

# Adult Siblings of Individuals with Disabilities

TIPS AND RESOURCES FOR SIBLINGS



## 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. For more detailed results from the National Adult Sibling study see reverse: National Sibling Research Consortium.

## 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?

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. Get involved and be prepared. 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 has been a process in which *all* family members have been involved. Planning ensures that families are prepared to handle adult transitions and are aware when and how services are provided. Adult transitions may include: The 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)

# Adult Siblings of Individuals with Disabilities

## How We Can Help

### Who We Are and Who We Serve

The **Vanderbilt Kennedy Center (VKC)** works with and for people with disabilities and family members, service providers and advocates, researchers and policy makers. It is among only a few centers nationwide to be both a University Center for Excellence in Developmental Disabilities and a national Developmental Disabilities Research Center. Futures Planning workshops are offered periodically to assist families in the "Letter of Intent" process.

### Tennessee Disability Pathfinder

This free statewide phone, web, and print referral service in English and Spanish connects the Tennessee disability community with service providers and resources. Its website database has 1,600 agencies searchable by Tennessee county and service. Pathfinder is a project of the VKC and the Tennessee Council on Developmental Disabilities. Contact [www.familypathfinder.org](http://www.familypathfinder.org) (615) 322-8529, toll-free (800) 640-4636.

### Vanderbilt Kennedy Family Outreach Center

This center provides families with a single point of entry into the many services and supports of the VKC, Vanderbilt University, and the community. Services include SibSaturdays, research projects, clinics, social work services, and recreational and arts programs. Contact [familyoutreach@vanderbilt.edu](mailto:familyoutreach@vanderbilt.edu), (615) 936-5118.

### Two Ways to Take Part in Research

The VKC serves families through research studies. **StudyFinder**, a searchable database, lists studies seeking people of all ages with and without disabilities. See [kc.vanderbilt.edu/studyfinder](http://kc.vanderbilt.edu/studyfinder). **Research Family Partners** allows families with and without disabilities to register and to be contacted when a study begins for which a family might be eligible. Contact [kc.vanderbilt.edu/RFP](http://kc.vanderbilt.edu/RFP), (615) 936-0448, toll-free (866) 936-8852.

### National Sibling Research Consortium

This Consortium is a collaborative effort of researchers from several universities interested in siblings of individuals with disabilities and The Arc of the US, with Vanderbilt Kennedy Center leadership. The Consortium has conducted a national survey of adult siblings of individuals with disabilities. Contact [disabilitysibs@vanderbilt.edu](mailto:disabilitysibs@vanderbilt.edu). [kc.vanderbilt.edu/kennedy/research/siblingconsortium.html](http://kc.vanderbilt.edu/kennedy/research/siblingconsortium.html)

### Tennessee Adult Brothers and Sisters (TABS)

This is a newly organized group for adult siblings of individuals with disabilities. TABS seeks to provide members with support and information. Quarterly support meetings are being offered and a conference is being planned for 2009. Contact (615) 322-8529 x15. [kc.vanderbilt.edu/kennedy/community/adultsiblings.html](http://kc.vanderbilt.edu/kennedy/community/adultsiblings.html)

### 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.uic.edu/orgs/rrtcamr/index.html](http://www.uic.edu/orgs/rrtcamr/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.

<http://sibleadership.blogspot.com>

#### 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](http://www.siblingsupport.org)

#### SibNet Listserv—for adult siblings

SibNet is the internet's first listserv for adult brothers and sisters of people with special health, developmental, and emotional needs.

[www.siblingsupport.org/connect/the-sibnet-listserv](http://www.siblingsupport.org/connect/the-sibnet-listserv)

**The Arc of Tennessee**, [www.thearctn.org](http://www.thearctn.org), (800) 835-7077 (615) 248-5878

**The Arc US**, [www.thearc.org](http://www.thearc.org), (301) 565-3842, toll-free (800) 433-5255

**Autism Society of America**, [www.autism-society.org](http://www.autism-society.org)

Tennessee chapters: East and Middle Tennessee

**National Down Syndrome Society**, [www.ndss.org](http://www.ndss.org), (800) 221-4602. Tennessee chapters: Chattanooga, East Tennessee, Memphis and Mid-South, Middle Tennessee, plus other affiliated organizations.

**Tennessee Developmental Disabilities Network**, [www.tennddnetwork.org](http://www.tennddnetwork.org)

**Contact the Vanderbilt Kennedy Center**  
Nashville (615) 322-8240  
Toll-Free (866) 936-VUKC [8852]  
[www.kc.vanderbilt.edu](http://www.kc.vanderbilt.edu)  
[kc@vanderbilt.edu](mailto:kc@vanderbilt.edu)

Please see reverse for information for adult siblings of individuals with disabilities.



**VANDERBILT KENNEDY CENTER**  
FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES