***Research in Social Sciences***
*Volume 8, Issue 3, pp. 51-61*
*2025*

# Am I my Brother's Keeper? Interviews with Individuals who have Siblings with Disabilities

♣***Sunaina Shenoy***: *University of New Mexico, United States.*
*E-mail:* shenoy@unm.edu

***Renee Howells***: *Idaho State University, United States.*
*E-mail:* reneehowells@isu.edu

***Alice Dunn***: *University of New Mexico, United States.*
*E-mail:* atapiadunn7@unm.edu

***Theresah Boateng***: *University of New Mexico, United States.*
*E-mail:* tnapetey@unm.edu

**ABSTRACT:** *Research on the impact of having a sibling with a disability has been contradictory in that some studies have cited positive lived experiences, while others have cited a negative impact on health and emotional well-being. This study explores the impact of having a sibling with a disability on typically developing adults. We explore this issue through several psychological constructs, including identity, attachment, family dynamics, responsibilities towards siblings, etc. We used grounded theory as a framework to conduct semi-structured interviews with ten individuals who had siblings with disabilities. Recorded interviews were transcribed and analyzed. The participants reported varied experiences regarding parent-sibling dynamics, the concept of disability, cultural aspects, current relationships with their siblings, employment, and relating to others in society. Implications for research and practice in counselor education and special education will be discussed.*

*Key words:* *Concept of disability, Interviews, Siblings with disabilities.*

## 1. Introduction

Sibling relationships are profoundly influential in life, as they have the potential to be the longest enduring of familial bonds and guide identity development and social discernment (Gibbons & Gibbons, 2016). Traditionally, sibling relationships inform social learning about the world and one's place within it. Understanding the factors that affect identity development and sibling relationships has been a curiosity for many mental health and educational researchers, as siblings are the first peer-group experience (Caplan, 2011; Gibbons & Gibbons, 2016). Themes of competition, comparison, sharing, alliance, and differentiation from and identification with the sibling create the cornerstone of identity development and socio-emotional intelligence (Caplan, 2011).

Throughout their lifespan, siblings of individuals with disabilities are often called upon as informal caretakers, teachers, interpreters, and pseudo-parent figures (Meltzer et al., 2021). Caring for a sibling can include varying contexts of physical, social, emotional, and logistical support, beginning in childhood and continuing into adulthood (Meltzer et al., 2021). Several studies within the greater domain of health literature

***Research in Social Sciences***
*Vol. 8, No. 3, pp. 51-61*
*2025*
DOI: *10.53935/26415305.v8i3.376*
*Email:* shenoy@unm.edu

have explored the impact of the cost of caring on non-disabled adult siblings (Caplan, 2011; LeClere & Kowaleswski, 1994; Hallion et al., 2016).

However, a consensus about the impact has not been reached, creating controversy within many health disciplines. LeClere and Kowaleswski (1994) found that non-disabled siblings are more likely to develop emotional distress and exhibit problematic behavior. Over the next twenty-five years, studies continued to posit the negative implications of the health and well-being of the non-disabled sibling. Several studies have cited an increase in physical and psychological impairment of non-disabled siblings (Hallion et al., 2016; Lee & Burke et al., 2018), postulating that having a sibling with a disability is, in itself, a risk factor (Marks et al., 2005). Physical impairment included the development of chronic illnesses and an increased likelihood of substance abuse and addiction in adulthood. Psychological impairment included the development of mental illnesses, financial distress, internalized guilt, aggression, resentment, avoidance, and fear persisting into adulthood (Caplan, 2011; LeClere & Kowaleswski, 1994; Hallion et al., 2016).

Conversely, research has also shown that having a sibling with a disability may bolster an individual's ability to self-regulate and thrive interpersonally. Rosetti & Hall (2015) reported that while risk factors exist, adult siblings of individuals with disabilities report more frequent feelings of joy, positivity, and social connectedness to others. Research has also noted that non-disabled siblings display a greater depth of empathy, resiliency, and resourcefulness (Milevsky & Singer, 2022; Rosetti & Hall, 2015; Wofford & Carlson, 2017).

The lack of congruence in findings is attributed to the focus on the medical model of pathology versus the wellness model in health-based research (Hallion et al., 2016). Given the research gap and lack of consensus in the field, we were interested in studying sibling relationships as they related to several key aspects, including; attachment, identity development, socio-emotional development, family dynamics, responsibility towards siblings with disabilities, and differences in reactions to siblings depending on the severity of the disability.

