



CENTER FOR
DEVELOPMENT
& DISABILITY

Support & Self Care for Siblings of Individuals with Disabilities

UNM LEND CAPSTONE PROJECT

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NM LEND 2020 - 2021



OUTLINE

- I. Problem-Framing
- II. Research Process
- III. Product
- IV. Dissemination
- V. References

Sibling Relationship = Most Important

- Serves as companions, confidants, and role models in childhood (Dunn, 2017).
- Spend more time with one another than other individuals.
- Longest relationship between two individuals.



Differences in Siblings With vs Without Disabilities

- Daily Routine

- Responsibilities

- Maturity

- Future Plans



Mental Health in Siblings

- Anxiety
- Depression
- Loneliness
- Pressure
- Guilt
- “Others Before Self”
- Worry
- Behavior Issues



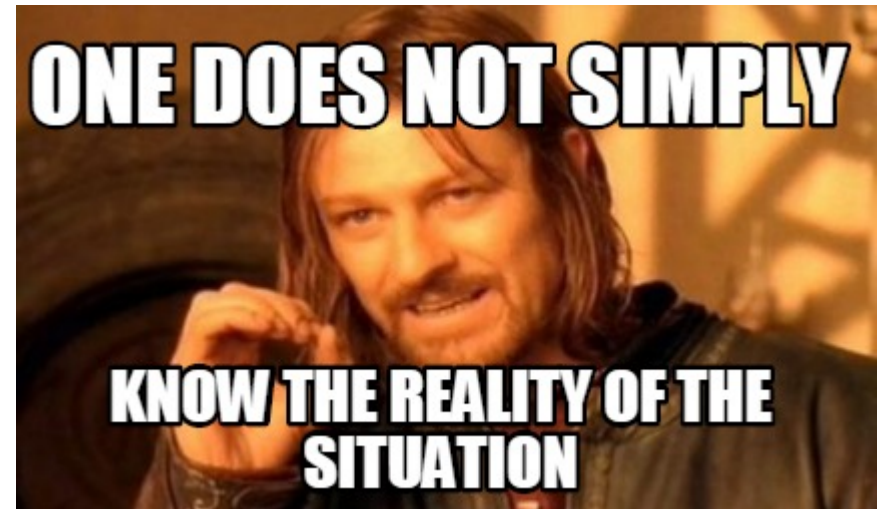
The Glass Child

- Definition: Sibling who has a brother or sister who requires ongoing attention and care above and beyond what we would consider normal parenting to be
- Looking right through the sibling on their emotional and psychological needs.
- Quiet and sensitive to parents and siblings needs



Problem-Framing

- Lack of supports for siblings of individuals with disabilities
- Mental health is compromised from an early age
- Unsure of how to take care of sibling now & in future
- Tend to forget to take care of self!



Overall Question

What type of Resources & Self Care is available for Siblings of Individuals with Disabilities?

LEND Competencies

Competency 1: Family-Centered/Culturally Competent Practice

- 1.5: Demonstrate an awareness/sensitivity to the impact of disability on family
- 1.6: Demonstrate awareness of the benefits of partnership with families at program/policy level
- 1.9: Identify family-centered care principles in the community and services system

Competency Five: Research and Critical Thinking

- 5.5: Demonstrate verbal presentation skills including use of PowerPoint and auditory augmentation system

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Research Methods

- Literature Review
 - Six Quantitative Articles
 - Topic: Mental Health & Siblings of Individuals with Disabilities
- Informal Discussions with Siblings
- Informal Discussions with Local Resources
- No IRB needed



Literature Review

- Overall Theme: Anxiety
 - Higher Anxiety Levels
 - Type of Disability
 - Relationship Quality
 - Socio-economic status
 - Interactions
 - Lower Anxiety Levels
 - Knowledge of Sibling / Sibling Needs
 - Inclusion in activities (including therapies)

Anxiety: "What if this happens?"

Me: "But it won't."

Anxiety: "But what if it does?"

