

# Siblings and Future Planning



Presented by:  
Katie Arnold & Kitty Porterfield



For people with intellectual  
and developmental disabilities

# Katie's Story



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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

<http://bit.ly/siblingsurvey>



# 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





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# Sibling Connections



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# Family Meetings



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# Decision Making Support





# **The Future is Now :**

## **A Future Planning Curriculum for Families and Adults with Developmental Disabilities**



Elizabeth DeRango, M.Ed.  
Joe Caldwell, M.S.  
Alan Faine, Ph.D.  
Tamar Heller, Ph.D.

Rehabilitation Research and Training Center on  
Aging with Developmental Disabilities  
Department of Disability and Human Development  
University of Illinois at Chicago

Chicago ABC  
Illinois Council on Developmental Disabilities

**[www.rrtcDD.org](http://www.rrtcDD.org)**



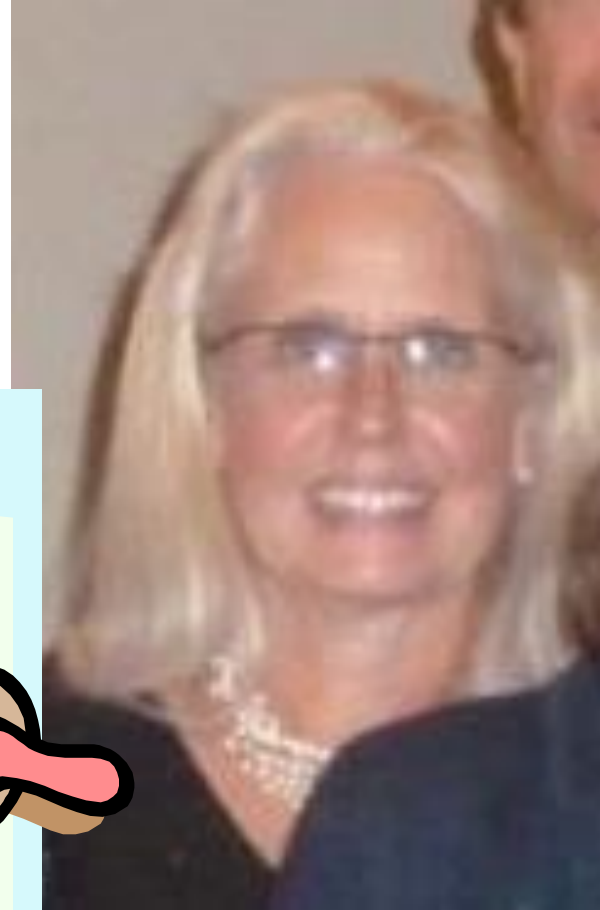
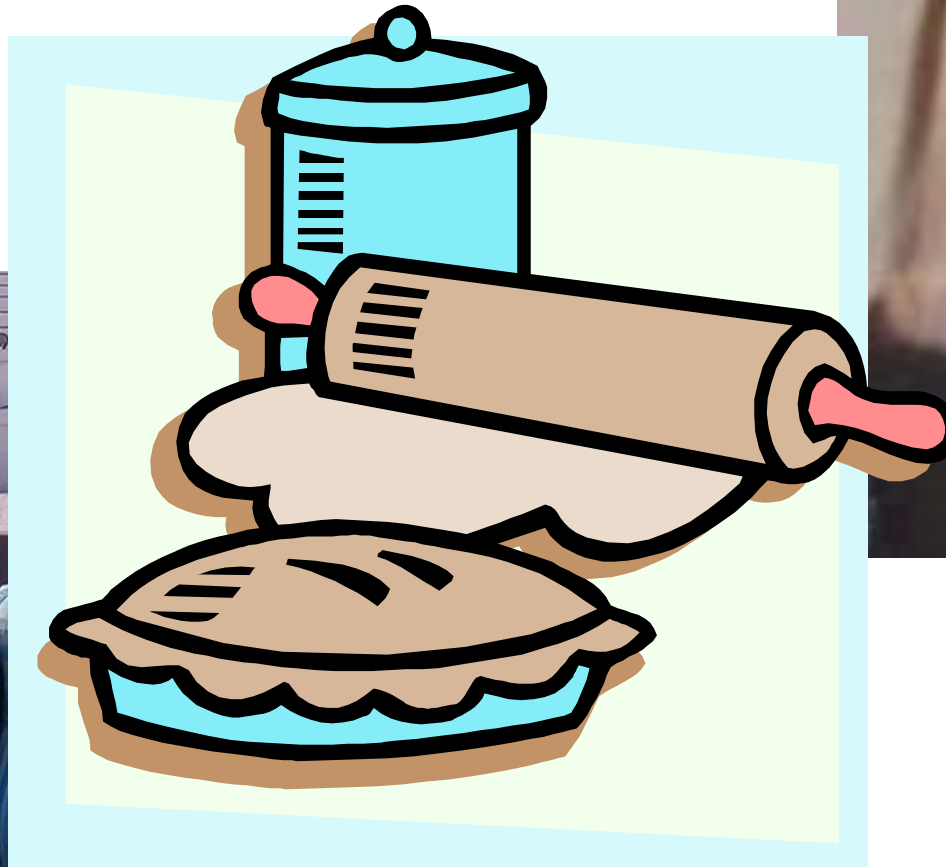
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# Natural Supports