## 2. Theoretical Framework: Grounded Theory

In the study, we utilized Corbin and Strauss's (2015) grounded theory. Originally developed by Glaser and Strauss (1967), grounded theory is a comprehensive qualitative methodology that allows researchers to examine lived experiences of participants from an array of perspectives as it provides a procedural concept map to identify how values, logic, and emotion underlie human behavior and meaning-making (Corbin & Strauss, 2015). Under this social constructivist paradigm, it is asserted that humans invent concepts and schemas to make sense of events and alter these constructions in light of new information. Specifically, the aim of grounded theory is to develop a framework to explain a process or action over time (Creswell & Poth, 2018), making it particularly appropriate to explore the research question: *How has having a sibling with a disability impacted your personal lived experience throughout your lifespan?*

In contrast to deductive research methods used to validate pre-existing hypotheses, Corbin and Strauss's (2015) grounded theory allows researchers to identify concepts and explanations derived from the data collected during the research process; theories are co-constructed with participants. Therefore, the purpose of this study was to construct a theory based on the participants' lifelong process of having a sibling with a disability.

## 3. Method

### *3.1. Participants*

We conducted semi-structured interviews with 10 individuals who had siblings with disabilities. The participants' demographic details are presented in Table 1 and the interview questions are presented in the Appendix. Our inclusion criteria were individuals 18 years and above who resided in the United States and had at least one sibling with a disability. Most of our participants (70%) were Caucasian, but we did have three participants who were Chinese American, Indian American, and African American, respectively. Most participants (80%) worked with students at the school or college levels as speech-language pathologists, learning specialists, counselors, lab managers, college professors and directors of student services at university campuses. Most family types (80%) were biological, but we did have one family type that was adopted and one that was blended. The siblings had a range of disabilities, including developmental disabilities (30%), mental health disorders (30%), and physical impairments (40%).

DOI: *10.53935/26415305.v8i3.376*
*Email:* shenoy@unm.edu

**Table 1.**
Demographics of Interview Participants.

| Name of Participant | Race/Ethnicity | Occupation | Family Type | Sibling's Disability Type | Onset of Disability | Severity of Disability |
|---|---|---|---|---|---|---|
| Amy | Caucasian | Director of Accessibility Resource Center at a university | Blended | Orthopedic Impairment | At birth | Mild-Moderate |
| Bella | Caucasian | Learning Specialist at a private school | Biological | Eating Disorder and Multiple Sclerosis | Middle School and Adulthood | Moderate-Severe |
| Chamisa | African American | Assistant Professor of Counseling at a university | Biological | Visual Impairment and Traumatic Brain Injury | At birth and in adulthood | Moderate-Severe |
| Karl | Caucasian | Graphic Designer/Illustrator | Biological | Spinal Muscular Atrophy | Preschool | Mild-Moderate |
| Lisa | Caucasian | Laboratory Manager/Research Technician at a university | Biological | Bipolar Disorder | Adulthood | Moderate-Severe |
| Madrid | Indian American | Director of Student Affairs at a university | Adopted | Attention Deficit Hyperactivity Disorder (ADHD) and Mental Health | Elementary | Mild-Moderate |
| Shen | Chinese American | Speech Language Pathologist at a high school | Biological | Schizoaffective Disorder | Adulthood | Moderate-Severe |
| Sienna | Caucasian | Legal Assistant/Litigation Paralegal | Biological | Spinal Muscular Atrophy | At birth | Moderate-Severe |
| Suzy | Caucasian | Speech Language Pathologist | Biological | Autism | Preschool | Moderate-Severe |
| Tamara | Caucasian | Graduate Student in School Counseling | Biological | Intellectual Disability | Preschool | Moderate-Severe |

### *3.2. Positionality*

Our research team is comprised of four cisgender women located in the Rocky Mountain region of the US. Authors 1 and 2 are tenure-track Assistant Professors of Special Education and Counselor Education, respectively. Authors 3 and 4 are graduate students pursuing their degrees in Special Education. Author 1 is South Asian, author 2 is White, Author 3 is White and Hispanic, and Author 4 is Black. All team members identify as non-disabled (abled), however, authors 2, 3, and 4 have immediate family members who have disabilities. In alignment with qualitative inquiry, our positionalities are shared to increase trustworthiness and credibility of our research.

Recognizing and accounting for potential sources of bias, especially those stemming from researchers' positionalities and preconceptions, is critical to the trustworthiness of naturalistic research. These "personal, professional, cultural, and theoretical lenses" (LeCompte & Schensul, 2013, p. 48) can potentially influence multiple stages of a research project. Our research team is diverse in each of these aspects, including, personal experience with monolingualism and multilingualism, identified disabilities among children of research team members and close family members, work histories, academic disciplines, ethnicities, cultural affiliations, countries of origin, and theoretical orientation, among others. Recognizing that these differences among research team members was a strength, we purposefully involved all the authors in different aspects

***Research in Social Sciences***
*Vol. 8, No. 3, pp. 51-61*
*2025*
DOI: *10.53935/26415305.v8i3.376*
*Email:* shenoy@unm.edu

of the project, including developing the research design, constructing the interview protocol, conducting interviews, identifying and discussing initial and coding categories, coding all the transcripts. During discussions, we sought to highlight differences in interpretations to widen the lenses through which we analyzed the data, asking what others saw in the data, probing for reasons for confirmation or disagreement on emerging coding categories, and working through all initially identified excerpts for a potential coding category.

