



Aging Parents with Adult Children with Disabilities

Mona Fuerstenau



About Bethesda

Founded in 1904 in Watertown, Wisconsin, Bethesda is a Christian organization, a national leader in providing homes and support, promoting awareness and advocating for people with intellectual and developmental disabilities.



Our Mission

- Enhance the lives of people with intellectual and developmental disabilities through services that share the good news of Jesus Christ.
- We provide these services as an RSO of the LCMS in **13** states across the country to over **1800** people with **3000+** staff and hundreds of congregations and community partners

We Celebrate God's Handiwork

Psalm 139:13-16

For you formed my inward parts;
you knitted me together in my mother's womb.

¹⁴ I praise you, for I am **fearfully and wonderfully made**.

Wonderful are your works;
my soul knows it very well.

¹⁵ My frame was not hidden from you,
when I was being made in secret,
intricately woven in the depths of the earth.

¹⁶ Your eyes saw my unformed substance;
in your book were written, every one of them,
the days that were formed for me,
when as yet there was none of them.



Research by the ARC and University of Minnesota

- Nearly 1 million households in which an adult with I/DD is living with caregivers 60 or older
- Nearly half of caregivers are over 50
- 10% are 75 or older
- 52% spend at least 40 hours per week, nearly double that of children caring for aging parents or spouses reported

Caregiver reality

- LOVE our children
- We are Tired
- Daily and constant demands
- Need support to plan for future
- Family can be tricky
- Housing – options? what options?
- Quality of life questions

Embrace God's comfort Psalm 147:3

- He heals the brokenhearted and binds up their wounds



Family and Individual Needs for Disability supports – FINDS survey concerns

- Quality of support for person with I/DD will go down 89%
- The person with I/DD will not have friends or will be socially Isolated 78%
- No one else will provide support for the family member with I/DD 78%
- The person with I/DD will have to live somewhere he or she does not want to live, such as a nursing home or an institution 76%
- The family member with I/DD will see his or her health deteriorate 74%
- The person with I/DD will be abused or neglected 73%
- The person with I/DD will be financially exploited 62%

Parent caregiver concerns

- Plan for emergency care
- Crisis
- Future planning
- Protecting financial resources
- Finding caregivers
- How to approach family members

He has a plan Jeremiah 29:11

- For I know the plans I have for you, declares the Lord, plans to prosper you and not to harm you, plans to give you a hope and a future
- We need to plan too!

Plan for emergency care

- Make a plan now for steps to be followed in an emergency situation
- Make a notebook with all important contacts and procedures
- Tell each important person where it is
- Discuss as much as possible with your child “In case of emergency”

Plan for Crisis

- Better to be proactive
- Identify key people
- How to calm your loved one during chaos
- Note personal preferences
- When does it become a long term plan?

Future planning

- Same level of lifestyle accustomed to
- Relationships
- Family traditions
- Church
- Work
- Leisure
- Transportation
- Medical professionals

Protecting financial resources

- ABLE accounts
- Guardianship
- Social security benefits
- Income limits
- Special needs trusts

Future planning

- 75% of families are not connected to services
- SIGN UP , even if it just puts you on a wait list
- 25% have a lack of resources even though connected
- Sometimes Crisis is the catalyst for services

It's a family affair – invite discussion

- Who is going to care about them?
- Where will they live?
- Who is going to care FOR them?
- How will we navigate that change/transition?
- How will we ensure quality of life is maintained or improved?

Finding Care and Housing

- Care registry
- Individual providers
- Supported Living
- Shared Living
- Host Homes
- Provider agencies like Bethesda

Bethesda's Cornerstone Village – A new model

- Address the nation's need to have an alternative to group home settings for persons with intellectual developmental disabilities I/DD
- Create a more independent lifestyle for persons with intellectual developmental disabilities
- Create Christian independent housing communities' that integrate up to 25% of individuals with I/DD with adults ages 55years and older

Enhance Bethesda's Mission By:

- Work with LCMS churches throughout the country who have surplus land to create these Christian housing communities
- Create a partnership with the LCMS church that supplements and supports the Christian environment within the housing community
- Grow Bethesda's I/DD population that we serve reaching more people for Christ
- Open up endless possibilities to reach older adults through the love of Jesus Christ

Vision of completed project



Resources

- [ARC Center for Future Planning](#) abundant free resources to assist families to plan for the future.
- [Future is Now](#) (DeBrine, Caldwell, Factor, Heller, Keiling & Kramer, 2009). The Future is Now is a curriculum developed by the Rehabilitation Research and Training Center on Aging with Developmental Disabilities at the University of Illinois at Chicago. The program is designed to assist aging family caregivers and adults with developmental disabilities to plan for the future when aging caregivers die or are no longer able to provide care. It received the National Alliance for Caregiving 2008 innovative program award.

- [Special Needs Alliance](#) SNA is a national organization comprised of attorneys dedicated to the practice of disability and public benefits law. Individuals with disabilities, their families, and their advisors rely on the SNA to connect them with nearby attorneys who focus their practices in the disability law arena.
- [Family Support and Research and Training Center](#) The FSRTC is a collaboration of researchers and organizations focused on synthesizing and generating knowledge about the needs and experiences of families who provide support to children and adults with disabilities across the life course.
- [Sibling Support Project](#) Founded in 1990, the Sibling Support Project is a national program dedicated to the lifelong and ever-changing concerns of millions of brothers and sisters of people with special health, developmental, and mental health concerns.

- [ABLE National Resource Center](#) Founded and managed by the National Disability Institute, the ANRC's goal is to provide consistent, reliable information concerning the benefits of an ABLE account, a new and critically important tool in financial planning for families that include someone with an intellectual or developmental disability.
- [State Developmental Disabilities Councils](#) a group of parents, self advocates and agency reps in each state who advise the governor about policy and typically have a wealth of resources for families.

Bethesda Support Team:

- Churches, organizations, and individuals who support Bethesda's long-term effort to enhance the lives of people with intellectual and developmental disabilities through services that share the good news of Jesus Christ.

Expectations of a Bethesda Support Congregation, Organization or Individual:

- **Committed** to Bethesda's mission for three years.
- **Engaged with** people supported by Bethesda and Bethesda staff.
- **Empowered** to use their gifts and talents to support Bethesda in ways that enhance their own personal ministry and grow God's family.

Bethesda Resources

- Bethesda residential services www.BethesdaLC.org
search locations and click on your state
- Regional director for your area or
Susan.Kaufman@BethesdaLC.org
- Cornerstone Village Tom.Campbell@BethesdaLC.org



Mona Fuerstenau

Mona.Fuerstenau@BethesdaLC.org

BethesdaLC.org