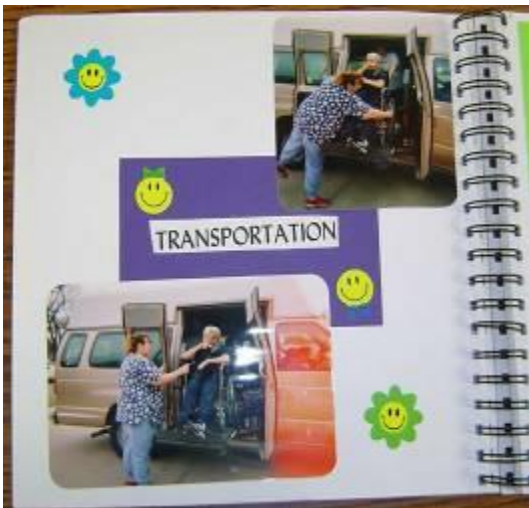
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# Building Supports





# Communication Support





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# Residential Planning



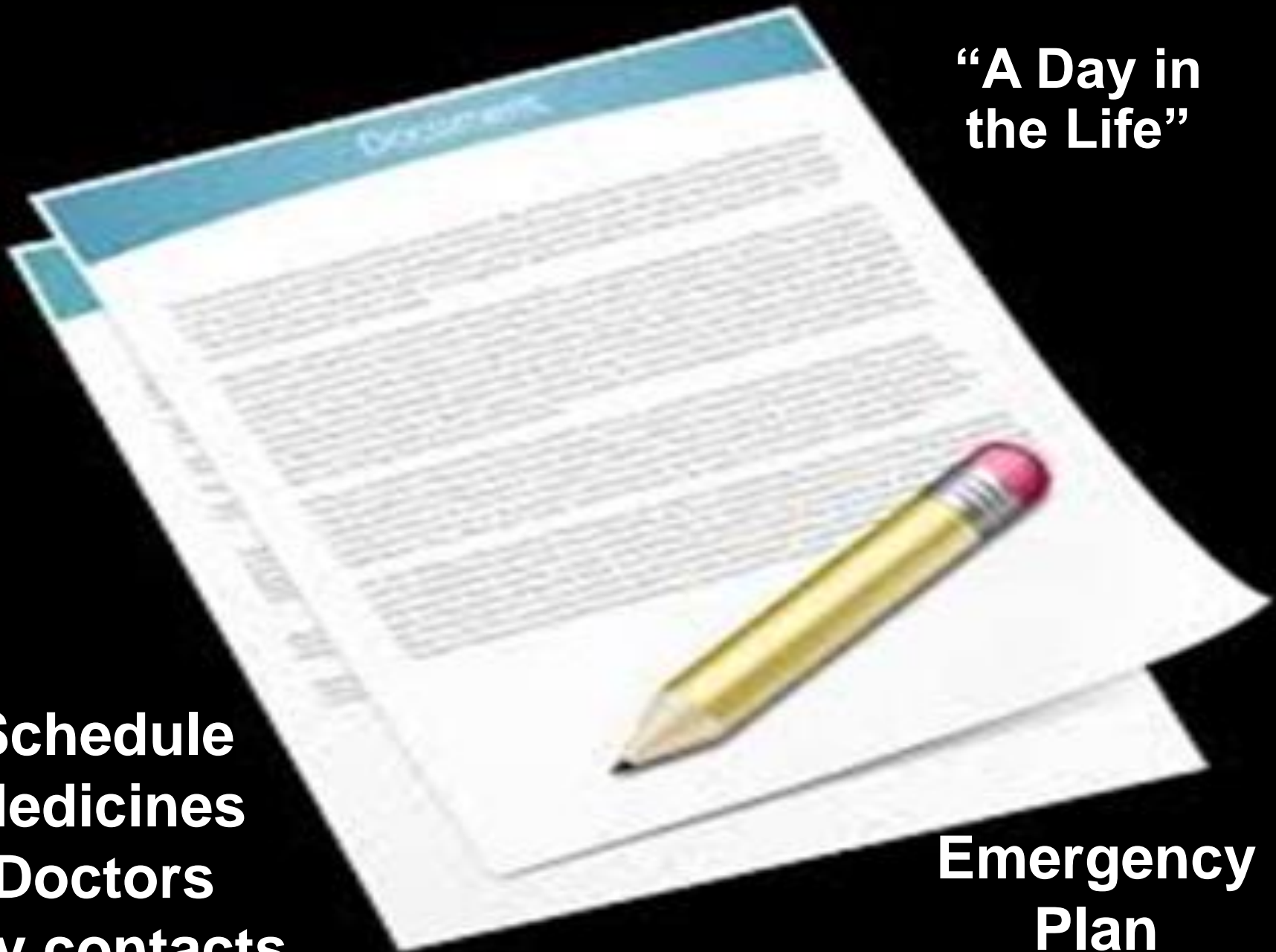
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**“A Day in  
the Life”**