We also deliberately sought diversity among the participants whom we interviewed by recruiting widely across various parts of the US, different work experiences, having siblings with different disability categories, representing different family dynamics, etc. to create a robust pool of participants.

### *3.3. Data Collection Procedures*

All data were collected after approval from the university's internal review board. Our interviews were conducted during the 2021-22 academic year, from August 2021 to May 2022. Before this, during the 2020-21 academic year, we conducted a survey with 338 participants, divided into three groups: 145 had siblings with disabilities, 104 had typical siblings, and 89 were only children. Out of the 145 participants who had siblings with disabilities, 17 participants indicated that they would like to commit to an interview the following academic year to share their experiences in more detail. Out of these 17 participants who were contacted in Summer 2022, seven either said they were not interested anymore or did not have time for an interview in their schedule and were dropped from our list. Ten participants responded positively and scheduled an interview with us; they constituted our final set of participants.

The survey participants, and by extension, our interview participants, were recruited using snowball sampling by first reaching out to the public and private universities across the US that we had attended ourselves or had collaborated with or were currently collaborating with in some capacity. Second, we reached out to friends or family members who had attended or were currently attending universities across the US, and they sent it along to other people within their network. The centers, institutes, and organizations were either affiliated with university campuses (e.g. Center for Developmental Disabilities) or professional organizations (e.g., National Association of Special Education Teachers (NASET), National Board for Certified Counselors (NBCC) for which we had a membership). We had originally planned to visit some sites in person to recruit more participants but could not do this because of the COVID pandemic.

### *3.4. Data Analyses*

We followed a systematic thematic analysis process to analyze the data, beginning with multiple readings of the transcripts and taking notes of initial impressions as the final interviews were completed (pre-coding). Before initiating formal coding, we deidentified the transcripts and uploaded them to Dedoose, an online qualitative data analysis software program. The second and third authors then identified preliminary codes, focusing on those that seemed most important and salient to the general purpose of the research. We met to reach consensus on the meaning of each emerging code by examining the excerpts within each code and attempting to provide our understanding of each code. We worked through two transcripts, developing and refining codes, challenging our assumptions and discussing our perceptions, assumptions, and possible biases that might lead each of us in certain directions. After completing this process, we began hierarchically organizing the codes, clustering those that appeared related to each other and identifying some as subordinate to others. Throughout our discussions, we used a two-fold criterion: (1) that the patterns must have been identified across participants, and (2) that it said something meaningful concerning the overall study's purpose (Braun & Clarke, 2006). Subsequently, the third and fourth authors coded all ten transcripts based on the developed codes. They reached an inter-rater reliability of 89%. We then exported the code analysis from Dedoose, representing the most frequently occurring themes. In this study, we report on themes related to the participants' roles and responsibilities towards their siblings with disabilities.

## 4. Results

Our thematic analysis yielded seven categories (also known as theories) related to the process by which participants made meaning of their lived experiences of having a sibling with a disability in their family system. These categories directly mirror the domains of the quantitative RIDDS scale developed by authors one and two (Author, 2023). However, these categories move beyond the original scale and provide a depth

DOI: *10.53935/26415305.v8i3.376*
*Email: shenoy@unm.edu*

of intra and interpersonal insights into the holistic experience of having a sibling with a disability, spanning from childhood to adulthood. The thematic categories are: (1) *Describing Siblings*, (2) *Concept of Disability*, (3) *Views on Disability*, (4) *Parent-Sibling Dynamics*, (5) *Current Relationship with Siblings*, (6) *Employment Choices*, and (6) *Relating to Others and Society*.

### *4.1. Describing Siblings*

The participants described their siblings as individuals who were driven and had much larger positive expectations (of themselves) with respect to their purposive contributions to society. Specifically, having a disability was not a limitation on their capabilities. The reflections the participants shared of their siblings with a disability stemmed from an empathetic approach (they did not deny the physical and social limitations due to having a disability) but also from a strength-based paradigm (the participants' believed their siblings with disabilities could achieve great heights). Bella made these statements about her two siblings with disabilities:

> ..my older sister's (physical) disability was ultimately very obvious. Growing up, it was evident that so many things in life were difficult for her. But she was, and continues to be, very courageous, tenacious, and unwilling to give in … And then my second oldest sister, (who has a socio-emotional disability), was a great athlete, she was a world-class runner in high school. She was (and continues to be) driven, really a perfectionist.

