

Adult Siblings of Individuals with Disabilities

TIPS AND RESOURCES FOR FAMILIES



Growing up with a sibling with a disability

Sibling relationships are often the longest-lasting relationships that children form. Like all siblings, they may or may not develop close emotional relationships depending on individual differences and circumstances. Regardless, a child's reaction to a sibling with a disability will have a lasting effect on siblings' self-esteem and emotional development.

General Well-Being of Siblings

According to reports from the National Adult Sibling study, overall, siblings of adults with disabilities are doing very well. Siblings report that, as a group, they spend a fair amount of time with, feel very affectionate and close to, and have benefited greatly from their brother/sister with disabilities. Most siblings report that their physical health is either very good or excellent. Only a small percentage of siblings report being or having been depressed or blue.

What Concerns Adult Siblings?

Because science and self-determination have so successfully contributed to the lengthened lifespan of people with disabilities, many questions arise for siblings about what the future will hold. Who will assist the sibling with a disability when the parents are no longer able to do so? Where will the brother or the sister with a disability live? How can typically developing siblings find their way through a maze of services that continually changes?

Get Involved and Be Prepared

When parents involve siblings in the practical everyday planning issues and in the futures planning process for the sibling with a disability, siblings have higher confidence levels and feel more prepared to face future challenges in their adult relationships with their brother or sister. While families might face complicated and challenging issues, siblings who have a brother or a sister with a disability often have well-developed coping skills and often are highly proficient in finding new and innovative service options.

Planning for the Future

Ideally, planning for the future is a process in which all family members are involved. Planning ensures that families are prepared to handle adult transitions and are aware when and how services are provided. Adult transitions may include: transition from school services to adult services; moving out of the family home; aging issues, including health and health care; marriage and children; and grief issues, such as the loss of a parent.

To ensure preparedness, many families draft a "letter of intent." While not a legal document, this letter can include information about family members and their preferences for the future as well as information on medical histories and behavioral strategies. The letter can serve as a "roadmap" to developing legal and financial arrangements. A letter of intent might include:

- Family history (traditions and stories)
- Support network (friends and neighbors)
- Medical history (doctors and medications)
- Personal histories (capabilities and interests)
- History of activities (education, jobs, social, and volunteer)
- A list of what works (behavioral strategies and motivators)
- Service options in your state (housing and independence)
- Financial planning (estate and legal plans)

Please see reverse for resources.



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RESOURCES

Who We Are and Who We Serve

The **Vanderbilt Kennedy Center (VKC)** works with and for people with disabilities and their family members, educators and service providers, researchers, students, and policy makers. Faculty and staff engage in interdisciplinary research, training, service, and information dissemination and work in collaboration with local, state and national networks and partners. (615) 322-8240, toll-free (866) 936-8852, vkc.vumc.org.

Tennessee Disability Pathfinder

Provides free information, referral sources, and help with navigating services via phone, email, and website. Assistance is available to individuals of all ages, all types of disabilities, and all languages spoken. Its website database has more than 3,000 agencies searchable by Tennessee county and service. Pathfinder is a project of the VKC and is partially funded by Tennessee Council on Developmental Disabilities and other state agencies. (615) 322-8529, toll-free (800) 640-4636, DisabilityPathfinder.org

Tennessee Kindred Stories of Disability

An annual collection of stories that highlight the challenges individuals with disabilities and their families face as they navigate service systems and supports. Booklets are shared with legislators and policymakers to contribute to improved service delivery across all areas of Tennessee. See vkc.vumc.org/kindredstories/

Sibling Programs

Support for siblings who have a brother or sister with a disability, chronic health care issue, or mental health concern. SibSaturdays, ages 5 to 12 and Tennessee Adult Brothers and Sisters (TABS), ages 18+. See vkc.vumc.org/sib

Two Easy Ways to Take Part in Research

StudyFinder is a searchable database that lists current VKC studies. Studies seek people of all ages with and without developmental disabilities. See vkc.vumc.org/studyfinder. Research Match is a secure place for volunteers and researchers to connect. See researchmatch.org

Contact the Vanderbilt Kennedy Center
Nashville (615) 322-8240
Toll-Free (866) 936-VUKC [8852]
vkc.vumc.org
kc@vumc.org

Local and National Resources

- **Autism Society of America**
www.autism-society.org
- **Autism Tennessee**
www.autismtn.org
- **National Down Syndrome Society**
Chapters in Chattanooga, East TN Memphis and Mid-South, Middle TN, plus other affiliated organizations.
www.ndss.org
- **Sib Leadership Network (SLN)**
This project aims to provide siblings of individuals with disabilities the information, support, and tools to advocate with their brothers and sisters and to promote the issues important to them and their entire families.
sibingleadership.org
- **Sibling Support Program**
This program is designed to support siblings of people with disabilities across the lifespan. The website provides information about statewide Sibshop support groups, workshops, national listservs, and general information about the needs and concerns of siblings.
www.siblingsupport.org
- **The Arc Tennessee**
www.thearctn.org
- **The Arc US**
www.thearc.org

Print Resources

- Hodapp, R.M., & Urbano, R.C. (2007). Adult siblings of individuals with Down syndrome: Findings from a largescale American survey. *Journal of Intellectual Disabilities Research*, 51, 1018-1029.
- Hodapp, R.M., Urbano, R.C., & Burke, M.M. (2010). Adult female and male siblings of persons with disabilities: Findings from a national survey. *Intellectual and Developmental Disabilities*, 48, 52-62.
- Burke, M.M., Taylor, J.L., Urbano, R., Hodapp, R.M. (2012). Predictors of future caregiving by adult siblings of individuals with intellectual and developmental disabilities. *American Journal on Intellectual and Developmental Disabilities*, 117(1):33-47.