**Schedule  
Medicines  
Doctors  
Key contacts**

**Emergency  
Plan**

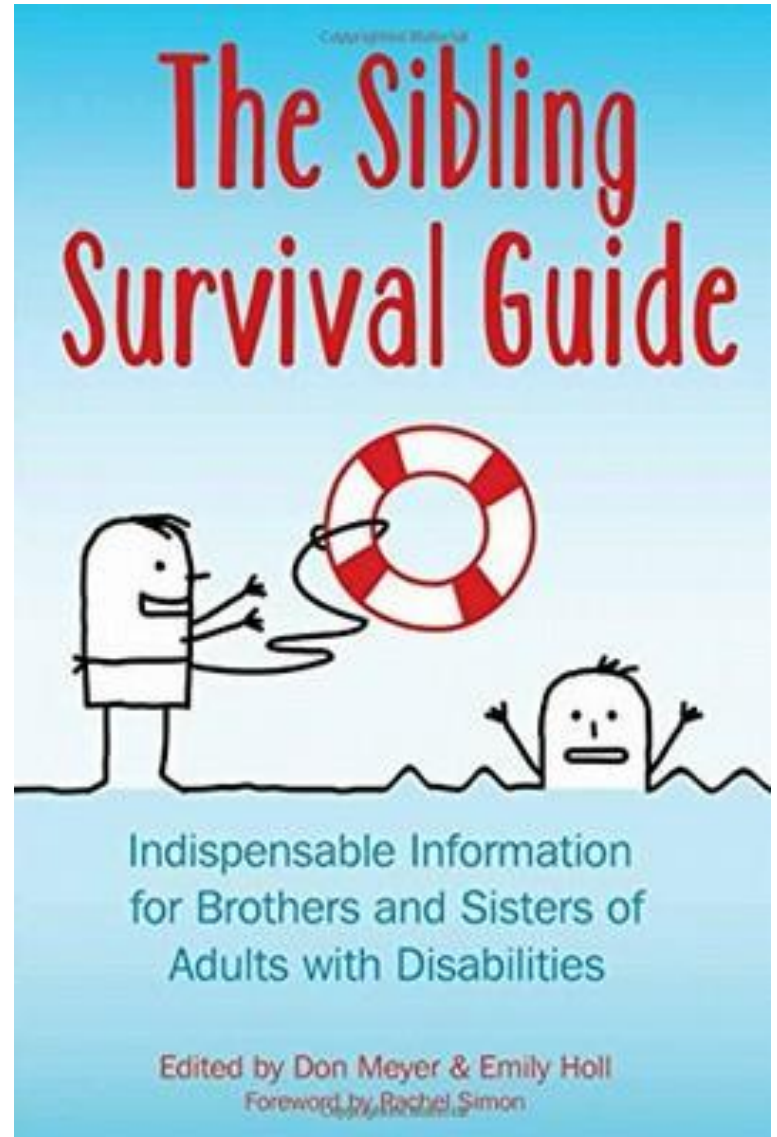




# Areas of Planning:

- 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](http://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







