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**Becoming a Primary Caregiver for your Adult Sibling with Special Needs:
a Webinar on Legal, Financial, and Medical Coverage Considerations**

UNM LEND CAPSTONE 2021

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OUTLINE

1. Problem-Framing
2. Research Process
3. Product
4. Dissemination
5. References

Problem-Framing

Families in New Mexico may not be prepared to transition care of their adult child with developmental disabilities to another primary caregiver, when it comes to navigating the legal, financial and healthcare systems.

LEND Competencies

- **Competency 1: Family-Centered/Culturally Competent Practice**
 - 1.1 Demonstrate knowledge of the principles of family-centered care
 - 1.2 Demonstrate an awareness of the primary importance of the family in the life of a child
 - 1.6 Demonstrate awareness of the benefits of partnership with families at program/policy level
 - 1.9 Identify family-centered practices in the community and services systems
- **Competency 2: Interdisciplinary Practice**
 - 2.2 Demonstrate awareness of roles of various disciplines in service provision
 - 2.3 Demonstrate the ability to effectively represent own discipline on an interdisciplinary team
 - 2.4 Demonstrate effective communication skills as a member of an interdisciplinary team
- **Competency 5: Research and Critical Thinking**
 - 5.1 Critically review literature (evidence, design, sample size, CI's, statistical tests)
 - 5.5 Demonstrate verbal presentation skills including use of PowerPoint and auditory augmentation system

Research Process

- IRB Consideration
- All research came from personal experience, literature reviews, online searches, and interviews with professionals

Research Process

Personal Experience

- I sat with my parents, and we had discussions regarding my 3 younger sisters' futures when the time comes for a transfer of caregiving
- We discussed current Power of Attorney, bank accounts, SSI, DD Waiver and Mi Via
 - We updated Power of Attorney for my 20-year-old sister, I was added as the 3rd person
 - I was added to my 20-year-old sister's bank account
 - Discussed living arrangements
 - Discussed what the future looks like for my two other sisters who are currently minors
- Finally, we discussed inheritance and financial security

Research Process

Literature Review

- Wiley Online Library
- Key search words used
 - Future planning
 - Sibling
 - Adult
 - Intellectual and developmental disability
- 4 journal articles

Research Process

- Brennan, D., McCausland, D., O'Donovan, M. A., Eustace-Cook, J., McCallion, P., & McCarron, M. (2020, March 28). Approaches to and outcomes of future planning for family carers of adults with an intellectual disability: A systematic review. *J Appl Res Intellect Disability*, 33, 1221-1233. doi:10.1111
- Lee, C. e., & Burke, M. M. (2020, June). Future Planning Among Families of Individuals With Intellectual and Developmental Disabilities: A Systematic Review. *Journal of Policy and Practice in Intellectual Disabilities*, 17(2), 94-107. doi:10.1111/jppi.12324
- Lee, C. e., Burke, M., Arnold, C. K., & Owen, A. (2019). Correlates of current caregiving among siblings of adults with intellectual and developmental disabilities. *J Appl Res Intellectual Disability*, 32, 1490-1500. doi:10.1111/jar.12644
- Lindahl, J., Stollon, N., Wu, K., Liang, A., Changolkar, S., Steinway, C., . . . Jan, S. (2019). Domains of planning for future long-term care of adults with intellectual and developmental disabilities: Parent and sibling perspectives. *J Appl Res Intellectual Disability*, 32, 1103-1115. doi:10.1111/jar.12600

Research Process

Themes of Literature Review

- Families are not prepared for transition of care
- Adults with developmental disabilities adjust better when able to stay in a living situation with which they are familiar
- Staying in the same state is imperative to maintain services

Research Process

Online Research

- Research was done online specifically through New Mexico Department of Health
 - DD Waiver
 - Mi Via
 - Medically Fragile Waiver
 - The Community Benefit
 - The Supports Waiver
- Google searched
 - Centennial Care Insurance Companies of New Mexico
 - The Arc of New Mexico
 - ABLE accounts

Research Process

Professional Interviews

- Cathy Salazar, Lead Healthcare Family Liaison, Parents Reaching Out
- Jane Ryle, MLS, Paralegal

How was this information synthesized?

