

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, 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.

Two Easy Ways to Take Part in Research

The Vanderbilt Kennedy Center serves families through research studies. StudyFinder is a searchable database that lists current VKC studies, including ASD research. Studies seek people of all ages with and without developmental disabilities. See kc.vanderbilt.edu/studyfinder, (615) 936-0448. Research Match is a secure place for volunteers and researchers to connect. Once you sign up and get added to the registry, a researcher will contact you if you're a possible match for the research study. See www.researchmatch.org.

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+. Contact (615) 936-8852.

Other National and Local Resources

- **Rehabilitation Research and Training Center on Aging with Developmental Disabilities (RRTCADD)**
This program promotes the successful aging of adults with intellectual and developmental disabilities in response to physical, cognitive, and environmental changes. It

provides information on sibling roles and interventions in planning for transitions.

www.rrtcadd.org/sibling_network/index.html

- **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
- **Adult Sibling Research**
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.
- **The Arc Tennessee**
www.thearctn.org, (800) 835-7077 or (615) 248-5878
- **Autism Society of America**
Chapters in East and Middle TN. www.autism-society.org
- **National Down Syndrome Society**
Chapters in Chattanooga, East TN Memphis and Mid-South, Middle TN, plus other affiliated organizations.
www.ndss.org, (800) 221-4602
- **Tennessee Developmental Disabilities Network**
www.tennddnetwork.org

Contact the Vanderbilt Kennedy Center

Nashville (615) 322-8240

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