**SIBLING**   
**LEADERSHIP**  
**NETWORK**

[www.siblingsleadership.org](http://www.siblingsleadership.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](http://futureplanning.thearc.org)**
- Connect with other sibs:



- Find us on **Facebook** and **Twitter**
- **SibNet**
  - [www.siblingsupport.org/connect/the-sibnet-listserv](http://www.siblingsupport.org/connect/the-sibnet-listserv)

A "Save the Date" poster for the 2015 National Sibling Leadership Network Conference. The poster features a background image of a large, ornate building with multiple spires, likely a racetrack grandstand, under a blue sky with clouds. In the foreground, there are vibrant pink and purple flowers. The poster includes the Sibling Leadership Network logo at the top. Below it, the text "Save the Date!" is prominently displayed. Underneath, there is a photograph of a group of seven people, four women and three men, smiling and posing together. Below the photo, the text reads "2015 National Sibling Leadership Network Conference" and "May 30 & 31, 2015 Louisville, KY". At the bottom of the poster, there is another photograph showing a group of people sitting at a table, possibly at a conference session. The website address "www.siblingleadership.org" is displayed in a blue banner at the very bottom of the poster.

**SIBLING LEADERSHIP NETWORK**

**Save the Date!**

**2015 National Sibling Leadership Network Conference**

**May 30 & 31, 2015**  
**Louisville, KY**

**[www.siblingleadership.org](http://www.siblingleadership.org)**





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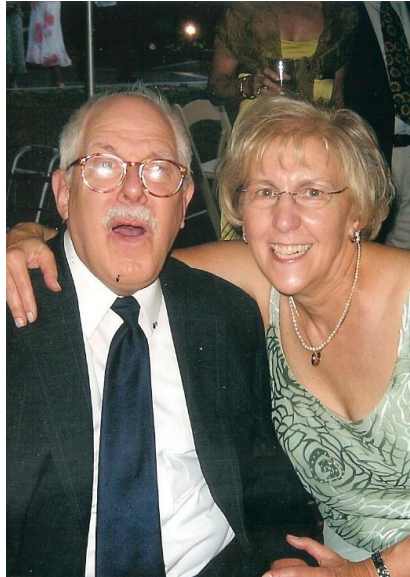


# ***Do You Take Mayo with That? Living in the Club Sandwich Generation***

Kitty Porterfield



# INTRODUCTIONS







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# THE DILEMMA

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# 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



**The Arc.**

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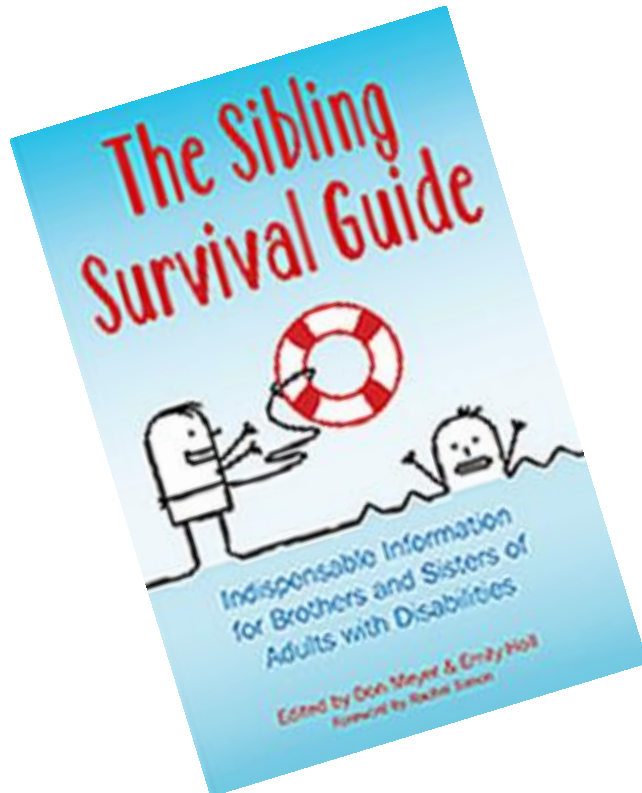
# Can you hear me now?