From Chamisa's reflection, though her sibling suffered a few setbacks, the struggles did not impede her willpower as a person. She shared her perspective by saying:

> My sister went all the way through college (delayed education due to disability) … having sustained a traumatic brain injury … (delay with her thought processes) … but I see my sister as being a very beautiful, proud, strong, black woman, who has been an exemplar for me.

Karl reflected on his sibling's academic prowess and communicated this with a level of more profound satisfaction, "My sister was always the brilliant one in my family, and she was an avid reader. And she got good grades."

### *4.2. Concept of Disability*

We now consider the more elusive *concept* of disability. Most participants' internal concept of disability was shaped by their experience of having a sibling with a disability. Several sub-themes surfaced, the most prominent of which included personal values, especially values of advocacy and inclusion, and the notion of disability as a "non-limiting" factor. Personal values relate to those foundational principles by which one chooses to live one's life. In the context of disability, our participants offered many examples of how their values were shaped by having a sibling with a disability. Bella stated, "People with disabilities are not different from other people in any really significant way." At the same time, Lisa talked about how her personal values partly emerged from her experience with her sister. She said, "I (have) a greater sense of empathy, and a big part of it is understanding that I cannot understand what life is like for her. I can't understand her behavior, which is part of the disability." Moreover, Madrid's concept of disability includes the value that "you are not your disability, but at the same time, this is part of who you are, and you decide how you want to carry that in the world." For Karl, having a sister with the same disability has positively shaped his values, normalizing the concept of disability for him. Karl stated,

> Growing up with a sibling who shares the same disability as I do was beneficial. I did not see myself as 'different.' It was common in my house to need help with this or that, it was normal. That was a significant benefit for me.

Most participants described some level of advocacy or support for people with disabilities. For Suzy, advocating for her brother throughout her youth led her to a career in speech-language pathology. Suzy said, "Everything I've done is to learn about autism because I wanted to help my brother." Similarly, Tamara stated that school counseling provided her with a direct path to "advocate and make sure that students are getting the support that they need at their levels of capabilities."

Many participants specifically described aspects of inclusion as an essential part of their concept of disability. Suzy spoke directly about providing inclusive experiences for her brother. "Just because he has a disability doesn't mean he cannot have life experience. I went out of my way to make sure he could have experiences that he wanted because there's a lot he will not be able to have." On the other hand, Amy spoke

***Research in Social Sciences***
*Vol. 8, No. 3, pp. 51-61*
*2025*
DOI: *10.53935/26415305.v8i3.376*
*Email:* shenoy@unm.edu

to the need for inclusive environments when she said, “It is about creating accessible environments. It is not putting the onus on the individual, but rather what we can do as a society, as a university, as a class.”

For many participants, their concept of disability was directly shaped by the immersive experience of watching their siblings overcome the challenges of disability. As a result, many participants proffered that disability is not necessarily a limiting factor in life. For example, Amy stated, “We never regarded him as a person with a disability. It never restricted what he could or could not do, or the expectations of what he could or couldn’t do.” Suzy suggested that disability does not have to be ‘limiting’ if appropriate accommodations are in place. She said, “We treat him like everybody else but still accommodate his needs.” On the other hand, Chamisa relayed that her sister must advocate for herself to make others aware that her disability has not limited her potential, “my sister will point out, she’s not slow, she has a graduate-level education, and sometimes folks speak to her as if she has problems with understanding.”

The preceding examples illustrate that many factors shape a person's concept of disability. One thing that can be said is that there is no clear or concise definition of a person’s internal concept of disability. Rather, this concept seems to develop as a result of the accumulation of many lived experiences, and for these participants, experiences that include having a sibling with a disability. Perhaps Tamara put it best when she commented, “Disability: there’s no one definition. It looks different for everybody. Moreover, every human has potential, and it’s just providing them the right environment to get there.”

### *4.3. Views on Disability*

Next, we focus on the cultural aspects that impacted the participants’ views on disability. Two major sub-themes emerged from our analysis. First, parents played a vital role in shaping participants’ views on disability. This should not be surprising because children look to their parents as role models from the earliest ages (Bowlby, 1951, Ainsworth, 1963, Minuchin, 1995)

For Madrid, a strong sense of giving back and helping others was embedded in her family dynamic, “my parents are social workers, and my older sister has a Psy.D. degree. Finding ways to help other people has always been a family value.” Bella remembered a strong familial orientation from an early age, “the family I grew up in was oriented towards social justice issues, and I share that orientation – then and now.”

The second sub-theme suggested that some families set expectations for the non-disabled sibling to care for their disabled sibling. Shen provided a clear example of the expectations set for her and her brother to care for their disabled sister. Shen stated, “I am not financially responsible for her, (but) my brother, definitely. I am preparing (to provide) the social-emotional capacity to manage her disability.” Similarly, Suzy’s commitment to caring for her brother stems from a strong cultural context, “I just felt this internal responsibility to make sure he is ok, because I think, this is your family, and your job is to take care of family members.”

### *4.4. Parent-Sibling Dynamics*

Several themes became evident across the interviews that will be discussed here. First, many participants reflected on the notion that their parents treated them differently than their siblings with disabilities because of the disability itself. Sienna reflected on this disparity by stating, “Her needs always came first, even though I was the younger child, which I guess is a little bit of a role reversal.” Sienna further explained that some of this treatment stemmed from feelings of guilt on her parents’ part, “you know, living with this terminal diagnosis over you, they always tried to get her what she wanted, whereas that was not an option for me.” On the other hand, some participants reflected that the disparity in treatment stemmed more from the fact that their parents were overwhelmed with caring for a person with a disability and that they had little time and energy left for the siblings that were not disabled. Madrid expressed this when she stated,

> (My parents) were busy helping my sister, and they didn’t always have time or energy to help me with the stuff that I needed. I do not know if they intended to treat us differently, but the result was that they did because she had more acute needs.

Realizing that her parents were spread thin from caring for their child with a disability, Lisa reflected that while she was treated differently, it was partly due to her desire to help alleviate the load for her parents. “The way I contributed to our family system was by not taking anything from it. It was two-fold in that I did not want to be a burden, and ultimately, whenever I did need help, they were not available.”

**_Research in Social Sciences_**
*Vol. 8, No. 3, pp. 51-61*
*2025*
DOI: *10.53935/26415305.v8i3.376*
*Email:* shenoy@unm.edu

These examples illustrate the complex nature of sibling perceptions in the context of the family dynamic. Most participants in this study, whether they had a disability or not, recognized a sense of inequality within their family-sibling dynamic. However, the focal point for many was whether they were treated with equity based on their unique family systems and resources.

### *4.5. Current Relationship with Siblings*

The participants' levels of attachment and interrelatedness with their siblings are borne out of common values they believed they shared and their family's general expectations of their roles and responsibilities. Some of the participants expressed having a strong relationship with their sibling with a disability as a result of having similar outlooks. Bella stated, "We are temperamentally more similar… that's true of my sister in Colorado, as well. … we kind of share … an orientation to the world that is more similar." Tamara, however, inherently perceived a leadership role from being the oldest and from the standpoint of her family's expectations of the oldest child. She was naturally expected to take the leading role in caring for her sibling with a disability as she communicated:

> In my family, people would say, 'What would Tamara do?' I always had a lot of pressure applied… And I internalized those little comments of, 'Check in with Tamara' or 'Tamara will do this,' and 'Tamara will like'… I think those expectations, played even stronger when it came to having a sibling with a disability.

### *4.6. Employment Choices (Service Industry)*

From our analysis of the participants' current professions, employment in the service industry was prominent. Most of our participants worked with individuals with disabilities in academic institutions, non-profit organizations, and research centers. From the summary reviews of the participants' informed choices of careers, the majority related their decisions to spring from having a sibling with a disability. None of the participants recalled having an innate interest in exploring the realm of disability. Rather, our participants' inclination to enter disability-related fields seemed to stem from a desire to understand their siblings' disability and also from bearing witness to the struggles faced by their parents and siblings as a result of the disability itself. Amy said, "For my whole career, I've worked in educational settings, working with people with disabilities. It felt like a natural fit". Tamara and Suzy explained that through their educational journey, they had always had an interest in pursuing a career that would advance their knowledge of supporting individuals with disabilities (borne from the lens of having a sibling with a disability).

Suzy made these compelling statements:

> I focus a lot on an attempt to help my brother,… which is one reason I focus more on the adolescent population and older adults ... Everything I have done is to learn about autism. It's all because I wanted to help my brother. And so now, I started my practice and specialize in autism because of my brother.

Moreover, Tamara added:

> Yeah, 100%. In high school, we had to do a senior project, which could be anything. You could choose any problem in the world, and we had to present and volunteer. I chose to present on people with disabilities, the history of it, where we are now, and where we need to go. That is the foundation of where I jumped off from because I went into that, realizing that I wanted to learn more about that area, that population, what that could be.

### *4.7. Relating to Others and Society*

The participants' reflections on their relationships with their siblings and subsequent interactions with *others* (individuals with disabilities and those without disabilities) carried both intuitiveness and empathy. Growing up with a sibling(s) with a disability transformed and challenged their personal values and increased awareness of others in society. Most participants reported a positive attitude in relationships with others and a sense of advocacy to others, especially individuals with disabilities. Bella's experiences with relating to others were contradictory and stemmed from having two siblings with disabilities. Within the context of referring to her sister with multiple sclerosis, Bella shared these statements regarding how she relates to others: "People with disabilities are not different from other people, you know, in any really significant way".

