

journeyforward

Workshop #2

Presented by


wisconsibs

Sisters & Brothers of People with Disabilities

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Proud to be the Wisconsin Chapter of the Sibling Leadership Network www.siblingleadership.org
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***Journey Forward** is a program of WisconSibs, Inc adapted for siblings and their families based on Future is Now! created by the Rehabilitation Research and Training Center On Aging and Developmental Disabilities Department of Disability and Human Development-University of Illinois at Chicago.*



Discoveries along Your Journey So Far

What action steps did you identify in Workshop #1?

⇒

⇒

⇒

Which action steps were most challenging?

What surprised you in working on your action steps?

What accomplishment do you feel best about?

What, if any, action steps did you add?

Any new questions?



I've Learned that...

On the morning of his 51st birthday, H. Jackson Brown, Jr began jotting down a list of things that more than a half-century of life had taught him. And then his friends, and their friends, and then complete strangers chimed in. The result was a little book called *Live and Learn and Pass It On*. What would you jot down?

I've learned that _____

I've learned that people _____

I've learned that I _____

Which of these quotes from his book is your favorite?

"I've learned that I will always be seeking my parents' approval." - Age 39

"I've learned that when giving advice, it's best to make it brief." - Age 80

"I've learned that whatever I love to do, I do well." - Age 48

"I've learned that people treat me the way I allow them to treat me." - Age 47

"I've learned that if you don't have a will or do some estate planning, the government and lawyers become your heirs." - Age 62



"I've learned that parents are very hard to live with." - Age 12

"I've learned that just when I get my room the way I like it, Mom makes me clean it up." - Age 13

"I've learned that you don't miss fighting with your sister until she's left for college." - Age 14

"I've learned that if you spread the peas out on your plate, it looks like you ate more." - Age 6



"I've learned that if you try to be perfect, you'll be frustrated all the time." - Age 26

"I've learned that to get the right answer, you have to ask the right question." - Age 39

"I've learned that I still have a lot to learn." - Age 92

"I've learned that when someone gives you free tickets, don't complain about the show." - Age 45

"I've learned that if you look for the worst in life in people, you'll find it. But if you look for the best, you'll find that instead." - Age 66

"I've learned that you shouldn't look back except to learn." - Age 70



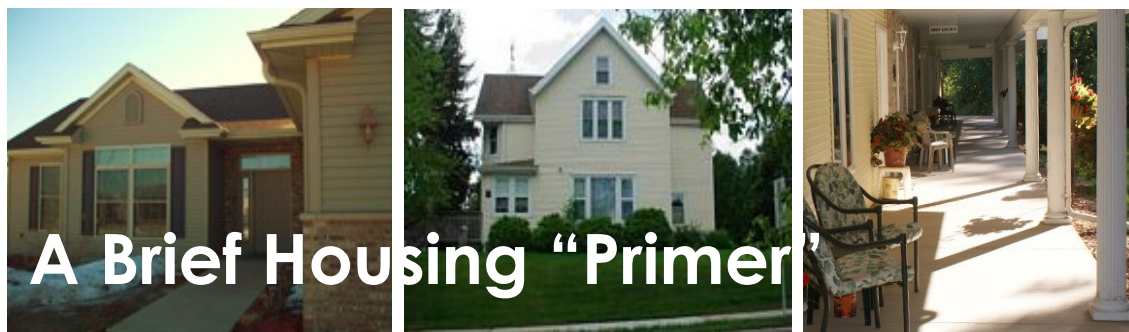
Based on your experience with future planning, what advice would you give to other siblings of people with disabilities?



Future Home—What's your sibling's dream?

journeyforward

1. My sibling wants to live in
 - ☐ A house
 - ☐ An apartment
 - ☐ A group home
 - ☐ Our current family home
 - ☐ Not sure
2. My sibling wants to live with
 - ☐ Family
 - ☐ A friend or friends
 - ☐ A group of people
 - ☐ A live-in support professional
 - ☐ No one (live by him/herself)
 - ☐ Not sure
3. Where does your sibling want to live
 - ☐ Someplace busy
 - ☐ Someplace quiet
 - ☐ Near _____
 - ☐ Not sure
4. My sibling wants to make these decisions (with or without help) about their home (check all that apply)
 - ☐ Paying rent or a mortgage
 - ☐ Hiring people to deal with maintenance
 - ☐ Paying property taxes
 - ☐ Requesting reasonable accommodations
 - ☐ Making modifications in the future
5. My sibling wants to make these decisions about people in their home (check all that apply)
 - ☐ Rules about the house and how people act in it
 - ☐ Being the person who decides who comes/goes in it
 - ☐ Being able to decide their daily schedule/activities
 - ☐ Being able to be alone when he/she chooses
 - ☐ Selecting and hiring own support providers
6. Rank the importance of each of these for your sibling
 - ☐ First-floor or one-floor home
 - ☐ Accessible (step-less entry, roll-in shower, etc)
 - ☐ An on-site manager for the home
 - ☐ Direct service workers provided by a home
 - ☐ Accessibility to visitors who may have disabilities
 - ☐ A place that accepts pets
 - ☐ Laundry facility in home
7. Rank the importance to your sibling in their community?
 - ☐ To be close to family
 - ☐ To be close to friends
 - ☐ To be close to work, school, or other daily activities
 - ☐ To be close to shops and the grocery store
 - ☐ To be near a bus stop or public transportation
 - ☐ To be near a park or greenspace
 - ☐ To be near his or her place of worship
 - ☐ To be near a medical facility
 - ☐ Something else (list): _____
8. Does your sibling want a home he or she can easily get to by public transportation or by car?
 - ☐ Yes
 - ☐ No
 - ☐ Not sure
9. What resources does your sibling plan to use for home?
10. Has your sibling applied for affordable housing assistance in your community?
 - ☐ Yes
 - ☐ No
 - ☐ Not sure
11. What else is important to your sibling in a future home?
12. When would your sibling want to move to this home?
 - ☐ Right now
 - ☐ In 6 months to 1 year
 - ☐ In 2-3 years
 - ☐ In 5 years
 - ☐ In 10 years
 - ☐ Another time (describe): _____



“I’m concerned about housing for my sibling. How do I even think about it? I don’t even know what is ‘out there’?”

While we learned in WORKSHOP #1 of Journey Forward that starting with person-centered questions about the interests, capabilities and dreams of your sibling are the first to address, it is important to understand some of the basics about housing for people with disabilities. So let’s look at “what is out there?”

So what is “out there”? -

In addition to skilled nursing homes, there are 3 types of assisted living homes regulated by State of WI:

• Adult Family Homes

- ◇ Must be licensed with the State (i.e. inspected every 2 years. State accountable is something goes wrong.)
- ◇ Home-like atmosphere for 3-4 adults age 18 or older.
- ◇ Each resident may receive up to 7 hours per week of nursing care.
- ◇ Cannot be related to the operator of the home
- ◇ Must require more care than simple room and board.
- ◇ Residential areas located for easy access to community activities and support services by walking or convenient private or public transportation.
- ◇ Must be accessible to all residents within the home.
- ◇ Licensee is responsible for planning activities and services with residents (cultural, religious, political, social and intellectual activities)
- ◇ Services promote health, well-being, self-esteem, independence & quality of life
- ◇ Licensee must provide copies of residents’ rights to person being admitted, their guardian, family members or any designated representative
- ◇ Residents rights involve:
 - Fair treatment
 - Privacy
 - Confidentiality
 - Presumption of competency
 - Self-direction
 - Management of financial affairs
 - Clothing and possessions
 - Choice of social activities, treatment, religion
 - Safe physical environment, freedom from abuse, seclusion and restraints
 - Prompt and adequate treatment, medication, mail, phone calls, visits
 - More details at <http://www.dhfs.state.wi.us>



Information by county available at <https://www.dhs.wisconsin.gov>

For example—see <https://www.dhs.wisconsin.gov/guide/dane.htm> or <https://www.dhs.wisconsin.gov/guide/outagamie.htm#fdd>

WI housing information also available at <http://wihousingsearch.org/Resources.html>

• Community Based Residential Facilities (CBRFs) i.e. Group Homes

- Must be licensed with the State (i.e. inspected. State accountable is something goes wrong.)
- Five or more unrelated adults reside in a CBRF and individuals may receive up to 3 hours of nursing services per week
- CBRF's have 6 different licensure or class levels



- **Class AA:** A class A ambulatory CBRF may serve only residents who are ambulatory and are mentally and physically capable of responding to an electronic fire alarm and exiting the facility without any help or verbal or physical prompting.
- **Class AS:** A class A semi-ambulatory CBRF may serve only residents who are ambulatory or semi-ambulatory and are mentally and physically capable of responding to an electronic fire alarm and exiting the facility without any help or verbal or physical prompting. Residents may use a walker or a cane.
- **Class ANA:** A class non-ambulatory CBRF may serve residents who are ambulatory, semi-ambulatory or non-ambulatory, but only if they are mentally and physically capable of responding to an electronic fire alarm and exiting the facility without any help or verbal or physical prompting. Residents may use a wheelchair.
- **Class CA:** A class C ambulatory CBRF may serve only residents who are ambulatory, but one or more of whom are not mentally or physically capable of responding to an electronic fire alarm and exiting the facility without any help or verbal or physical prompting.
- **Class CS:** A class C semi-ambulatory CBRF may serve only residents who are ambulatory or semi-ambulatory, but one or more of whom are not mentally or physically capable of responding to an electronic fire alarm and exiting the facility without any help or verbal or physical prompting.
- **Class CNA:** A class C non-ambulatory CBRF may serve residents who are ambulatory, semi-ambulatory or non-ambulatory, but one or more of whom are not mentally or physically capable of responding to an electronic fire alarm and exiting the facility without any help or verbal or physical prompting.