- 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.

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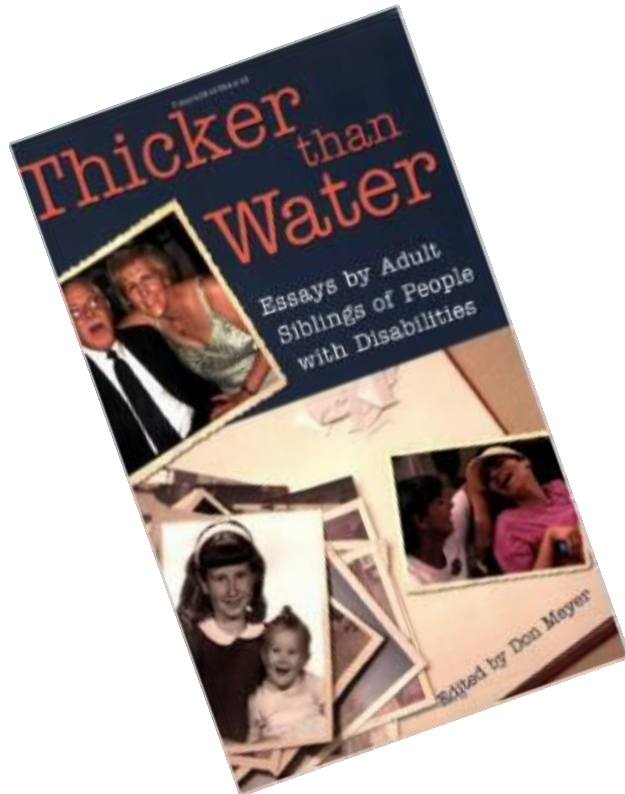
# Resource: Hot off the press



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



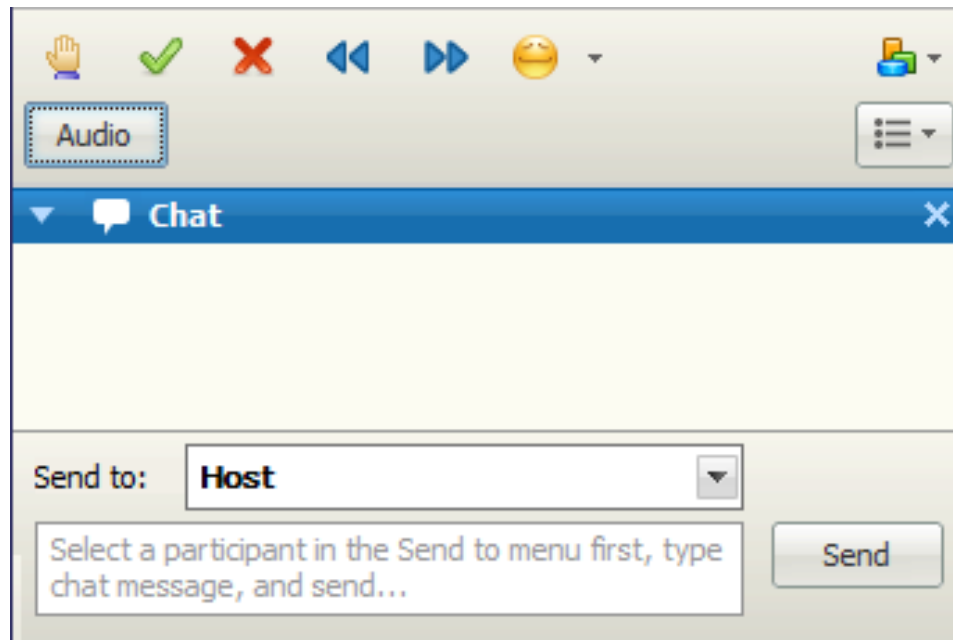
Stories written by adult siblings of all ages, describing their experiences growing up in a family with a sibling with disabilities.

