

Discussions on Aging and Developmental Disabilities – Program #1

Transitioning from Parent Care to Sibling care

September 17, 2019
UNO Barbara Weitz Center



University of Nebraska
Medical Center

MUNROE-MEYER INSTITUTE

Joint Presentation



UNIVERSITY OF NEBRASKA MEDICAL CENTERSM

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So You're a Sib

by Don Meyer & Emily Holl

Welcome, too, to a club whose members serve long terms of service. Brothers and sisters will be in the lives of their siblings who have disabilities longer than *anyone* – certainly longer than any service provider, and likely longer than even parents. The sibling relations is one that can easily exceed sixty-five years. Consequently, sibling issues are lifespan issues that change and evolve as siblings do...

Our club has a diverse membership. We come from all economic, religious and cultural backgrounds. We have sibs who have autism, intellectual disabilities, cerebral palsy, Down syndrome spina bifida, fragile X and other disabilities.....

Some of us have parents who have done a wonderful job of preparing for the future of their children who have disabilities, and of considering our futures, as well. Others have parents who have meant well, but their efforts have left much to be desired. An others have parents who refuse to face the fact that their children with disabilities will likely outlive them.

“The Sibling Survival Guide.” *Indispensable information for Brothers and Sisters of Adults with Disabilities*, edited by Don Meyer and Emily Holl. Foreword by Rachel Simon Woodbine House 2014 , pp.1-2



Topics and Resources

1. Wills
2. Guardianship or POA
3. Letter of Intent
4. Financial
5. Government Benefits
6. Medical Considerations
7. Living Arrangements
8. Overall Resources

“Examples” are available



Sibling Panel

Patty Scamperino sister to Sandy, age 61

Beth Recker sister to Jonathan age 39

Jamie Gehringer brother to Jacob age 24

Nancy Goodwin sister to Paul age 55

Amanda Auberry sister to Matthew age 37



Wills

Variety of presentations presented by other organizations.

Why do a will?

- Without a will a portion of your estate will be left to your child with I/DD. This will prevent government benefits such as SSI and Medicaid.
- Name the successor guardian or power of attorney. Without a will, the court will decide who should take care of your adult child. Provision for the Representative Payee must also be established.
- If there are no siblings, consider establishing an advocate in your will.
- Wills should be completed upon diagnosis of a disability.



Panel Discussion

Wills



Guardianship vs. Power of Attorney (POA)

In Nebraska individuals become a legal adult at age 19. For federal benefits such as SSI individuals become eligible at age 18.

Without guardianship or a POA you will be prevented from making health and legal decisions for your child.

Information about guardianship and conservatorship provided through Nebraska Supreme Court

1. <https://supremecourt.nebraska.gov/programs-services/guardianship-conservatorship>

Additional information available

2. <https://www.guardianship.org/what-is-guardianship/>



Guardianship vs. Power of Attorney

1. Research before making a decision
2. Attend one of the classes through the NE Court System
3. Nebraska has higher rates of guardianship vs. other US states

Myths of Guardianship

- Individuals cannot vote. False! Individual can vote
- You must get guardianship. False! POA for Medical and Financial also allow you to do almost the same thing.

Cons of Guardianship in NE

- Amount of paperwork required to report annually
- There are expenses. You must go through a lawyer and court.

ARC of Frederick Co Maryland

3. https://www.arcfc.org/what_we_do/future-planning.html



Panel Discussion

Guardianship vs. Power of Attorney (POA)



Letter of Intent

Might be one of the most important documents you can do. This is not a legal document but let's your family know your wishes and also gives information about your adult child.

It can include the following:

- Family History
- General Overview
- Daily Schedule
- Food
- Medical
- Benefits Received
- Employment
- Residential, Social and Religious Environment
- Behavior Management
- Final Arrangements



Letter of Intent Examples

- . ARC of Frederick Co Maryland – why do a letter of intent

4. https://www.arcfc.org/file_download/fd53a1ff-217e-4907-9ae1-8fc77f523f1f **Example**

ARC of Frederick Co Maryland –Word Document Template

5. https://www.arcfc.org/file_download/be556e54-a064-4a02-bf37-aad7d79680c2 **Example**

Littman Crooks LLP – most detailed

6. <https://www.littmankrooks.com/wp-content/uploads/2015/06/Letter-of-Intent-Special-Needs-2015.pdf> **Example**

From the Movie Mimi and Dona – has a written example

7. http://www.mimianddonamovie.com/pdfs/Writing_Letter_of_Intent_FORM-April%202014.pdf **Example**



Panel Discussion

Letter of Intent



Financial

Special Needs Trust

➤ Can be costly and you need a lawyer to complete.

8. <https://www.specialneedsalliance.org/the-voice/two-different-types-of-special-needs-trusts/> **Example**

9. <https://www.autismspeaks.org/tool-kit-excerpt/special-needs-trusts> **Example**

ABLE Accounts

10. ENABLE Account of Nebraska
<https://www.enablesavings.com/> **Example**

11. National ABLE <http://www.ablenrc.org/>

12. How do I enroll/comparisons? <http://www.ablenrc.org/get-started/how-do-i-enroll-in-a-program/>



Panel Discussion

Financial



Government Benefits

Medicaid

13. <https://autisticadvocacy.org/policy/toolkits/medicaid/>

Example

Social Security: Can be SSI or SSDI

14. <https://www.ssa.gov/redbook/eng/overview-disability.htm>

15. <https://www.ssa.gov/pubs/EN-05-10026.pdf> **Example**

16. <https://www.ssa.gov/planners/disability/qualify.html#anchor7>

Medicare

Available after working enough quarters or 24 months after parent goes on Medicare.