• Residential Care Apartment Complexes (RCACs)

- Not required to be licensed. May be certified to receive WI Medical Assistance waiver funding, or simply be “registered” with the State (inspection not required and State takes on no risk)
- 5 or more adults
- Up to 28 hours per week of skilled and supportive home care
- Living options are located in a variety of settings and sizes. Some are free standing complexes while others are a part of continuing care retirement communities.
- Residents must be competent. If resident requires a guardian, this is not a possible option.
- "Certified" RCACs will be monitored by the State because they are eligible to receive Medical Assistance waiver funding.

Which of these appear to provide the type of home or living option you identified as part of “the dream”?

For you personally, what would turn it into a nightmare?

How could the nightmare be avoided?

What about staying in the “family home”?

If your sibling determines that staying in the family home works best for them, be aware there are several administrative issues, to work out, including:

- Rather than charging rent, a sibling should pay their fair share of living expenses (utilities, cable, telephone, etc.). This will not add to the family's income tax or tax preparation burden. It also helps keep assets within the \$2000 limit so they can continue to be eligible for benefits.
- If you or a parent provides care and gets compensated, there should be a written personal care agreement in place that lists types of services to be provided and the compensation (otherwise, compensation may be regarded by IRS as gifts which can lead to loss of benefits.)
- Make sure to work with an attorney to have a plan. Failure to document the arrangement and payments can be trouble.
- You may also be interested in the following services.



Supportive Homecare

COST— There is a wide variety of services and agencies available, both private pay and provided through a variety of public programs. If your sibling needs 12 or more hours of care per day, it is about the same cost as if living in assisted or skilled care options. Assessment is critical to determining need.

SAFETY with DIGNITY —These objectives are key to understanding the purpose for supportive homecare. Services are designed to assist the individual to remain as independent as possible in the setting of their choice while maintaining maximum quality of life.

Adult Day Services

Services offered are a wide variety and may include:

- Physical, occupational, speech, recreational or music therapy
- Meals, transportation, bathing, hair and nail care
- Medical and mental health services
- Treatment, education and consultation tailored to individual's needs
- Activities like current event discussions, arts and crafts, health education, exercise, swimming, supervised cooking, bible study, music, aroma therapy, massages, etc.

These services are licensed by the State of Wisconsin and inspected every 2 years by the Department of Health and Family Services, Bureau of Quality Assurance. <http://www.dhfs.state.wi.us>

Those who benefit most are those needing:

- Social interaction
- Supervision
- Assistance with eating, walking, toileting, dressing and bathing

Do these options appear to be part of your sibling's “dream”?

For you personally, what would turn it into a nightmare?

How can the nightmare be avoided?



Work, Education, and Leisure

My greatest concerns are around programming for my sister. She has a severe disability and is in her last year of school. My family doesn't know what we are going to do with her after that.
- Sibling

My sibling wants to have a job, stay in Special Olympics and be free to have social activities. I want to make sure she receives great health care and has transportation. - Sibling

Assuming each circle below represents 24 hours, divide each into wedges according to how you and your sibling spend time.

	PRESENT	FUTURE
Your Sibling		
You		



More to life than sitting on the couch

Finding employment -

What methods have you used to assist your sibling to get or keep employment?

If using an employment service providers, find out:

1. What is their agency/business philosophy?
2. What types of occupations do their past clients work?
3. What percentage of clients receive health benefits?
4. How many people have they placed in the last year?
5. What is the average salary of past clients?
6. What are their employment support strategies?
7. How do they develop natural supports in the workplace?
8. What other supports are offered?

Getting additional training or education-

What methods have you used to assist your sibling to get training or education?

When seeking educational opportunities, find out:

1. What is the school's philosophy?
2. What services are available on campus for people with disabilities?
3. What percentage of students have disabilities?
4. How do they help students with disabilities develop marketable skills?
5. What type of job placement assistance is available?
6. What are their placement rate for students with disabilities?
7. What are the major social activities?
8. Are buildings accessible? Get details.
9. What types of tutoring services are available?
10. Is there a school visit program to experience the culture?



More to life than sitting on the couch (continued)

Finding leisure/recreation/social -

What methods have you used to assist your sibling to find meaningful leisure, recreational, or social opportunities

If using a service provider, find out:

1. What is their agency philosophy?
2. What types of activities do clients like most?
3. What percentage of programs or activities are only for people with disabilities?
4. How many people have participated in the last year?
5. What are their leisure/recreational/social support strategies?
6. How do they develop natural supports in social situations?
7. What other supports/programs are offered?

