



SiblingResources

Sibling Webinar: Future Planning

**Presented by Katie Arnold of the
Sibling Leadership Network**

Sponsored by the NYS DDPC and in collaboration with



**Developmental
Disabilities
Planning Council**



Cornell University



Welcome to SiblingResources

- A collaborative partnership between
 - Cornell University's Yang-Tan Institute
www.yti.cornell.edu - Carol Blessing
 - Sibling Leadership Network
www.siblingleadership.org – Katie Arnold & Amy Halm
 - sibsNY www.SibsNY.org – Lindsay Hyland

Welcome to SiblingResources

- SiblingResources is a new resources available to adult siblings of people with intellectual and/or developmental disabilities
- Funded by the NYS Developmental Disabilities Planning Council – 2nd grant for sibling focus
- Response to a comprehensive Sibling Survey/2011 Report recommendations



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SiblingResources.org

- Our mission is simple:

expand the existing sibling data base and therefore, the sibling network throughout New York state by designing, implementing and sustaining a web-based information and resource portal specific to

- adult siblings and to
- service provider professionals committed to engaging siblings within the service delivery system



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SIBLING
LEADERSHIP
NETWORK





Mission

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.



- sibsNY is a volunteer organization dedicated to providing the siblings of individuals with intellectual, developmental and learning disabilities with information and support.

<https://www.meetup.com/sibsNY/>
sibsny.org

Ways to Find Us!



- Website: SibsNY.org
- Facebook: SibsNY as well as SibsNY support
- Twitter: SibsNY
- Meetup.com: SibsNY

Katie's Siblings



Overview



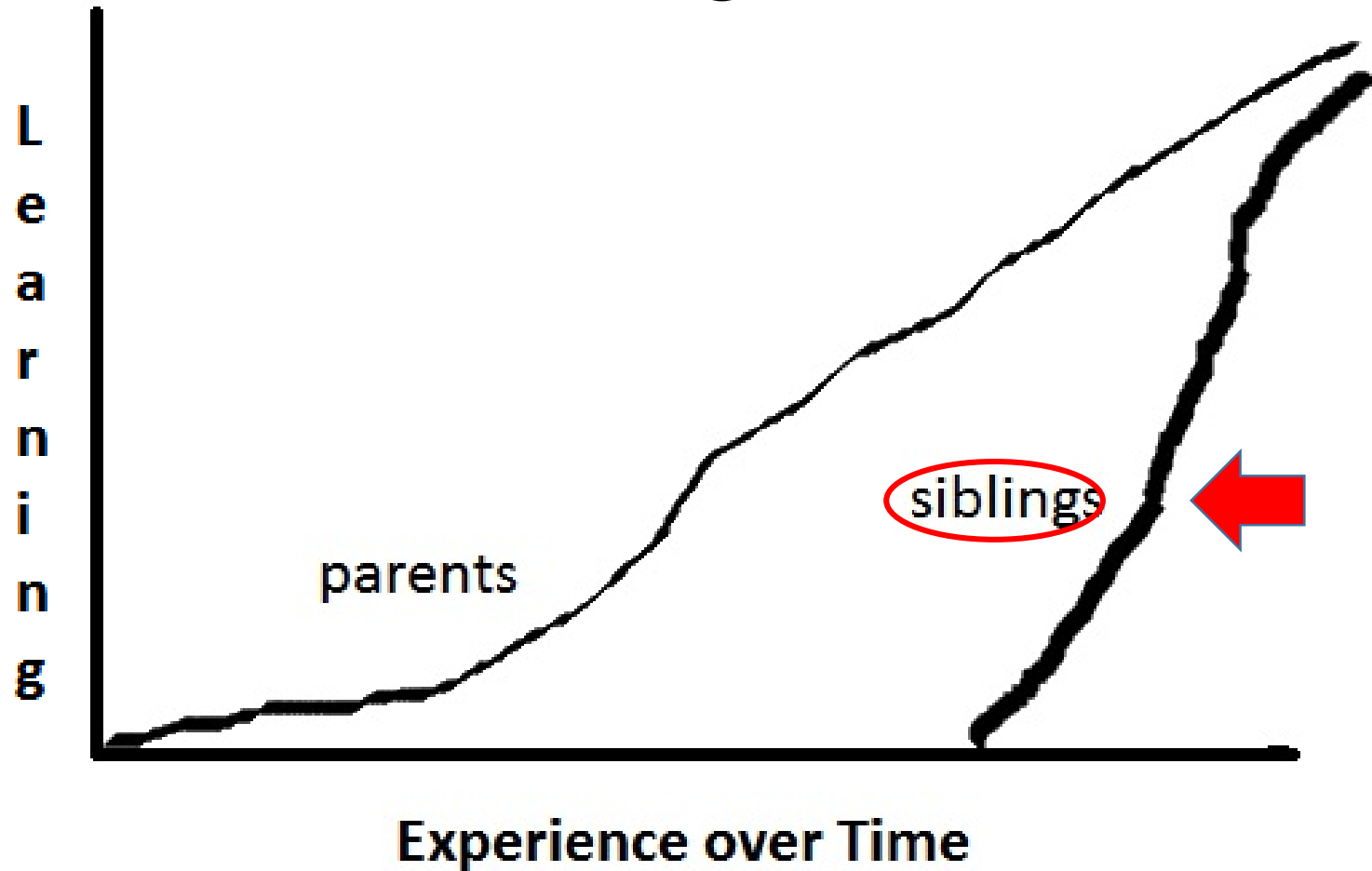
- Sibling Role in Future Planning
- Starting the Difficult Dialogue
- Areas of planning:
 - legal,
 - financial,
 - residential,
 - communication supports, and
 - building relationships and social support networks
- Resource for Sibling Support

