Sibling Webinar: Future Planning

Presented by Katie Arnold of the Sibling Leadership Network

Sponsored by the NYS DDPC and in collaboration with
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 resource 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
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
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
Sibling Resources

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
Family Meetings
Perspective of Parents
Decision-Making Supports
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
Special Needs Alliance

• http://www.specialneedsalliance.org/
National Resource Center on Supported Decision-Making

http://supporteddecisionmaking.org/about
Future Planning Resources

The Future is Now:
A Future Planning Curriculum for Families and Adults with Developmental Disabilities

My Life Book
Future Planning for People with Developmental Disabilities

www.rrtcDD.org
www.lookiris.com
Natural Supports
Building Support Networks
Increasing Social Capital
Communication Support
Person Centered 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
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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