

Sibling Needs Across the Life Course

The needs of siblings of people with disabilities are complex, varied, and change over time. This document reflects the consistent needs that have been expressed by siblings during Sibling Leadership Network (SLN) meetings, conversations, and collaborations. This chart shares the needs that many siblings experience, though each sibling experience is unique.

Life Course Stages Siblings May Need

Childhood

- Developmentally appropriate information about their sibling's disability. (What is the name of the disability? How does it affect their sibling? How did their sibling acquire their disability and did they in any way cause it or can they catch it?)
- Information to respond to questions from other people about their sibling's disability. (ie. a script that they can use to answer questions that other children, or adults may ask about their sibling.)
- Guidance on how to include their brother or sister with disabilities in play together
- Quality time alone with parents
- To meet peers who are also siblings of people with disabilities who understand their concerns
- Strategies for addressing bullying of their sibling and/or themselves
- Adults at school and home who are interested in hearing what they have to say
- Parental explanations about potential differences in expectations and rules between themselves and their sibling with disabilities
- Professional support such as counseling, when appropriate

Teen Years

- Increasing information about their sibling's disability
- Opportunities to spend time alone with their friends
- Time alone with parents
- A chance to play a role other than caregiver in their family
- Opportunities to talk to their family about their questions about what the future may hold with their sibling with disabilities
- Role models to teach them how to advocate with their siblings
- Trusted peers who understand their concerns

Teen Years

- Strategies to address peer reactions and bullying. In this stage there is potentially increasing embarrassment due increasing awareness that sibling's behavior is different and societal stigma.
- An invitation to provide input into the IEP process (if their brother or sister with disabilities wants them to do this—check first.)
- To learn how to address guilt – guilt that they have more friends, guilt about moving toward higher education, guilt about not having a disability, and more.
- A safety plan, when appropriate, if their sibling's behavior is violent.
- Space and guidance to plan for life outside of the family (leaving to go to college/readjusting familial relationships).
- Opportunities to help their brothers and sisters with disabilities learn to advocate for themselves.

Adulthood

- Spaces to address concerns about future planning and future responsibilities. Through adulthood there are increasing questions about living arrangements, finances, and caregiving. Siblings need time and space to discuss and process this both within their family and possibly with other people outside the family as well.
- To talk within the family about shifting roles and what this means for them.
- To be included in appointments (medical, etc.) or provided information about this to have a better sense of the routine and needs of their brother or sister with disabilities.
- Their parents to recognize their need for adult relationships with their brothers and sisters with disabilities.
- Peer support from other siblings of people with disabilities related to concerns about implications for their romantic relationships (dating, marriage, in-laws, etc.).
- To have discussions about raising their own children and considering heritability of disabilities. These conversations are often not only medical but often emotional.
- Guidance on how to navigate the “system” of services and support related to their brother or sisters disabilities.
- To learn how to support their brother or sister with disabilities live a self-determined life. This can include getting guidance on how to advocate with their brothers and sisters with disabilities as well as to support their sibling with disabilities self-advocate both individually and with a collective group of peers.
- Information on how to support their brother or sister with disabilities in his/her sexuality and intimate relationships.
- Forums to address the stigma of disabilities and to raise awareness of disability and the importance of inclusion for people with disabilities.

Adulthood

- To navigate the role of their brother or sister with disabilities as an aunt/uncle to their children. This may involve supporting their children and their sibling with disabilities to have a successful relationship with each other.
- Tools to manage juggling multiple caregiving roles – caring for their own children, their brother or sister with disabilities, and aging parents.
- Avenues to participate in advocacy for disability issues - at an individual, community, and legislative level.
- Information about how to respect the dignity of their sibling's decisions while still providing guidance when needed.
- Assistance with understanding finances – including legal fees to prepare future planning documents, implications of long-term decisions.
- Recognition of implications of intersectionality – disability, gender, social class, religion, race, sexual orientation.
- Respect from friends and colleagues that sometimes siblings want to “just be me.”
- Coping mechanisms for the feelings/judgements that may emerge, including guilt that they are not doing enough.

Older Age

- Tools for addressing end-of-life issues.
- Support for the issues of grief and loss – how to support your sibling when parents die; how to support yourself in grief; the loss of a brother/sister.
- Increased support for the transition of caregiver roles shifting.
- Support for managing life across state lines from your brother/sister.

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