- I sat with Cathy Salazar on several occasions and interviewed her
- Email was used to communicate with both Cathy Salazar and Jane Ryle

PRODUCT

Power Point Webinar and Worksheet

A 10-minute Power Point webinar and accompanying customizable information worksheet was created.

This webinar will be recorded with Kaltura Capture.

Narration done by Allison Salazar

Power Point Webinar

Becoming a Primary Caregiver for your Adult Sibling with Special Needs: a Webinar on Legal, Financial, and Medical Coverage Considerations

Allison Salazar, BA, NM LEND Trainee, Family Discipline
Capstone Project

Why am I making this?



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General Tips

- Start having open conversation about future caregiving plans
 - Discuss the who, what, when and what if's
 - Do not shy away from talks regarding finances
 - Ask about which services your sibling are receiving
 - Discuss who are the important contacts in your sibling's care.
 - Remember these conversations can happen over time and they do not have to be scary

What will this presentation cover?

- Supported decision making
 - Guardianship
 - Power of Attorney
- New Mexico Waiver Programs
- Supplemental Security Income (SSI)
- Health Insurance
- Finances
- Resources



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Supported Decision-Making

What is Supported Decision-Making?

According to the American Bar Association it is defined as supports and services that help an adult with a disability make his or her own decisions by relying on trusted friends, family members, professionals, and others.



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Supported Decision- Making

There are two legal options

- 1) Guardianship
 - 2) Power of Attorney
- Your adult sibling's current caregiver/s will have one or the other

Guardianship

- This an expensive process that involves lawyers and attorneys
- Estimated cost is (\$5k-12k)
- Guardianship is overseen by the courts
- Guardianship transfer is best done beforehand
- *Does not transfer states*

Power of Attorney

- Is much easier to obtain and is much less expensive
- Your sibling will have to have the cognitive ability to consent to this arrangement
- This can be done before the time is needed
- Cost is minimal

Resources

- Parents Reaching Out
 - <https://parentsreachingout.org/>
- Pegasus Law Firm
 - <https://pegasuslaw.org/kinship-guardianship/>
- Guardianship and Care Management Services, LLC
 - <https://www.marygalvezguardianship.com/>
- New Mexico Developmental Disabilities Planning Council
 - <https://www.nmddpc.com/>
- The Arc of New Mexico
 - <https://www.arcnm.org/>
- National Resource Center for Supported Decision-Making
 - <http://supporteddecisionmaking.org/>

New Mexico Waiver Programs

- Chances are your adult sibling receives support and services from a New Mexico Waiver Program. There are several waivers:
 - Medically Fragile Waiver
 - Developmental Disability waiver (DD Waiver)
 - Mi Via Waiver
 - The Supports Waiver
 - Centennial Care Community Benefit Waiver



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New Mexico Waiver Programs

Medically Fragile Waiver

- For those who received qualifying diagnoses before age 22
- Nurse Case manager
- Yearly level of care review
- Monthly check-ins



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New Mexico Waiver Programs

Developmental Disability Waiver (DD Waiver)

- Case manager
- This waiver gives funding for a variety of services
 - Therapies
 - Living supports
 - Respite
- How and where money is spent is tracked and, in some cases, needs approval

New Mexico Waiver Programs

Mi Via Self-Directed Waiver

- A self-directed waiver
- Can be used for both DD Waiver and Medically Fragile
- Family, individual, legal caregiver assumes larger control of their waiver budgets

New Mexico Waiver Programs

The Supports Waiver

- This waiver is for those on the DD Waiver waitlist
- This Waiver offers
 - Supports services
 - Medicaid
 - Annual budget of \$10,000
- Waiver is accessed through:
 - Agency Based Services or Participant Directed Services.



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New Mexico Waiver Programs

Centennial Care Community Benefit Waiver

- The Centennial Care Managed Care Organizations (MCO's) provide the Community Benefit
- For those who qualify for nursing facility care but want to remain at home
 - Does not pay for 24-hour care
 - Goal is to offer supports for natural givers
- Care Coordinator
- Waiver is accessed through:
 - Agency Based Services or Participant Directed Services
- Resource
 - Individual insurance company



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Resources

- Developmental Disability Waiver
 - <https://www.nmhealth.org/about/ddsd/pgsv/ddw/>
 - Program Manager is [Marie Velasco](#)
505-660-0766
- Medically Fragile Waiver
 - <https://www.nmhealth.org/about/ddsd/pgsv/mfw/>
 - Program Manager is [Iris Clevenger](#), RN MA BSN CCM
505-841-2913
- Mi Via
 - <https://www.nmhealth.org/about/ddsd/pgsv/sdw/>
 - Acting Program Manager is [Jennifer Rodriguez](#)
505-476-8840
- The Supports Waiver
 - <https://www.nmhealth.org/about/ddsd/pgsv/csw/>
 - Program Manager is [Jennifer Roth](#)
575-476-8917



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Supplemental Security Income, (SSI)

What is Supplemental Security Income?

- It is a need-based benefit
- Intended for those who are elderly, blind or disabled who have little or no individual income and resources



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Supplemental Security Income, (SSI)

How SSI Works

- To qualify the individual must have less than \$2000 in resources.
- The New Mexico monthly benefit is \$794
 - Paid on the 1st of the month
- Requires medical documentation to qualify
- Requires financial documentation
 - Must keep all records of what is saved and spent
 - Annual spending reports are required
- Redetermination (non-medical) happens annually
- Representative Payment Program

Resources

- Social Security Administration
 - www.ssa.gov
 - 1-800-772-1213
- Parents Reaching Out
 - <https://parentsreachingout.org/>
 - 505-247-0192

Health Insurance and Healthcare

Health Insurance

- Chances are your sibling has Medicaid or private health (aca 26)
 - New Mexico uses Managed Care Organization
 1. Presbyterian Health Care Services
 2. Blue Cross Blue Shield of New Mexico
 3. Western Skies

Health Insurance and Healthcare

Important things to ask and know before hand

- What insurance or insurances are they covered by?
 - Know which is primary and which is secondary
- Do they have a care coordinator (Medicaid only)?
- Know who their Primary Care Provider (PCP) is
 - And any other specialists or healthcare service providers

Health Insurance and Healthcare

Important documents you'll need for medical care

- Insurance card
- Have proof of Supported decision-making, if applicable
- Carry your sibling's ID with you
- Some hospitals give you a Medical Records Number card, have that with you
- Keep an accurate and current medication list if applicable

Resources

- Blue Cross Blue Shield of New Mexico Centennial Care
 - <https://www.bcbsnm.com/community-centennial>
- Presbyterian Healthcare Services Centennial Care
 - <https://www.phs.org/health-plans/centennial-care-medicaid/Pages/default.aspx>
- Western Sky Community Care
 - https://www.westernskycommunitycare.com/?utm_source=Nexstar&utm_medium=CPC&utm_campaign=Albuquerque%2C%20NM%20Metro%20Area-SEM
- For specific insurance questions: Call insurance company directly

Financials

Yes, an uncomfortable but important topic to discuss



Financials

Start with the basics

- What bank does your sibling have their personal account at?
 - Ask if you can be put on that account ahead of time
- Does your supported decision making allow you to have access to you sibling financials and/or do they want your help?
- Ask about their current budget and get to know their spending habits
- Are their current financial needs met?
- Get to know if your personal finances will be affected by role as primary care giver

Financials

Will there be inheritance or a trust of some kind?

- Discuss this beforehand because a trust or inheritance can affect your sibling's services
- Talk to trust lawyers if needed



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Financials

Important notes

- You will need to keep records of where your sibling's money is going
 - SSI will require specific and accurate accounting
- You need to be organized



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Resources

- **ABLE New Mexico**
 - <https://ablenewmexico.com/>
- **Special Needs Alliance**
 - <https://www.specialneedsalliance.org/the-voice/two-different-types-of-special-needs-trusts/>

This transition does not
have to be scary.