Me:



Literature Review

- Suggestions
 - More research on siblings in different age groups
 - Providers include Siblings in Family Practices
 - Therapeutic Outlets



Discussion with Local Resources

- Loma Linda Community Center
 - Programs
 - Community Center: Grades K -12
 - Mark Twain & McCollum Elementary School: K-5
 - Registration
 - Limited Spaces
 - Priority for Children with Disabilities (Second Priority is Siblings)
- New Mexico Autism Society
 - Club Programs
 - Enrolled in Club Programs
 - No Time
 - Survey
 - Looking at Community Input on Groups/Events
 - 2% interest (100 + Surveys)

Discussion with Siblings

- Sibling Concerns:
 - Knowledge of Benefits
 - Transition to Guardianship
 - Finances
 - Employment
 - Transportation
 - Balancing Life
 - Marriage Strain



Discussion with Siblings

Beneficial Resources:

- Friendships with Other Siblings
- Online Support Groups
 - Sib20
 - SibNet
 - Facebook Groups
- SibShops
- Sibling Leadership Network
- Counseling/Psychotherapy
- Conferences

SIBLING 
LEADERSHIP
NETWORK

 SibNet



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Brochure

- Validating Thoughts/Feelings
- Resources
 - Online Support Groups
- Self-Care Awareness





FEELINGS / THOUGHTS / CONCERNS COMMON AMONG SIBLINGS

Taking on more responsibilities
(including Caregiver
responsibilities) at an early age

Heightened Anxiety

“In The Dark” on
Services/Resources for Sibling.

Concerns about the future (What
role will I be taking on? How will
my sibling influence my future?)

Lack of Support



“The siblings of special
needs children are quite
special. Absolutely
accepting and totally
loving, from birth,
someone who is different
mentally, and has a
different way of seeing the
world, is a wonderful trait.
It’s a trait I wish there was
another way of getting,
but there isn’t. And it does
involve a degree of not
having it fantastically
easy.”

- Sally Phillips



Resources for Siblings with Disabilities

New Mexico Leadership in
Neurodevelopmental and
Related Disabilities Program

2020 - 2021



BOOKS FOR SIBLINGS

Little Big Sister by Amy McCoy

Rules by Cynthia Lord

Special Brothers and Sisters by Annette Hames & Monica McCaffrey

The Sibling Survival Guide: Indispensable Information for Brothers and Sisters of Adults With Disabilities by Don Meyer and Emily Holl

Living with a Brother or Sister with Special Needs: A Book for Sibs by Don Meyer & Patricia Vadasy

Boy Alone: A Brother's Memoir by Karl Taro Greenfeld

Being the Other One: Growing Up with a Brother or Sister Who Has Special Needs by Kate Strohm

ONLINE SUPPORT GROUPS

Sib 20

- <https://www.facebook.com/groups/118970768514797/>

SibNet

- <https://www.facebook.com/groups/SibNet/>

Sibling Leadership Network

- <https://siblingleadership.org>

Sib-in-Laws

- <https://www.facebook.com/groups/647850432331785>

Sibling Support Project

- <https://siblingsupport.org/>

Siblings with a Mission

- <http://www.siblingswithamission.org/>

SELF-CARE TIPS

Positive Statements

- Utilize “I am” statements, including positive words that reflect you and your journey (ex. “I am Strong”, “I am a Great Sibling”)

State Your Wants/Needs

- It is okay to tell the individuals (family, friends, etc.) what you need. Make a checklist and work towards your goals!

Write in a Journal

- Write down your thoughts and feelings. Talk about your ideas and future plans! Let your mind wander!

Other Ideas:

- Read a Book
- Meditate
- Have a Dance Session
- Make a Vision Board
- Exercise
- Do Something with a Friend
- Take a Nap

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Dissemination: Local Resources

- NM Autism Society
- Bridges Inc.
- Jumpstart
- Kidpower
- UNM CDD
- Elevate the Spectrum



Steven W Skinner
@SkinnerSteven

"Bro, you want this pamphlet?"

"Brochure"

11/16/18, 11:12 AM

4,652 Retweets **18.7K** Likes

Dissemination: National Resources

- Online Sibling Groups
- Sibshops
- Sibling Leadership Network
- Sibling Support Project
- Siblings with a Mission



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Landman, K. (2020, May 11). Growing up alongside a sibling with a disability. Retrieved April 24, 2021, from <https://www.nytimes.com/2020/05/11/parenting/children-sibling-disability.html>

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O'Neill, L. P., & Murray, L. E. (2016). Anxiety and depression symptomatology in adult siblings of individuals with different developmental disability diagnoses. *Research in Developmental Disabilities*, 51, 116-125.

Pollard, C. A., Barry, C. M., Freedman, B. H., & Kotchick, B. A. (2013). Relationship quality as a moderator of anxiety in siblings of children diagnosed with autism spectrum disorders or Down syndrome. *Journal of Child and Family Studies*, 22(5), 647-657.

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