

Supporting Siblings: A Lifelong Journey

From being a first friend to a lifelong advocate, siblings of an individual with HADDS, 10q26 deletion syndrome, or any other disability play a crucial role.

Emotional support, practical resources, and connections with peers in similar roles can ensure that siblings thrive throughout their lives. If you're a sibling looking for support, know that you are not alone—there is a global community ready to walk this journey with you. Thank you to all the wonderful siblings in our EBF3 HADDS and 10q26 deletion community for everything you do!

The Unique Role of Siblings

Siblings of individuals with disabilities often serve in multiple unique roles:

- **First Friend & Best Friend** – The sibling relationship is one of the longest-lasting bonds in a person's life, often providing companionship and understanding.
- **Protector** – Many siblings take on a natural role of protection, ensuring their sibling's safety and well-being.
- **Advocate** – As they grow, siblings often become strong advocates for accessibility, inclusion, and awareness.
- **Future Caregiver** – For some, a sibling may become an adult caregiver or guardian, which can bring both fulfillment and challenges.

Insights from Research

Studies on siblings of individuals with disabilities highlight both positive and challenging aspects:

- **Resilience & Empathy** – Siblings often develop heightened compassion, patience, and advocacy skills.
- **Mixed Emotions** – Feelings of pride, love, and responsibility are common, but so are feelings of isolation, guilt, and concern for the future.
- **Glass child syndrome** or a tendency to always put others first, may describe the experience of some siblings.
- **Importance of Support** – Access to peer support, information, and coping strategies can improve well-being for siblings.



Read more here:

[Siblings of people with intellectual and developmental disabilities: a systematic review on their quality of life perceptions in the context of a family.](#)

[Support Needs of Siblings of People with Developmental Disabilities.](#)

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How to Support Siblings

- **Acknowledge Feelings** – Siblings may experience a range of emotions, and open, nonjudgmental conversations help them feel understood. The experience of the sibling may mirror that of their parents as they are living in the same household and observing the same differences or challenges they may see with their sibling.
- **Encourage Open Communication** – Explaining HADDs / 10q26 deletion syndrome to the sibling from a young age can help them better understand and accept their sibling and confidently answer questions that may come up from peers or others.
- **Differentiate Between Parent and Sibling Roles** – For young siblings, parents can strive to avoid parentification of the sibling (taking on family responsibilities that aren't developmentally appropriate; acting as another parent or adult) and be aware of the risk for glass child syndrome. As siblings mature, honest discussions about responsibilities, equity, challenges, and family dynamics can ease potential stress.
- **Provide Age-Appropriate Support** – Siblings' needs change over time; ensuring they have the right support at each stage is essential. Consider seeking a therapist or professional support outside of the family as an option for your child to share their feelings and learn additional strategies.
- **Ensure Meaningful One-on-One Time** - dedicated time with parents for each sibling is important regardless of life stage.

[This podcast](#), featuring Emily Holl, the Director of the Sibling Support Project from SibShops, has some excellent ideas on sibling support.

There are books also focused on sibling support, for parents and for siblings themselves.

- *Views from Our Shoes: Growing Up with a Brother or Sister with Special Needs* – Donald Meyer
- *The Sibling Survival Guide* – Don Meyer & Emily Holl
- *Being the Other One: Growing Up with a Brother or Sister Who Has Special Needs* – Kate Strohm

Organizations

There are wonderful programs and organizations focused on sibling support around the world, offering both in-person and online support.

Formal Programs & Peer Support

- [Sibshops \(International\)](#) – Workshops for young siblings to meet peers and share experiences
- [Siblings with a Mission \(Global\)](#) – Online community for siblings to connect and find support
- [The Sibling Leadership Network \(U.S.\)](#) – Resources for advocacy, caregiving, and community building
- Young Carers Networks ([UK](#), [Canada](#), [Australia](#)) – Support for siblings taking on caregiving roles

Organizations by Country

- United States: [Sibling Support Project](#), [The Arc's National Sibling Council](#)
- United Kingdom: [Sibs UK](#)
- Canada: [Young Carers Program](#), [The Sibling Collaborative](#)
- Australia: [Carers Australia](#) – [Young Carers Program](#)

