

Parenting a Child With a Disability

TIPS AND RESOURCES FROM JOURNEYS IN DISABILITY*



The Day the World Changed

When parents first learn that their child has a disability, they may experience feelings of grief. Parents often describe a sense of sadness and a feeling that the dreams they held for their child have been lost. Grief has many stages and may include a wide range of negative feelings. 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.

Coping

When you are ready, you may begin to focus on what your child needs and on the strengths that your family will bring to meet challenges. Actively forgive yourself and others. Practice gratitude. Reaching a place of hope and optimism takes time. It is a gradual process that will take place as you begin to understand the disability and your child.

Moving Forward

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

- Love Your Child. Your child with a disability is still the same wonderful and unique person that he or she was before the diagnosis came along.
- Learn to appreciate the things that make your child happy.

- Don't look for the "disability" in everything your child does. Read up on age-appropriate behaviors. Children with disabilities go through many of the same stages as typically developing kids, just differently. Look for your child's strengths and build on them.
- Aim for the stars and make decisions based on the long-term goal of helping your child to be as independent as possible.
- Do not have high expectations, and 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 effectively, so do you. Take the time to care for yourself so that you can be the best you for your family. Consider becoming part of a support community. There are many parent groups focusing on specific disabilities. Surround yourself with people who "get" you and your child.

You Are Your Child's Greatest Advocate

You know your child best. You will be well-suited to advocate on your child's behalf until he or she gets older and learns to be a self-advocate. Remember the goal of independence. Assume that people have your child's best interests in mind, but make sure they know what you think is in your child's best interest.

Educate yourself 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.

Please see reverse.



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TIPS AND RESOURCES FOR FAMILIES

- 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, Ph.D, as part of Journeys in Disability: Information and Support For Families.*

Who We Are and Who We Serve

The **Vanderbilt Kennedy Center (VKC)** works with and for people with disabilities and their family members, service providers and advocates, researchers and policy makers. It is among only a few centers nationwide to be a University Center for Excellence in Developmental Disabilities, a *Eunice Kennedy Shriver* Intellectual and Developmental Disabilities Research Center, and a Leadership Education in Neurodevelopmental and Related Disabilities Training Program. The following are some of the ways the Center's programs and staff can assist families, educators, and other service providers.

Tennessee Disability Pathfinder

Tennessee Disability Pathfinder is a free statewide phone, web, and print referral service in English and Spanish. It connects the Tennessee disability community with service providers and resources. Its website database has over 3,000 agencies searchable by Tennessee county and service. Pathfinder is a project of the VKC, TN Council on Developmental Disabilities, TN Department of Health, and the TN Department of Intellectual and Developmental Disabilities. Contact www.familypathfinder.org, (615) 322-8529, toll-free (800) 640-4636.

Other Resources

- **STEP (Support and Training for Exceptional Parents)** - Provides free information, advocacy training, and support services to parents of children who are eligible to receive special education services under the Individuals with Disabilities Education Act (IDEA) and who reside in Tennessee. (800) 280-STEP, www.tnstep.org
- **TEIS (Tennessee Early Intervention Services)** - A voluntary educational program for families with children ages birth through two years of age with disabilities or developmental delays. The primary goal is to support families in promoting their child's optimal development and to facilitate the child's participation in family and community activities. (800) 852-7157, tn.gov/education/teis
- **Tennessee Department of Education, Division of Special Education** - The purpose is to "promote educational services and programs for all Tennessee's children with special education needs that will enable them to lead productive and independent lives." (888) 212-3162, www.tennessee.gov/education/student_support/special_education.shtml
- **Family Voices of Tennessee** - A health information resource for families who have children with special health care needs: disability, chronic illness, physical or mental health conditions. (888) 643-7811, www.tndisability.org/familyvoices
- **The Arc Tennessee** - Advocates for the rights and full participation of all people with intellectual and/or developmental disabilities. www.thearctn.org, (800) 835-7077
- **Partners in Policymaking** - A free leadership and advocacy training program for adults with disabilities and family members of persons with disabilities. Facilitated through the Tennessee Council on Developmental Disabilities. ned.solomon@tn.gov, (615) 532.6556

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