The Sibling Relationship

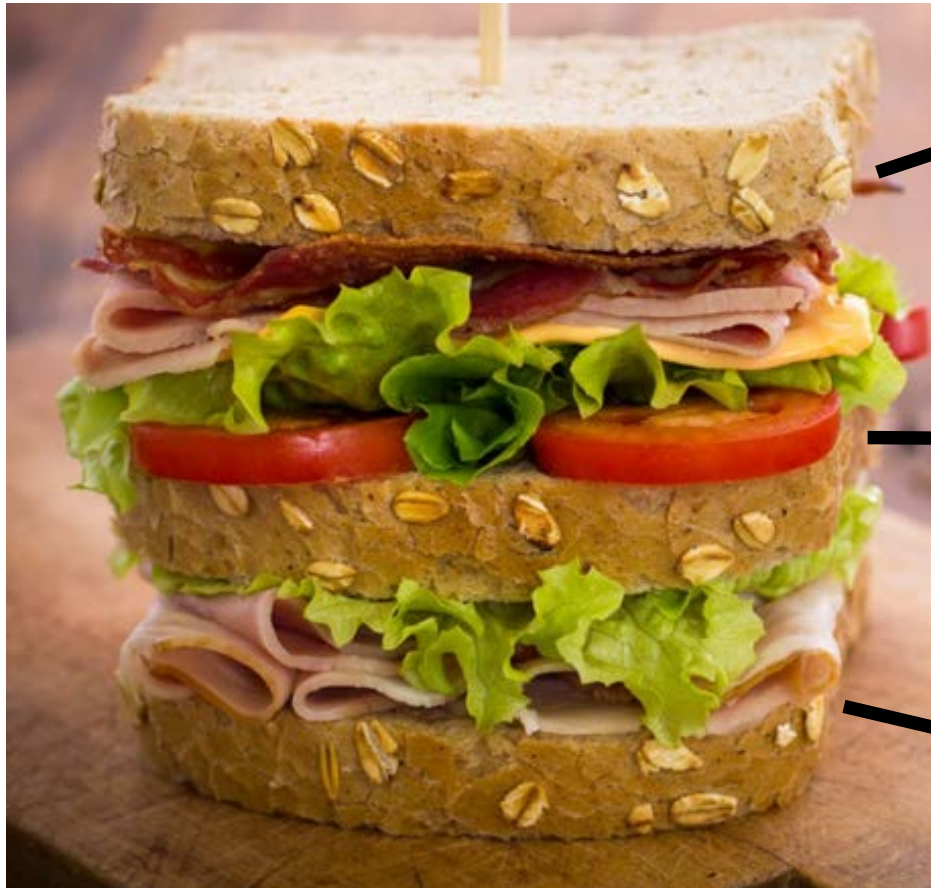
- Siblings have longest relationship
- Sibling experiences are often overlooked
- Siblings have a peer perspective