***Research in Social Sciences***
*Vol. 8, No. 3, pp. 51-61*
*2025*
DOI: *10.53935/26415305.v8i3.376*
*Email:* shenoy@unm.edu

While describing a different sister diagnosed with an eating disorder, Bella said: "Kind of made me a little bit less … trusting or open in some ways." Bella made these statements to express her misconception and uncertainty regarding her sister's disability while growing up which negatively impacted her relationship with others in society. Growing up, Bella shared a strong bond with her sister. However, their relationship dynamic shifted rather abruptly, and without explanation, due to her sister's change in behavior. "I feel like, you know like my memory is we were close, and then all of a sudden we weren't, and I think that was hard for me as a young child", Bella reflected.

Lisa's views were fairly different, however. She explained that the degree of her interactions with others would be the same irrespective of having a sibling with a disability. She, however, credited her sibling as having some level of impact on her relationship with others "I don't think, at large, it's changed much how I relate to other people, but I think I'm a little bit more tolerant of others or a little bit more empathetic".

## 5. Discussion

Overall, our data analysis resulted in vast and enriching information about how individuals who have siblings with disabilities make meaning of their lived experience on intrapersonal, interpersonal, and systematic levels. Our categories revealed how participants view their own self-awareness and personal motivations in life (identity, emotion, values), while also exploring how integration into a system (family dynamics, culture, politics, community) influenced their world schemas. Regardless of their relationship descriptors, our participants identified a strong and intimate connection with their siblings with disabilities. The majority of the participants explicitly mentioned a desire for reciprocity. Specifically, they discussed a drive to 'give back' to their families and society. The passion for inclusion, equity, and accessibility was palpable and consistent. Many of these participants advocated for an integrative approach in how disability is colloquially understood. In fact, many communicated their beliefs that disability is simply part of the human condition, and should not be seen as separate, limited, or othering. A sense of hope and optimism was present in all participant narratives. Perhaps more than any other family relation, these participants believe their sibling(s) are capable of living authentically, fully, and without apology.

While this sentiment is empowering, it does not discount the hardships of having a sibling with a disability. Caretaking, whether or not participants were (or will be) directly responsible for the care of their disabled sibling(s), had meaningful and long-term impacts on our participants. Caring for and supporting their sibling or their family members (parental support) causes emotional and physical stress. Several participants identified how growing up in such an environment affected their relationships with themselves and others, career choices, and worldviews. Our research team noted the theme of co-dependency and a lack of preventative self-care practices within participants' stories of their family system and identity development. Participants spoke about having minimal resources and an overdeveloped sense of personal responsibility in caring for their family members as children, which often continued into adulthood, even outside familial contexts. This was demonstrated through the service-based career choices of 80% of our participants.

### *5.1. Implications for Research and Clinical Practice*

Implications for research reveal a continued need for further analysis of multigenerational family systems and adult relationships between siblings. Numerous qualitative and quantitative studies have explored the impact that occurs in childhood for typically developing siblings, yet long-term effects in adulthood, remain limited (Meltzer, 2018; Milevsky & Singer 2022). Specifically, more cross-disciplinary or transdisciplinary research teams from various health and education fields are warranted to ensure non-siloed knowledge sharing and professional development. This is reflected in best practices for clinical practice, in the growing application and prominence of wrap-around care, and interprofessional treatment teams. As counselors and educators (i.e., when providing mental health services or administering assessments) in these healthcare teams, it is vital to remain rooted in advocacy and strengths-based approaches when working with typically developing persons or persons with a disability as much prior research surrounding disability and family relations has been deficit-based (Dickinson, 2021; Wofford & Carlson, 2017).

Additionally, increasing cultural scope is an area for future consideration. In particular, extending this research question internationally and multi-generationally would allow for a more comprehensive global perspective on the phenomenon. While international studies concerning the development of typically

***Research in Social Sciences***
*Vol. 8, No. 3, pp. 51-61*
*2025*
DOI: *10.53935/26415305.v8i3.376*
*Email:* shenoy@unm.edu

developing siblings have been published in recent years, a consensus concedes the need for additional studies that consider the perspectives of all family members to represent the complexity of this subject more accurately (Bhattashali & Ostrosky et al., 2018; Paul & Hussey et al., 2022). Such a call is particularly important as disability is a multicultural and pluralistic aspect of personhood but has no universal consensus concerning diagnosis, treatment, resources, and holistic impact (Meltzer, 2018; Jajodia & Roy, 2022).