Panel Discussion

Government Benefits



Medical

- Doctors and Dentists – moving from Pediatric to Adult Care.
- Listing of all doctors, dentists, therapists and medications.
- Understanding medical conditions that go with aging that might be part of their disability.
Dementia and Alzheimer's
- Conversations about end of life care. Examples: Palliative Care, Hospice
- Letter of Intent can include a lot of this information.



Panel Discussion

Medical



Living Arrangements

This issue cannot be ignored or never discussed. An accident or illness can happen at any time where parents cannot take care of their adult child. Sibling panel will discuss further.

- Living with family.
- Living in a group home run by a provider.
- Shared Living (new name) or EFH –Extended Family Home
- ICF – Intermediate Care Facility
- Independent living in an apartment
- Familiar with options available in your community.



Panel Discussion

Living Arrangements



Overall Resources

The ARC Center for Future Planning

17. <https://futureplanning.thearc.org/>
18. <https://futureplanning.thearc.org/pages/learn/future-planning-101>
19. Where to Start
<https://futureplanning.thearc.org/pages/learn/where-to-start/expressing-wishes-for-the-future>
20. <https://www.thearc.org/siblings>



Overall Resources

National Down Syndrome Society

Alzheimer's Disease & Down Syndrome: A Practical Guidebook for Caregivers **Example**

21. https://www.ndss.org/wp-content/uploads/2018/12/NDSS_Guidebook_FINAL.pdf

Aging and Down Syndrome: A Health & Well-being Guidebook **Example**

22. <http://www.ndss.org/wp-content/uploads/2017/11/Aging-and-Down-Syndrome.pdf>

Books in Spanish

23. <https://www.ndss.org/about-down-syndrome/publications/>



Overall Resources

National Down Syndrome Society

24. <https://www.ndss.org/about-down-syndrome/down-syndrome-through-the-lifespan/>
25. <https://www.ndss.org/about-down-syndrome/publications/caregiver-guide-order-form/>
26. <https://www.ndss.org/about-down-syndrome/publications/>



Overall Resources

National Down Syndrome Congress - Adult Sibling Program

27. <https://www.ndsccenter.org/programs-resources/adult-siblings/>
Example

Autism Speaks for individuals 22+

28. [28https://www.autismspeaks.org/adults-22](https://www.autismspeaks.org/adults-22)

Autism - Society –

29. <https://www.autism-society.org/living-with-autism/autism-through-the-lifespan/adulthood/>

Autism Self Advocate Network ASAN

30. <https://autisticadvocacy.org/resources/>



Dementia

Nebraska Caregiver Resource Guide

31. <https://www.unmc.edu/mmi/community-resources/lifespan-resources/adult-NE-caregiver-resource-guide.pdf> **Example**

DSA of Midlands – link to May, 2019 by Dr. Seth Keller on Aging and Decline

32. <https://www.dsamidlands.org/resources/education-series-speaker-supplements/dr-keller.html> **Example**

National Task Force on Intellectual Disabilities and Dementia Practice

33. <http://aadmd.org/ntg>



Siblings

The Sibling Survival Guide edited by Don Meyer & Emily Holl

34. <https://www.woodbinehouse.com/product/sibling-survival-guide-indispensable-information-brothers-sisters-adults-disabilities/>

Example

Sibling Leadership Network

35. <https://siblingleadership.org/>

36. <https://siblingleadership.org/services-and-supports/adult-sibs/>

37. <https://thearc.org/get-involved/siblings/>



Upcoming Discussions on Aging and Developmental Disabilities

Tuesday November 12, 2019 – 6:30 to 8:30 UNO Community Center
Community Options for Adults with I/DD – age 21 and older

Tuesday January 28, 2020 – 6:30 to 8:30 UNO Community Center
Housing Options for Adults

Tuesday April 7, 2020 – 6:30 to 8:30 UNO Community Center
Planning for Adult Healthcare



Munroe-Meyer Institute's Transition Educational Series

Assisting families navigate the transition to adulthood.



Please join us for an education series of information and discussion about the transition process and preparing for this new chapter in your family's life.

Topics covered during this session include:

August 29: Parent & Self Advocate Panel
September 12: Guardianship
September 26: Medical and Healthcare
October 10: Social Security
October 24: Education & DD Services
November 7: Employment & Voc Rehab
November 21: Self Determination

University of Nebraska Medical Center

Buffett Cancer Center
505 S. 45th Street
Room LVL Ground 0-12101
6:30-8:30 PM

FREE for families with a child with a disability between the ages of 14 and 21.

Seating is limited so please register at:

<https://www.signupgenius.com/go/70A0B4BAFA72BA1F49-munroemeyer>

Please contact Rhonda Haitz at 402-559-5726 or
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