Edited by Don Meyer  
Woodbine House 2009

**Kitty Porterfield**  
**kbporterfield@comcast.net**

# Questions?

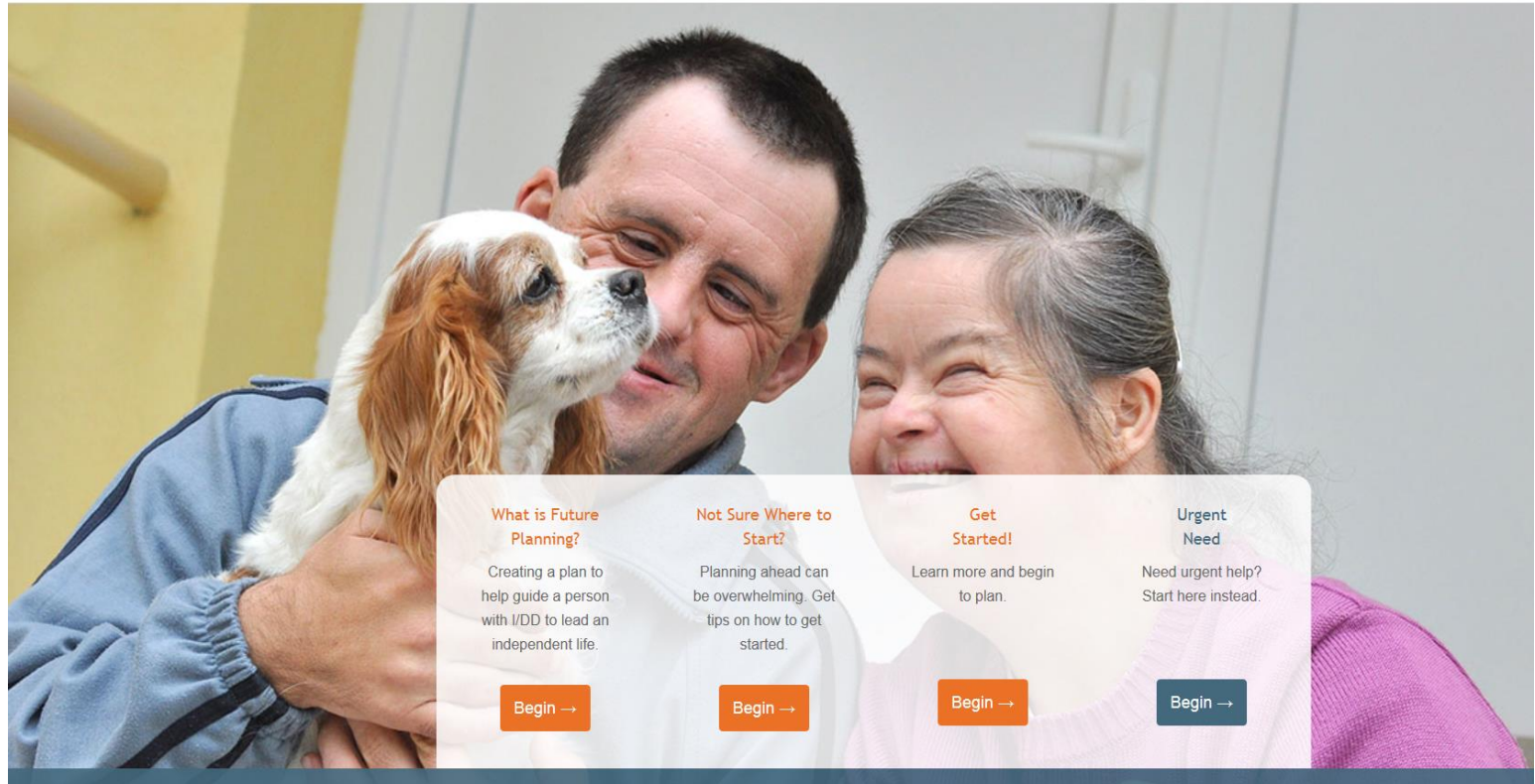
Please raise your hand and we will call on you OR type your question into the chat box.





# Center for Future Planning

[See how others have planned →](#)



<b>What is Future Planning?</b> Creating a plan to help guide a person with I/DD to lead an independent life. <a href="#">Begin →</a>	<b>Not Sure Where to Start?</b> Planning ahead can be overwhelming. Get tips on how to get started. <a href="#">Begin →</a>	<b>Get Started!</b> Learn more and begin to plan. <a href="#">Begin →</a>	<b>Urgent Need</b> Need urgent help? Start here instead. <a href="#">Begin →</a>
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**futureplanning.thearc.org**

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## 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](mailto:futureplanning@thearc.org)