

journeyforward



Workshop 1

Practical and unique help for adult siblings of people with disabilities to stop the worry and start the journey forward.

Your facilitator: Harriet Redman



The Journey Forward

- ❑ Identify barriers to planning
- ❑ Assess planning progress
- ❑ Identify plan for action
- ❑ Make connections with siblings, professionals and family members to clarify relationships, roles and responsibilities
- ❑ Develop strategies for enhancing family teamwork and communication
- ❑ Prepare a “Letter of Intent”



A unique and practical experience...

HOW?



...allowing siblings and their families to

- ☐ Reflect
- ☐ Share
- ☐ Learn
- ☐ Plan
- ☐ Act
- ☐ Evaluate

and journey**forward**



Connecting with Resources



- Linda Brandt, ADRC Outagamie Co
- Sarah Kons, Attorney at Law – Hooper Law
- Tanya Peterson, CP



We are

• • • • •
wisconsibs
Sisters & Brothers of People with Disabilities

Why?

SIBLINGS ARE:

- Role models
- Teachers
- Therapists
- Advocates
- Protectors
- Companions
- Care givers
- Coaches
- Interpreters
- Friends
- Antagonists...***longer than anyone!***





CONNECTING SIBLINGS WITH RESOURCES FOR THEIR LIFELONG JOURNEY

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**WisconSibs is a founding
chapter of the national
Sibling Leadership Network**

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Who is on this Journey today?

- One page scrapbook
 - Individuals
- Family – Life cycle



Why?



<https://www.specialneedsplanning.com/investment-news-video>

Why? Your Sibling is an individual with Developmental Disabilities

And will likely eventually join the over 682,000 people with developmental disabilities who are age 60 and older.

By 2030 estimate will be 1.3 million (UIC)



How old will you be in 2030? 2040? How old will you be when you Sib is 60?

Siblings are Caregivers

AARP Studies (June 2015)

**# of adults in U.S. caring for their
siblings ages 18-49**

728,000

(about 13% of caregivers compared to 32% being parents)

Average duration of care = 5.8 years

of adults in U.S. caring for their parents over 50

1,607,400

Average duration of care = 3.7 years

Average age of parent = 74.7 years old



75 % of adults with developmental disabilities in the United States live at home with at least one parent

Of these, 25% live with parents over the age of 60
(Braddock, 2001)



Why so many? Lots of reasons, including:

- Parents didn't plan because they thought they would outlive their child
- They fear what will happen if child lives elsewhere
- Child becomes a companion
- Other?_____

Parents are reluctant to involve other children with planning (Fujiura, 1996)

Only 3.6% of parents completed all 11 tasks of future planning. 32% completed some. (Burke, 2018)



Yet.... 78% of parents said they discussed future planning with sibling (Griffiths and Unger) and **want sibling involvement** in the future

So what's the problem?

64% of these same
siblings

**don't know
what the
plan is**





How do I get more involved now in case I have to handle things later? My parents have had full control of my brother's future, and I feel "clueless" as to exactly what their wishes are.

-Quote from Sibling

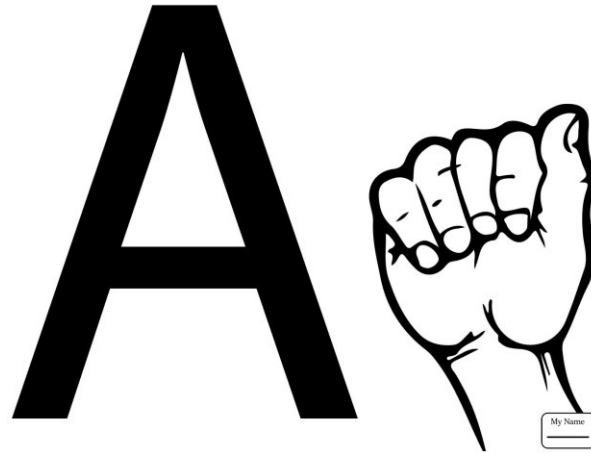
58% of siblings say they don't feel financially ready to take on the role of caregiver.