Product

Information Worksheet

The Village it Takes

My Name:	DOB:	
My Person (Supported decision making): Where and with whom do I live Emergency contacts	Name	Phone
	Name	Address
	Name	Address
	Name	Address
Important Things to know about me:	Primary Diagnosis:	Other Important Information:
Insurances:	Primary	Phone Number
	Secondary	Phone number
Insurance Care coordinator:	Name	Phone number
Waiver Program:		
Case Manager:	Name	Phone Number
Primary Care Provider:	Name	Phone Number
Other service providers:	Name	Phone Number
	Name	Phone Number
	Name	Phone Number
Do I receive SSI?		Where are the directions and Paperwork?
Financial Institution:		Where are the directions and Paperwork?

Dissemination

- This webinar will be posted onto YouTube by May 30th.
- Other options are waiting approval
 - Promoting through PRO
 - LEND Portal
- Other
 - New Mexico PCPs
 - Social Media

What I learned

- That even the most prepared and organized families are not prepared for transitioning care from one family member to another.
- How to script and record a webinar
- Developing skills with the interview process both through email and in-person

References

1. Brennan, D., McCausland, D., O'Donovan, M. A., Eustace-Cook, J., McCallion, P., & McCarron, M. (2020, March 28). Approaches to and outcomes of future planning for family carers of adults with an intellectual disability: A systematic review. *J Appl Res Intellect Disability*, 33, 1221-1233. doi:10.1111
2. Guardianship and Care Management Services, LLC. (2020). *What is Guardianship*. Retrieved from Guardianship and Care Management Services, LLC: <https://www.marygalvezguardianship.com/faq's>
3. Jane Ryle, M. (n.d.). Paralegal. (A. Salazar, Interviewer)
4. Lee, C. e., & Burke, M. M. (2020, June). Future Planning Among Families of Individuals With Intellectual and Developmental Disabilities: A Systematic Review. *Journal of Policy and Practice in Intellectual Disabilities*, 17(2), 94-107. doi:10.1111/jppi.12324

References

5. Lee, C. e., Burke, M., Arnold, C. K., & Owen, A. (2019). Correlates of current caregiving among siblings of adults with intellectual and developmental disabilities. *J Appl Res Intellectual Disability*, 32, 1490-1500. doi:10.1111/jar.12644
6. Lindahl, J., Stollon, N., Wu, K., Liang, A., Changolkar, S., Steinway, C., . . . Jan, S. (2019). Domains of planning for future long-term care of adults with intellectual and developmental disabilities: Parent and sibling perspectives. *J Appl Res Intellectual Disability*, 32, 1103-1115. doi:10.1111/jar.12600
7. NMDDPC. (n.d.). *Office of Guardianship*. Retrieved from The New Mexico Developmental Disabilities Planning Council: https://www.nmddpc.com/guardianship_program
8. NMDOH. (n.d.). *Developmental Disabilities Waiver*. Retrieved from New Mexico Department of Health: <https://www.nmhealth.org/about/ddsd/pgsv/ddw/>

References

9. NMDOH. (n.d.). *Medically Fragile Waiver*. Retrieved from New Mexico Department of Health : <https://www.nmhealth.org/about/ddsd/pgsv/mfw/>
10. NMDOH. (n.d.). *Mi Via Self-Directed Waiver*. Retrieved from New Mexico Department of Health: <https://www.nmhealth.org/about/ddsd/pgsv/sdw/>
11. NMDOH. (n.d.). *Supports Waiver*. Retrieved from New Mexico Department of Health: <https://www.nmhealth.org/about/ddsd/pgsv/csw/>
12. Parents Reaching Out. (2020). *Healthcare*. Retrieved from Parents Reaching Out: <https://parentsreachingout.org/health-care/>
13. Pegasus Legal Services for children. (2021). *KINSHIP GUARDIANSHIP*. Retrieved from Pegasus Legal Services for children: <https://pegasuslaw.org/kinship-guardianship/>
14. Salazar, C. (2021). Lead Healthcare Family Liaison, Parents Reaching Out. (A. Salazar, Interviewer)

Questions?