

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



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RESOURCES

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.

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

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

Contact the Vanderbilt Kennedy Center
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