34% of siblings say they didn't feel emotionally ready

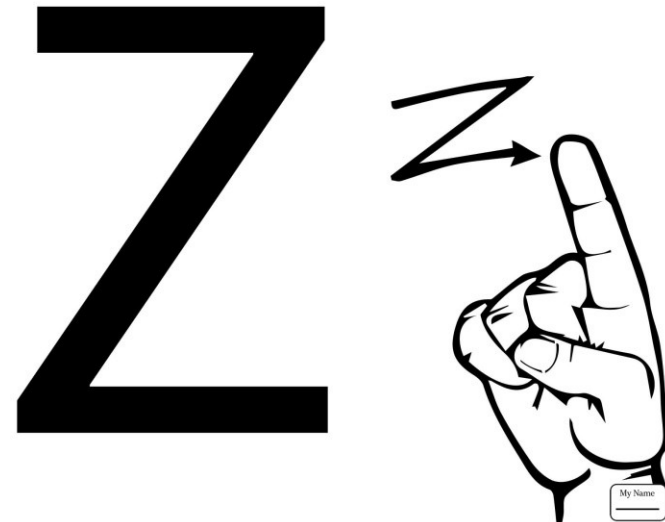
Source: Easter Seals

What are barriers to planning?

- From A



- to Z



Barriers to Planning - A to Z

Suggestions by Journey Forward participants

- A – Accessibility to information/
staff/funds
- B – Being overwhelmed with
life/systems
- C – Confused about changing laws,
staff, funding
- D – Dependency on companionship
- E – Emotional toll on parents,
siblings, self-advocate
- F – Failures in past. Fear of future
- G – Goals not clear
- H – Health issues
- I – Intimidated by professionals
- J – Job consumes time – attitude
“not my job”
- K – Keeping things the same
- L – Lack trust
- M – Motivation, money
- N – No time for preparing
- O – Off putting...“I’ll do it when..”
- P – Procrastination. Perfectionism.
- Q – Quality services not available.
- R – Readiness/ Reluctance to talk
- S – Separation from person with disability
- T – Terminology
- U – Urgency not felt – waiting for crisis
- V – Value of effort
- W - Waiting for answers
- X – Excuses
- Y – Yawn! Boring!
- Z – Zucchini needs to be picked

What happens next?

Adult siblings are most likely family members to take over care and advocate for sibling (Heller/Caldwell, 2006)

5 million and counting are caring for or expect to care for sibling in the future



19% of siblings expect to co-reside with brother or sister

- 75% of siblings who expect to reside with sibling with developmental disability are SISTERS. Also more likely to reside together if disability is less severe, is a woman and mother is in ill health.

In a three year follow up, 10% of siblings co-resided with brother or sister

44% are willing to be a future caregiver

60% expect to be a future caregiver (Greenberg,
Seltzer, Orsmond)

Group discussion

Parents / Siblings



- List what you have learned from your parent (or children) that makes you grateful.
- List what your parent (or children) could tell you that would help you feel more prepared for the future.

Welcome to the Club!



The Club Sandwich Generation



Adults squeezed between caring for

- aging parents
- growing children
- and their sibling with disabilities.

Are you a member?
Do you know someone who is?
Is she hiding next to you?

<http://www.griswoldhomecare.com/blog/infographic-sandwich-generation/>

<http://www.pewsocialtrends.org/2013/01/30/the-sandwich-generation/>

Over 5 million people are
or expect to be “members”!
(over 500,000 in Wisconsin)



Importance of planning

- Without adequate plans an individual with developmental disabilities is at greater risk for institutional care (Freedman, Kraus & Seltzer)
- Planning with other family members at a younger age increases likelihood of successful outcomes.

Early planning reduces stress

Reducing stress on working individual who is caregiver avoids lost productivity equal to \$2110 for every full-time worker who cares for an adult*.

*study by the MetLife Market Mature Institute and the National Alliance for Caregiving states that U.S. companies pay between \$17.1 billion and \$33.6billion annually on lost productivity equalling \$2,110 for every full-time worker

Young caregivers (including Sibs)
provide fewer total hours of care, but experience MORE STRESS.

Journey Forward offers help for the Club Sandwich Generation

Financial



Family &
Support



Legal



Government
Benefits



Emotional