Learning Curve



Siblings juggle caregiving roles: The “Club Sandwich” Generation



Aging Parents

Siblings with Disabilities

Children



Barriers to Planning

- Anxiety about mortality
- Unaware of options and opportunities
- Lack of resources and options
- Afraid to “burden” siblings



Siblings Role in Future Planning



- Identify concerns and share
- Gather helpful information
- Advocate for services and supports
- Network with other siblings and families

How to get the conversation started



- Talk to your parents and sibling(s)
- Think about your role
- Think about the people who should be part of the conversation

The Arc's Center for Future Planning:
futureplanning.thearc.org

Sibling Gatherings



Role Models



Everyone in the family should have a
voice and a choice in the process



Sibling Connections



Family Meetings



Perspective of Parents



Decision-Making Supports



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The Sibling Survival Guide



Indispensable Information
for Brothers and Sisters of
Adults with Disabilities

Edited by Don Meyer & Emily Holl
Foreword by Rachel Simon

Chapter 11: Planning for the Future

- Alternatives to guardianship:
 - Representative payees
 - Power of attorney
 - Health care surrogacy

[https://www.siblingsupport.org/
publications/our-amazon-astore](https://www.siblingsupport.org/publications/our-amazon-astore)

Special Needs Alliance

- <http://www.specialneedsalliance.org/>



National Resource Center on Supported Decision-Making

<http://supporteddecisionmaking.org/about>

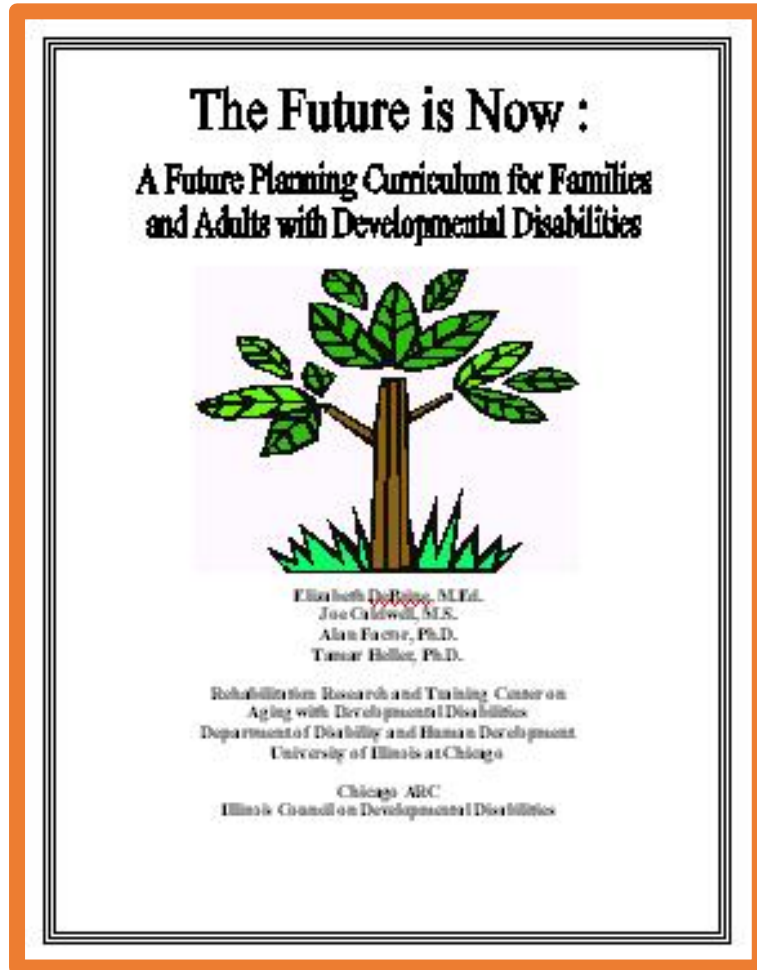


Quality Trust

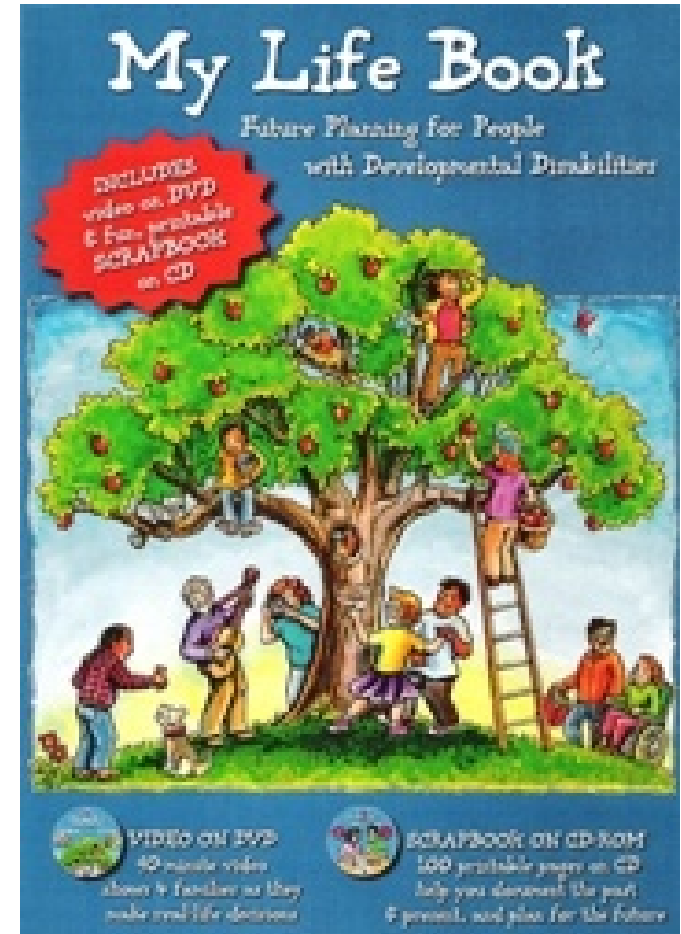
for Individuals with Disabilities

Educate • Advocate • Empower

Future Planning Resources



www.rrtcDD.org



www.lookiris.com

Natural Supports



Intentional Supports



Building Support Networks



Increasing Social Capital



Communication Support





Person Centered Planning



Residential Planning



“A Day in the Life”



Schedule
Medicines
Doctors
Key contacts

Emergency
Plan

Making Decisions as a Family



Areas of Planning:

- Legal Planning
- Financial Planning
- Residential Planning
- Support Networks



Family Dynamics



Resources for Siblings

Connect with other sibs:

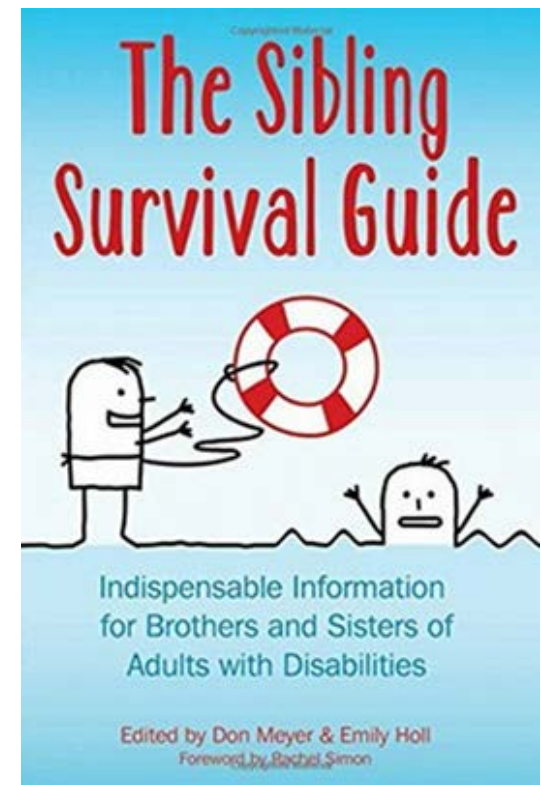
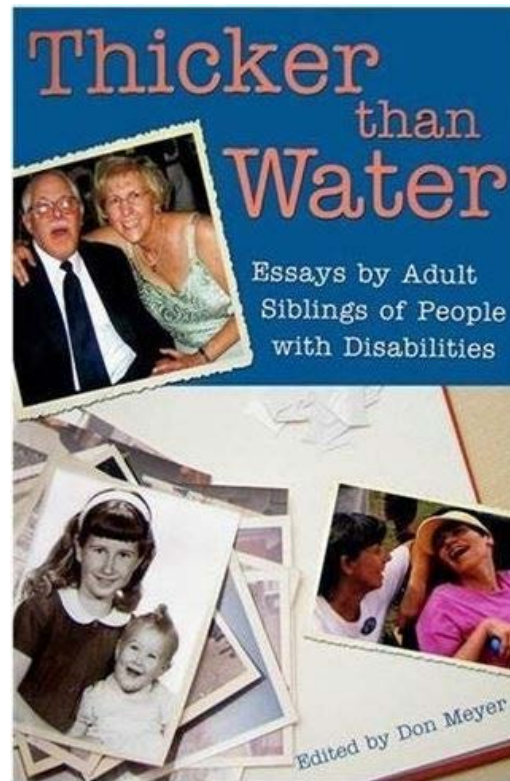
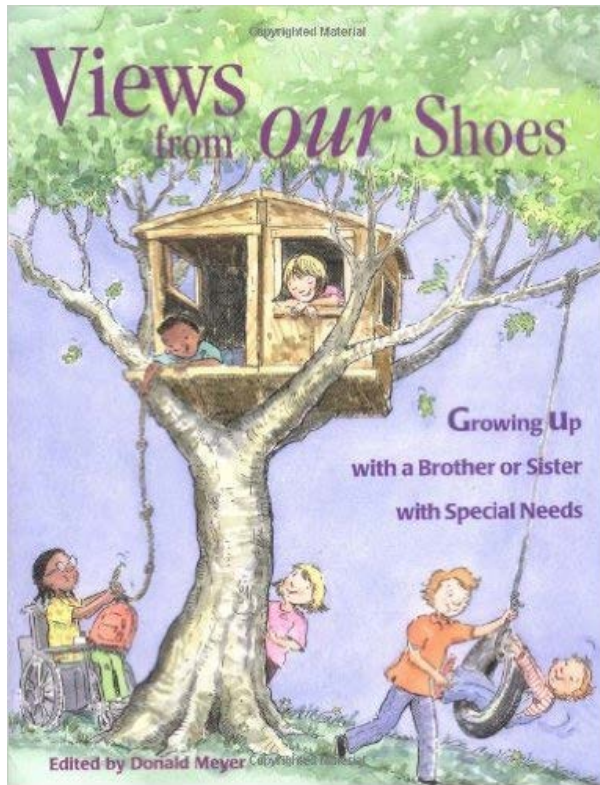
- Join the SLN – www.siblingleadership.org
- Join sibsNY – www.sibsNY.org

Online networks by Sibling Support Project:

- **SibTeen:** for teenager
- **Sib20:** for sibs in their 20
- **SibNet:** for adult sibs



Books written by and for siblings



<https://www.siblingsupport.org/publications/our-amazon-astore>



SiblingsResources.org



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SiblingResources.org

- is being designed to offer:
 - a blend of self-paced, live and archived web-based training opportunities,
 - links to relevant resources and current service delivery system information,
 - downloadable documents and tools
 - Access to and membership in a statewide and national sibling network

Visit the site! Join the network! Give us feedback!

Growing SiblingResources Together!!

You are Invited!

Sibchats:

- February 7, 7-8pm ET Topic: Future planning
- March 12, 7-8pm ET Topic: Sibling support and advocacy
- May 10, 7-8pm ET Topic: Navigating the system

Register for FREE at siblingresources.org





Save the Date!

SIBLING 
LEADERSHIP
NETWORK

2017 National Conference

June 24 & 25
Hartford, Connecticut



For updates on details: siblingleadership.org





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