### *5.2. Limitations and Future Directions*

Throughout the study, our research team sought to uphold the qualitative principle of trustworthiness. Seminal work by Lincoln and Guba (1985) outline a framework for assessing the trustworthiness of qualitative research through questions of credibility (the degree to which findings can be considered truthful), dependability (the degree to which research processes can be audited and critiqued) transferability (the degree to which findings can be applied to similar contexts), and confirmability (the degree to which other researchers can confirm findings). While our study adhered to these concepts satisfactorily, it must be noted that our participant sample was skewed toward graduate degree-seeking individuals, which may impact broader transferability. As mentioned, our participants were recruited via snowball sampling from university listservs, where primary readership is involved in higher education. In the future, our research efforts could be made more accessible by widening our recruitment protocols (i.e., advertising in doctors' offices, public libraries, gyms, etc.). Another limitation of our study is the modality of our qualitative interviews. Our RIDDS quantitative survey (author one & author two et al., 2023) and our qualitative interviews were conducted online, which can prove challenging for participants with certain disabilities and/or those with limited access to technology. A final limitation to consider is the retrospective nature of our research agenda. Some of our interview questions required or invited participants to reflect on their earlier years (childhood, early adulthood) in their family systems or memories involving their sibling with a disability. While this is not a flaw of the study, it may color the veracity of participant experience, as memory can be distorted over time.

## 6. Conclusions

This qualitative study aimed to holistically explore the adult identity development of individuals who have siblings with disabilities. Through semi-structured grounded theory interviews with ten participants, six major categories (themes) emerged that shed light on how typically developing siblings made sense of disability (both in concept and action); of their family systems (parent and sibling relationships); society at large (i.e. community); and of themselves (e.g., self-esteem, purpose, personhood). Participants gave voice to their inner and outer worlds, which is timely and has notable implications for continued counseling and special education research. Adults who have a sibling with a disability represent a diverse population, and our research findings suggest there is a collective desire to redefine the message of 'limited' to 'limitless' in disability discourse.

## References

Ainsworth, M. D. (1963). The development of infant-mother interaction among the Ganda. Determinants of infant behavior, 67-112.

Bhattashali, A., Ostrosky, M. M., & Monda-Amaya, L. (2018). Perceptions of typically developing children in India about their siblings with disabilities. International Journal of Inclusive Education, 22(12), 1257–1271. https://doi.org/10.1080/13603116.2017.1420253

Bowlby, J. (1951). Maternal care and mental health (Vol. 2). Geneva: World Health Organization.

Caplan, R. (2011). Someone else can use this time more than me: Working with college students with impaired siblings. Journal of College Student Psychotherapy, 25(2), 120-131. https://doi.org/10.1080/87568225.2011.556933

Corbin, J. M., & Strauss, A. (1990). Grounded theory research: Procedures, canons, and evaluative criteria. Qualitative Sociology, 13(1), 3-21. https://doi.org/10.1007/BF00988593

Corbin, J., & Strauss, A. (2015). Basics of qualitative research: Techniques and procedures for developing grounded theory (4th ed.). SAGE.

Creswell, J. W., & Poth, C. N. (2018). Qualitative inquiry and research design: Choosing among five approaches (4th ed.). SAGE.

Denzin, N. K., & Lincoln, Y. S. (2018). The SAGE handbook of qualitative research (5th ed.). SAGE.

Dickinson, R. (2021). Siblings of individuals with disabilities: Experiences in Southern India. Journal of Family Issues, 42(9), 1998–2018. https://doi.org/10.1177/0192513X20960794

Gibbons, H. M., & Gibbons, C. M. (2016). Siblings with disabilities: A duoethnography on the intersections between a sibling relationship and disability. Disability & Society, 31(6), 820-837.

Glaser, B. G., & Strauss, A. (1967). The discovery of grounded theory: Strategies for qualitative research. Aldine Publishing Co.

***Research in Social Sciences***
*Vol. 8, No. 3, pp. 51-61*
*2025*
DOI: *10.53935/26415305.v8i3.376*
*Email:* shenoy@unm.edu

Hallion, M., Taylor, A., & Roberts, R. (2018). Complete mental health in adult siblings of those with a chronic illness or disability. Disability and Rehabilitation: An International, Multidisciplinary Journal, 40(3), 296–301. https://doi.org/10.1080/09638288.2016.1251500

Jajodia, P., & Roy, P. (2022). Sibling issues in disability: A thematic analysis of sibling, parent & expert perspectives. International Journal of Disability, Development & Education, 1–18. https://doi.org/10.1080/1034912x.2022.2060948

LeClere, F. B., & Kowalewski, B. M. (1994). Disability in the family: The effects on children's well-being. Journal of Marriage and the Family, 457-468.

