

Sibling Support Throughout Life



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Overview

- ◆ The Sibling Experience throughout life:
 - Childhood
 - Teen years
 - Adulthood
 - Older age



- ◆ Resources for siblings can be found at the Sibling Leadership Network website: siblingleadership.org



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. (i.e. 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

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Life Course Stages Siblings May Need

Teen Years

- Strategies to address peer reactions and bullying. In this stage there is potentially increasing embarrassment due to 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.

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Tell us about yourself!

Are you a:



- Person with a disability
- Sibling of a person with disabilities
- Sib-in-law of a person with disabilities
- Parent of a person with a disability
- Other family member
- Professional

Katie's Siblings





The Sibling Relationship

- ◆ Siblings have longest relationship
- ◆ Sibling experiences are often overlooked
- ◆ The sibling experience is varied and important



Sisters: Amy and Emily



Childhood



Resources for childhood

- ◆ Sibling Support Project

www.siblingsupport.org

- ◆ Sibshops



- ◆ Books:

- Views From Our Shoes

- My Brother Charlie

Adolescence



- ◆ Adolescence is a time of physical and emotional change
- ◆ Sibling relationships help prepare people for the world outside the family
- ◆ Impact on sibling relationships:
 - Differential Parental Treatment (perceived by the child)
 - Conflict can be positive and important for development

Teen Sibling Experiences

- ◆ Learn to be an advocate
- ◆ Problem-solver
- ◆ Jealousy & annoyance
- ◆ Learn new skills
- ◆ Companionship and emotional support
- ◆ Embarrassment



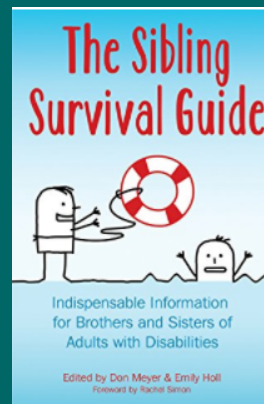
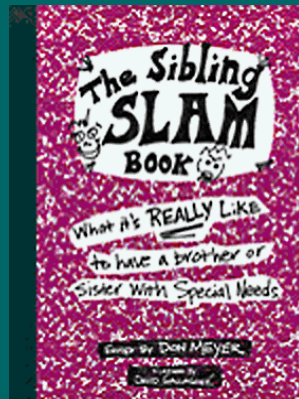
Teens

- ◆ Siblings can help navigate social situations
- ◆ Transition age can be difficult
- ◆ Ask teens how they feel about upcoming transitions
- ◆ Connect teens with peer support



Resources for Teen Siblings

- ◆ SibTeen-for teen siblings to connect with each other online
- ◆ Tips on What Siblings Would Like Parents and Service Providers to Know
- ◆ Books by and for siblings:



Adulthood



Siblings juggle caregiving roles: The “Club Sandwich” Generation



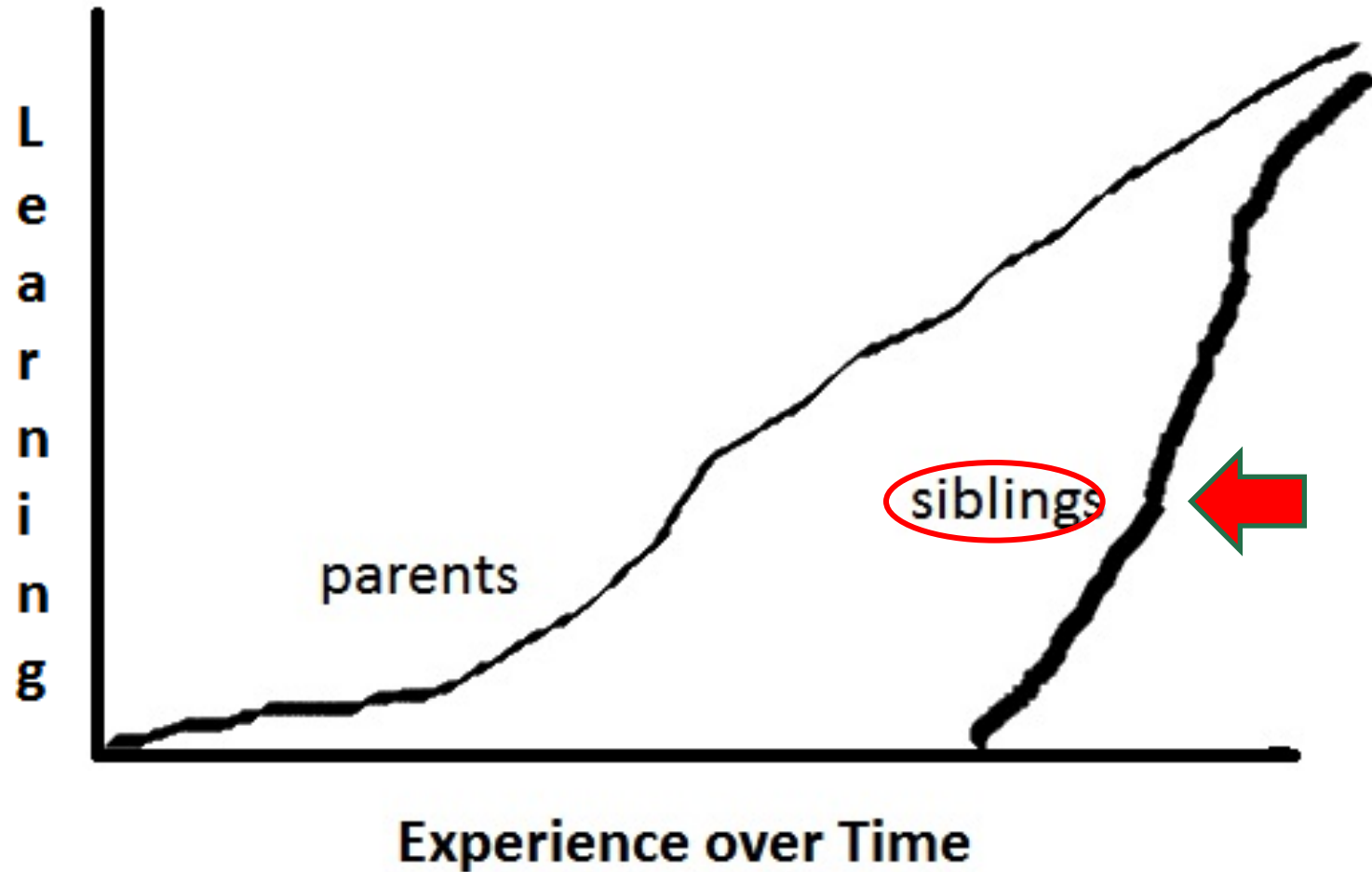
**Aging
Parents**

**Siblings with
Disabilities**

Children



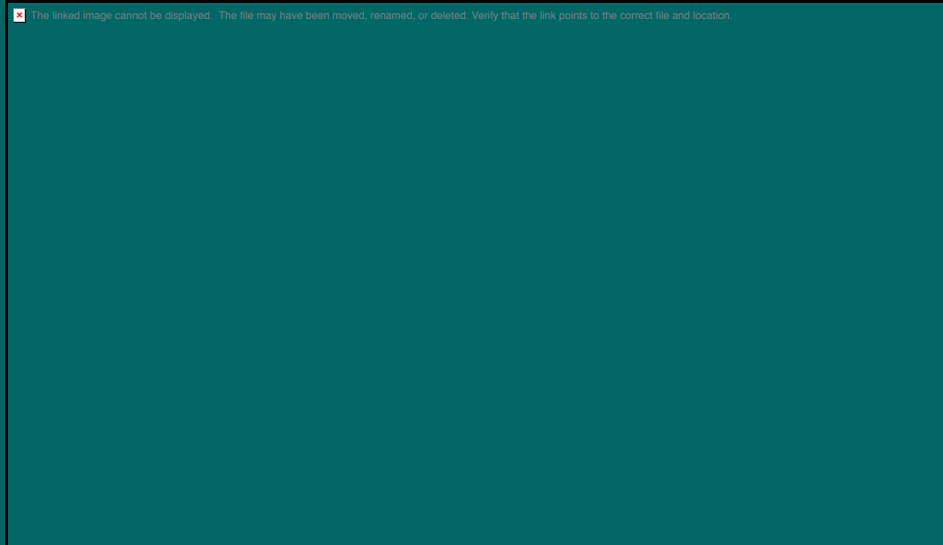
Learning Curve



Future Planning



Resources for Adult Siblings



Online Resources for Adult Siblings

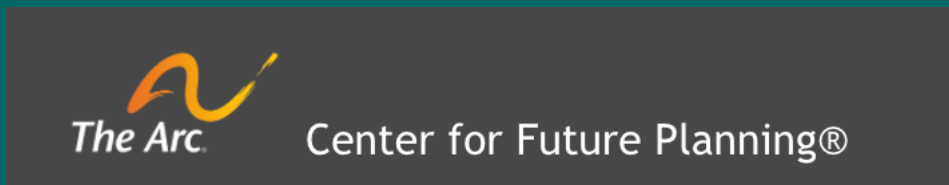
◆ Sibnet on Facebook



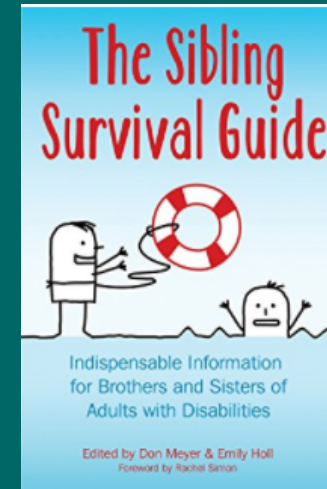
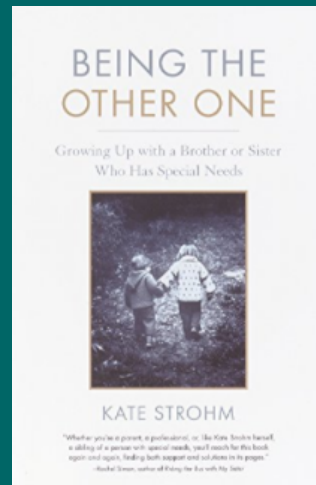
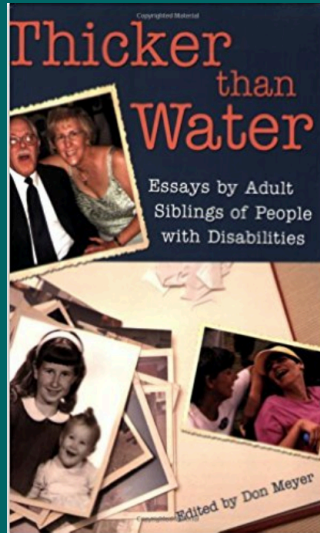
◆ SiblingResources.org



◆ Arc Center for Future Planning



Books for Adults





Older Age



- ◆ Siblings negotiate caregiving for aging parents
- ◆ Quality of sibling relationship can impact health, well-being, and social functioning
- ◆ Social support from siblings is important
- ◆ Ongoing planning for the future, including end of life planning
- ◆ Support for grief and loss

Cultural Diversity in Sibling Relationships

- ◆ Culture, race, and ethnicity play a role in sibling relationships



What can you do?

- ◆ Continue to learn about siblings
- ◆ Create programs that support siblings
- ◆ Share information and resources
- ◆ Invest in siblings





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