Interview with _____



Who Will Be the Keeper of the Dream?



**Graduates of
Journey
Forward**

Marialyce Dorman, Kathi Hansen, Rebecca Derenne, Ashley Baldwin, Katie Ketter, Nancy Rezmer, Greg Hoffman

What barriers to future planning have you overcome so far?

- ☐ _____
- ☐ _____
- ☐ _____

What goals have you not yet accomplished or new issues you want to address?

- ☐ _____
- ☐ _____
- ☐ _____

What, if any, barriers are keeping you from addressing them?

How will you overcome these barriers?



Who Will Be the Keeper of the Dream? (continued)

Who do you trust with future care and planning?

- ☐ _____
- ☐ _____
- ☐ _____

What in your opinion qualifies this person(s)?

- ☐ _____
- ☐ _____
- ☐ _____

Have you spoke with them about it? If so, what was their reaction?

What long-term or short-term support would they need from you or others?

What are the next steps to moving forward with the Keeper of the Dream?

- ☐ _____
- ☐ _____
- ☐ _____

Examples of Family Caregivers' Hopes for Their Relatives with Developmental Disabilities

- Have a full and active life to the best of her capabilities and to be happy in her environment.
- Adjust and be happy with the future whatever it may bring
- Have security, happiness, and contentment.
- Have the ability to get along without me and be satisfied in new surroundings.
- Die one day after my son or daughter dies.
- Live happy healthy successful lives.
- Live a happy life full of love and God.
- Have contentment.
- Have a happy life and healthy thirst for knowledge, God fearing, honest.
- Keep his a great imagination.
- Be well taken care of after my death, safe place to live, with caring people and loving people.
- Have good health, training and care.
- Have a normal life and to be married with about 5-6 kids
- Live independently.
- Have a happy life and success in his personal business.
- Do better in his life and to make progress.
- Continue to improve and hope she will always stay in the family circle and be happy.
- Live a life as normal as possible with supports with job caring people
- Be safe, happy, active, working, loved.
- Continue to inspire and encourage me to continue my work for those at my agency. (Son died at age five).
- Have the best care for my daughter after I am gone. Someone to handle her finances.
- Count money, tell time, and take care of her, and have a good life.
- Have a good job, but most of all love and God.
- Find her passion and have great love and happiness.

A Sibling Story

via [SibNet on Facebook](#)

printed with permission from the author, [Pammeke van der Feest](#)

My father had knee replacement surgery on Monday, and I was his caretaker through his hospital stay and the first few days home (I'm taking the weekend off to be with my boyfriend but am going back tonight for another few days to make sure he takes his meds, gets the PT/OT/VNA visits he needs, and generally follows medical orders). My brother usually spends weekends at home with Dad (week days at his group home, which transports him to & from work), but since he couldn't this weekend, my boyfriend & I drove up, took him to Dad's house (our childhood home) for a visit, then took him out on the town.



We decorated Dad's small Christmas tree with ornaments we made or received as kids (been boxed up for years). Here is David [see photo] so proud (so proud!) that he put the star on the top and pushed it down just hard enough so it would stay. And we had pizza, went bowling, sang songs we used to love as kids, played skee-ball, got burgers, and ended the night at a homemade ice cream place we only used to go for special occasions.

We talked about David's future living arrangements (his group home is closing in April, and he hates the answer "right now we're working on a plan" but he understands it's all we can say for now), how we miss our Mum (who passed in '06) and Grandma (who passed in '81), how my boyfriend has different car rules than Dad (we could sing and talk loudly and no one would tell us to be quiet), how much David wants to play in the bowling tournament Special Olympics has every November but Dad hasn't signed him up for since the 2000's.

David also said to me, "You and Dad are my guardians. I need guardians because I am... M.R." I asked him if that bothered him, and he said yes, and pointed out that my boyfriend is his own guardian. We comforted him that he is still his own person and an independent adult man and makes his own choices. Dad and I just help him [by] making his choices happen the way he wants them to. But he (David) is still in control. I know that our father has blurred this a bit because everything is always on his terms, what he thinks is best for David, and of course I want what's best for David too, but I also want him to feel in control of what happens in his life.

I'm emailing his old bowling team tomorrow morning to make sure I'm the one who gets contacted as soon as they start tournament planning. Happy Holidays to all my fellow sibs - I feel like we're each other's extended family.

Of the factors important in future planning (legal, financial, government benefits, emotional, or family & support), which one is this sibling tackling? What other strategies could she take? Have you experienced similar occasions when you've had practice being the "one in charge" of parent AND sibling? What thoughts/actions do you recall?

Questions + Connections