With a Disability

Tips and Resources from Family Voices Indiana



The Day the World Changed

When parents first learn that their child has a disability, they may experience feelings of grief, including a sense of sadness and a feeling that the dreams they had for their child are lost.

Others may experience anger, feelings of isolation, and other emotions associated with grief. All of these feelings are perfectly valid. Allow yourself to mourn the loss of your original dreams, and know that acceptance and hope are sure to follow. When you are ready, you may begin to focus on your child's needs and how your family will face challenges resulting from those needs. Gradually, as you understand your child's needs and diagnosis, you will begin to cope with those needs to move forward.

Moving Forward

Parenting is an amazing journey, and you have been given the gift of a child. Focus on being the best parent that you can be.

- **Love Your Child.** Your child with special needs is still the same wonderful and unique person that he or she was before the diagnosis. Learn to appreciate the things that make your child happy.
- **Don't look for the "disability"** in everything your child does. Children with special needs go through many of the same stages as typically developing kids, just differently. Read about age-

appropriate behaviors. Look for your child's strengths and build on them.

- **Aim for the stars.** Make decisions based on the long-term goal of helping your child be as independent as possible.
- **Have high expectations for your child.** Try not to overcompensate or overprotect.

Make a Plan for Your Family

- **Determine lifetime goals for your child with a disability.**
- **Make time for you and your significant other to be together.**
- **Take time with your other children to enjoy and appreciate them.**
- **Make time for the whole family to enjoy being together.**

Take Care of Yourself

Just as a car needs to refuel to run efficiently, so do you. Taking care of your family requires that you take time for yourself. Consider becoming part of a support community. We can help connect you with needs specific groups. Surround yourself with people who understand the special needs, challenges, and joys that you and your child face.

Be an Advocate for Your Child

You know your child best. Educate yourself so that you can effectively advocate for your child and use your voice to do so. Encourage your child to become a self-advocate, always remembering the goal of independence. When advocating, assume others have your child's best interests in mind but also share your observations, opinions, and your child's needs. Be informed about:

- **Your child's educational rights.** Children under the age of 3 are eligible for early intervention services. Children 3 or older are eligible for special education services through the local public school system.

- Your insurance. Read your policy carefully to determine benefits. Keep detailed, up-to-date records and make notes on all phone conversations. Ask for a supervisor when necessary and don't give up at first refusal if you think you are right. Include medical documentation, explanatory letters, etc. when appealing a ruling.

Share the responsibility by:

- Seeking support from others.
- Prioritizing. Don't try to do everything at once. Decide on a course of action.
- Seeking balance for your life. Use respite (specialized child care while you take a break).
- Empowering your child with the words to understand his or her disability and with a story to tell others.

*Content provided by Lynnette Henderson, PhD, as part of Journeys in Disability: Information and Support for Families; Vanderbilt Kennedy Center

Family Voices Indiana

Family Voices Indiana (FVIN) works with and for people with disabilities and their family members, service providers and advocates. FVIN can connect you with trained family leaders, who have children with special health care needs and expertise in these programs: health care financing, Medicaid, Medicaid waivers, respite, First Steps, and special education. FVIN also shares advocacy opportunities and updated information on issues that impact Indiana families of children with disabilities or special health care needs.

Find out more about FVIN at:

www.Fvindiana.org and
<http://Facebook.com/fvindiana>

Contact us to find resources and support in your local community.

info@fvindiana.org
844-F2F-INFO (844-323-4636)

Other Statewide Resources:

First Steps – Indiana's Early Intervention System (Age 0-3)

<http://www.in.gov/fssa/4655.htm>
1-800-545-7763 or FirstStepsWeb@fssa.in.gov

Indiana Dept of Education –

<http://www.doe.in.gov/specialed>
877-851-4106 or specialeducation@doe.in.gov

ASK - Family support, online resource directory.

www.aboutspecialkids.org
800-964-4746 or
familynetw@aboutspecialkids.org

IN*Source - Ensures effective educational services and programming.

www.insource.org
800-332-4433 or insource@insource.org

Disability-Specific Organizations:

The Arc of Indiana – Supporting individuals affected by developmental disabilities.

www.arcind.org
800-382-9100

United Cerebral Palsy of Greater Indiana -

Supporting individuals affected by cerebral palsy.

www.ucpaindy.org
317-871-4032

Down Syndrome Indiana – Supporting individuals affected by Down Syndrome.

<http://www.dsindiana.org/>
888-989-9255 or info@dsindiana.org

Autism Society of Indiana – Supporting individuals affected by autism.

www.inautism.org and www.arnionline.org
800-609-8449 or info@inautism.org