

Adolescent & Young Adult Siblings of Individuals with Disabilities

TIPS AND RESOURCES FOR FAMILIES



Growing up with a sibling with a disability

Sibling relationships often are the longest-lasting relationships that children form. Relationships vary greatly, based on the ages, gender and age span of the children, their shared interests and their family's lifestyle. Variations in closeness, time spent together, and warmth in sibling relationships are expected in families where one child has a disability. Each sibling is affected by their brother or sister and by the relationship they form.

How might a typically developing adolescent feel about having a sibling with a disability?

Feelings vary between people and over time periods in their lives. Typically developing teen or young adult siblings may experience a range of emotions including:

- Increased understanding and empathy—many siblings of children with disabilities develop a maturity about the needs of others and appreciation of their own health.
- Pressure to overachieve in order to “compensate” for a sibling.
- Worry about the well-being of their brother or sister with a disability and/or worry about what the future holds for both them and their brother or sister.
- Anger or embarrassment about a sibling's appearance or behavior in public.
- Jealousy of time and attention a sibling receives because of a disability.

How might siblings relate as they get older?

Adolescence and young adulthood are times of change for typically developing brothers and sisters, for their siblings with disabilities and for families. As young people become independent and leave home for school, work, or new

relationships, family members change their longstanding patterns of interaction and shared time. Many transition issues will be the same when one sibling has a disability. However, issues about expectations and future responsibilities for the sibling with a disability may make this time more challenging for families. These years may be a critical time for sibling relationships. Emotional closeness in adolescence is predictive of the siblings' future relationship.

Discussing a disability with a typically developing teen

Once children have progressed to their teen/young adult years, they have a greater capacity to understand more complex information about their sibling's disability and the impact on daily and long-term functioning. Open communication in the family about the sibling with disabilities sets the stage for greater understanding and more realistic expectations. The more typically developing siblings understand and are understood, the more likely they will be able to communicate a full range of feelings about having a sibling with a disability.

What might a typically developing child need during adolescence or young adulthood?

There may be gaps between a sibling's intellectual understanding of a disability and their emotions. Take time to talk through these emotions. Sibling support groups can connect your child to other siblings. One-on-one counseling may prove to be beneficial as well. At this age, typically developing siblings often begin to worry about their future and how their plans will be impacted by their sibling with a disability. It is important to talk openly about their concerns, to encourage their questions about the future, and to share information about family planning. When possible, include the adolescent or young adult sibling in planning for their brother or sister's future. Include the sibling with the disability as well.

What are the special needs of the family?

A family will benefit from participation in traditional family activities whenever possible. All children should be encouraged to develop as much independence as possible, contributing to the family and having responsibilities within their capabilities. Discuss future care-taking needs of a child with a disability. Request and value the opinions of all family members. Avoid steering typically developing siblings into a care-taking role and encourage them to take time to work towards achieving their own personal goals. Help the child with a disability understand why other siblings leave home (for school or work) or spend more time with other friends as they get older. Encourage all family members to develop new ways to stay in touch even when they are not living in the same household.



VANDERBILT KENNEDY CENTER
FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES

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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.

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 (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**, (a sibling support group), research projects, clinics, social work services, and recreational and arts programs. Contact 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. **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, (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. 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. A conference is being planned for 2009. Contact (615) 322-8529 x15. 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

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

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

The Arc of Tennessee, www.thearctn.org, (800) 835-7077 (615) 248-5878

The Arc US, www.thearc.org, (301) 565-3842, toll-free (800) 433-5255

Autism Society of America, www.autism-society.org

Tennessee chapters: East and Middle Tennessee **National Down Syndrome Society**, 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

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