Lee, C., & Burke, M. M. (2018). Caregiving roles of siblings of adults with intellectual and developmental disabilities: A systematic review. Journal of Policy and Practice in Intellectual Disabilities, 15(3), 237–246. http://dx.doi.org/10.1111/jppi.12246

Lincoln, Y. S., & Guba, E. G. (1985). Naturalistic inquiry. SAGE.

Lincoln, Y. S., Lynham, S. A., & Guba, E. G. (2011). Paradigmatic controversies, contradictions, and emerging confluences. In N. K. Denzin & Y. S. Lincoln (Eds.), The Sage Handbook of Qualitative Research (4th ed., pp. 97-128). SAGE.

Marks, S. U., Matson, A., & Barraza, L. (2005). The impact of siblings with disabilities on their brothers and sisters pursuing a career in special education. Research and Practice for Persons with Severe Disabilities, 30(4), 205-218.

Maxwell, J. A. (2013). Qualitative research design: An interactive approach (3rd ed.). SAGE.

Meltzer, A., Dowse, L., Smith, L., & Dew, A. (2021). A framework for interconnected benefits of peer support for family members of people with disability. Australian Journal of Social Issues, 56(4), 579-595. https://doi.org/10.1002/ajs4.130

Meltzer, A. (2018). Embodying and enacting disability as siblings: Experiencing disability in relationships between young adult siblings with and without disabilities. Disability & Society, 33(8), 1212–1233. https://doi.org/10.1080/09687599.2018.1481016

Milevsky, A., & Singer, O. (2022). Growing up alongside a sibling with a disability: A phenomenological examination of growth and deficiency in adulthood. Research in Developmental Disabilities, 130, 104336. https://doi.org/10.1016/j.ridd.2022.104336

Minuchin, P. (1988). Relationships within the family: A systems perspective on development. In R. A. Hinde & J. Stevenson-Hinde (Eds.), Relationships within families: Mutual influences (pp. 7–26). Oxford, United Kingdom: Clarendon Press.

Mruck, K., & Mey, G. (2019). Grounded theory methodology and self-reflexivity in the qualitative research process. In A. Bryant & K. Charmaz (Eds.), The SAGE handbook of current developments in grounded theory (pp. 470-496). SAGE.

Paul, A. M., Hussey, M. M., Woodman, A. C., Smith, A. L., & Shriver, T. P. (2022). Experiences of siblings of people with intellectual disabilities: Multiregional perspectives. Family Relations: An Interdisciplinary Journal of Applied Family Studies, 71(2), 671–685. https://doi.org/10.1111/fare.12608

Robson, C. (2011). Real world research: A resource for social scientists and practitioner-researchers (3rd ed.). Blackwell.

Rosetti, Z., & Hall, S. (2015). Adult sibling relationships with brothers and sisters with severe disabilities. Research and Practice for Persons with Severe Disabilities, 40, 120–137.

Wofford, J. R., & Carlson, R. G. (2017). A literature review and case study on the strengths and struggles of typically developing siblings of persons with disabilities. The Family Journal, 25(4), 398–406. https://doi.org/10.1177/1066480717732167

***Research in Social Sciences***
*Vol. 8, No. 3, pp. 51-61*
*2025*
DOI: *10.53935/26415305.v8i3.376*
*Email:* shenoy@unm.edu

# Appendix

## *Interview Schedule*

Tell me a little about yourself and your occupation.

Tell me a little bit about your sibling's disability.

**Q1.** How has having a sibling with a disability affected you? (Self-Concept/Self-Awareness)

  a. How do you see yourself?
  b. How do you relate to others?

**Q2.** How has having a sibling(s) with a disability influenced your world view? (Values)

  a. How has (if at all) your political/social issues/human rights evolved?

**Q3.** How has your experience with your sibling(s) influenced your career goals? (Vocational Interest)

  a. Do you participate/gravitate towards service-related opportunities?
  b. Do you engage in volunteer or advocacy work?

**Q4.** How would you describe your family dynamics? (Attachment)

  a. Were you treated differently from your sibling(s)?
  b. Did you feel as though your needs were met?
  c. How would you describe your sibling(s)?
  d. What was your role in the family growing up?
  e. How has your family dynamics shifted over time?

**Q5.** How has your cultural background influenced your concept of disability? (Cultural Intersectionality)

  a. Does your concept vary from your parents or other family members?
  b. What are your cultural beliefs around disability?

**Q6.** Describe the role of caregiving of your sibling(s). (Responsibility)

  a. Do you believe that you will be responsible for your sibling(s) care in the future?
  b. If so, do you feel prepared to fulfill this role? (I.e. resources, financial capabilities. Etc.)
  c. How has COVID impacted this role?

***Research in Social Sciences***
*Vol. 8, No. 3, pp. 51-61*
*2025*
DOI: *10.53935/26415305.v8i3.376*
*Email: shenoy@unm.edu*