Siblings and Future Planning

Presented by:
Katie Arnold & Kitty Porterfield
Katie’s Story
The Sibling Leadership Network (SLN) is a national nonprofit with state chapters created to provide information and support to siblings of people with disabilities.

– Lifespan approach
– Welcome sibs of people with ALL types of disabilities, including I/DD
Overview

- Sibling role in future planning
- Starting the future planning conversation
- Power of peer support for siblings
- Resources for siblings in the future planning process.
The Sibling Relationship

• Siblings have longest relationship
• Sibling experiences are often overlooked
• The sibling experience is varied and important
• Siblings anticipate taking on a greater supportive and caregiving role in the future
Research

Sibling Survey for:

- Siblings of people with disabilities
- People with disabilities
- Parents of people with disabilities
- Professionals working with people with disabilities and their families

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

• Network with other siblings and families

• Advocate for services and supports
Sibling Connections
Family Meetings
Decision Making Support

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

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Chicago RRTC
Illinois Council on Developmental Disabilities

www.rrrtcDD.org

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Natural Supports

Achieve with us.
Building Supports
Communication Support
"A Day in the Life"

Schedule
Medicines
Doctors
Key contacts

Emergency Plan
Areas of Planning:

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

Order through Sibling Support Project’s Amazon Store:
www.siblingsupport.org/publications/sibling-related-books-and-movies
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
Family Dynamics
JOIN US!

SIBLING LEADERSHIP NETWORK

www.siblingleadership.org

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SLN Committees

- Policy and Advocacy
- Research
- Communications
- Chapter Development
- Support & Information
Resources for Siblings

• The Arc’s Center for Future Planning: futureplanning.thearc.org
• Connect with other sibs: [Image]
• Find us on Facebook and Twitter
• SibNet
  – www.siblingsupport.org/connect/the-sibnet-listserv

Achieve with us.
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Do You Take Mayo with That?
Living in the Club Sandwich Generation

Kitty Porterfield
INTRODUCTIONS
THE DILEMMA
Club Sandwich Menu: Pick Three

- **Sibling with disability**
- Aging parents
- Two toddlers
- Demanding job
- New baby
- Three teenagers
- Ill parents
- Broken leg
- Absent partner
COPING SKILLS
Research Has Confirmed

Siblings have at least three *highly developed* (and highly useful) skills:

- Stamina
- Resilience
- Problem-solving
Use Your Skills Confidently

• Triage is a discipline.

• Build support team(s).

• Connect with other sibs.

• Listen.

• Communicate. Communicate. Communicate.
THE RIGHT BALANCE
Not Brain Surgery

• Be intentional about your own care. *(Adjust your own oxygen mask first.)*
• Eat well.
• Move.
• Laugh.
• Treat yourself.
• Track you progress.
• Take small steps.
LONG DISTANCE CARE-GIVING
**Can you hear me now?**

• Identify issues early.
• Keep your expectations high, but realistic.
• Make friends with your sib’s staff, colleagues, roommates, friends.
• Visit when you can.
• Use all available media/technology to connect.
• Build your contacts list.
• Say thank you.
Resource: Hot off the press

A new resource guide with chapters written by adult sibs who walk you through future planning, advocacy, family issues, and more.

Edited by Don Meyer & Emily Holl
Woodbine House
2014
Resource: Also of note

Stories written by adult siblings of all ages, describing their experiences growing up in a family with a sibling with disabilities.

Edited by Don Meyer
Woodbine House 2009
Kitty Porterfield
kbporterfield@comcast.net
Questions?

Please raise your hand and we will call on you OR type your question into the chat box.
Next Webinar:

What’s Next: The ABLE Act and Tax Tips
February 10, 2015 from 2:00 – 3:00 pm Eastern

If you have any questions, please contact us at futureplanning@thearc.org