

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.

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 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.

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.

Tennessee Kindred Stories of Disability

A collection of stories from individuals with disabilities, families, friends, and disability service providers in Tennessee. See kc.vanderbilt.edu/kindredstories/

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. siblingleadership.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
- **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 Tennessee**
www.thearc.org, (800) 835-7077 or (615) 248-5878
- **The Arc US**
www.thearc.org, (800) 433-5255
- **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

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