

BREAKING THE SILENCE: SIBLINGS OF INDIVIDUALS WITH DISABILITIES
SPEAK-UP ABOUT THEIR SPPORT NEEDS

by

Gillian Neff

Peabody College of Vanderbilt University

May 2024

Major Area: Special Education

Number of Words: 227

Sibling relationships are important in that they can help predict the social-emotional development, understanding, and outcomes, and help shape the relationship between them. Due to these multi-facet predictors, it is critical that siblings of individual with disabilities feel supported from their childhood to their adult lives as they navigate the new responsibility and caretaking for their sibling with a disability. Unfortunately, research on siblings of individuals with disabilities is a lacking field of special education. There is a need for research to better understand and determine the unique needs of the sibling of individuals with disabilities. Therefore, the purpose of this study was to analyze the views of siblings on what could have been helpful to support them while growing up, through their childhood and teenage years. Through an online and paper survey siblings' perspective were collected, and the views of 446 siblings of individuals with autism spectrum disorder, Down syndrome, and cerebral palsy were analyzed. A total of six themes were identified from the perspectives of these siblings. Findings suggest that most siblings felt they were 'not adequately' supported during childhood, and identified various supports as potentially beneficial, to them, their families, and their communities. Implications for future research and future practice are discussed.

Alexandra Da Fonte

2/7/2024

Name of Committee Chair, Major Professor

Date

BREAKING THE SILENCE

BREAKING THE SILENCE: SIBLINGS OF INDIVIDUALS WITH DISABILITIES
SPEAK-UP ABOUT THEIR SUPPORT NEEDS

by

Gillian Neff

Master's Thesis

Submitted to the Faculty of

Peabody College of Vanderbilt University

in Fulfillment of the Requirements

for the Degree of

MASTER OF EDUCATION

in

Special Education, Low Incidence Severe Disabilities

May 2024

Alexandra Da Fonte

Major Professor

2/7/2024

Date

Robert M. Hodapp

Second Reader

2/7/2024


Date

Joseph Welby

Department Chair

2/20/2024

Date



Dean of Peabody College

2/26/24

Date

TABLE OF CONTENTS

Chapter	Page
I. INTRODUCTION	1
II. METHODS	8
Research Design.....	8
Participants.....	8
Survey Instrument.....	8
Procedures.....	9
Sampling Size and Response Rate.....	10
Data Analysis	10
Thematic Analysis.....	11
Descriptive Statistics and Correlates	11
III. RESULTS.....	12
Participants.....	12
Thematic Analysis.....	12
Supports Needed (RQ1).....	15
Type of Supports (RQ2).....	16
IV. DISCUSSION AND CONCLUSION.....	24
The Need for Support (RQ1)	24
Advocating for Supports (RQ2).....	26
Practical Implications.....	30
Limitations and Future Research Questions	31
Conclusion	32
REFERENCES	33

LIST OF TABLES

Table	Page
1. Participants' Demographics	13
2. Participants Siblings' Demographics	14
3. Comparisons of Participants' Demographics and Identified Themes	21
4. Comparisons of Participants Siblings' Demographics and Identified Themes	22
5. Comparisons of Continuous Demographics and Identified Themes	24

CHAPTER I

INTRODUCTION

Family relationship research has been conducted for decades (Aldrich, 2021; Brighouse et al., 2014; Cox, 2010; Dirks et al., 2015). The focus of this line of research, has been to better understand parent-child relationships. Parents, in most situations, have an intimate, authoritative relationship with their children, where they act based on how they believe their child should behave (Brighouse et al., 2014). This role begins in infancy and plays throughout childhood and beyond, where parents influence their child's socio-emotional development (Quintigliano et al., 2023). In fact, these factors determine the relationship between a parent and a child, building the foundation for the child's future relationships with others (Brighouse et al., 2014). There are four types of parenting styles: authoritative, authoritarian, permissive, and uninvolved (Lanjekar et al., 2022). Parenting styles have a direct influence on parent-child relationships. This relationship may be based on the parent feeling secure, wanted to avoid, grounded in ambivalence, and considered disorganized (Magaña et al., 2014). It is essential to understand the different types of relationships as these not only have an impact on the relationship but also on the child's cognitive development (Lanjekar et al., 2022). Beyond parent-child relationships, another important consideration is sibling relationships. Sibling relationships are some of the longest-lasting bonds an individual will experience in their

lifetime. Sibling relationships have been described as “some of the most intimate, enduring, troubling, and conflictual relationships that we may experience in our lives.

Beyond parent-child relationships, another important consideration is sibling relationships. Sibling relationships are some of the longest-lasting bonds an individual will experience in their lifetime. Sibling relationships have been described as “some of the most intimate, enduring, troubling, and conflictual relationships that we may experience in our lives” (Hindle, 2018, p. 4). Dunn and colleagues in the 80s’ conducted research on sibling relationships, which drew attention to the field. This line of research began to spark interest (Hindle, 2018), due to its importance in determining how these relationships differ and how they may have some similarities to parent-child relationships. Although sibling relationships are alike parent-child relationships, as there is a family tie that keeps them emotionally bonded, they are also unlike. A key difference is the age gap between siblings helps them connect differently than with their parents (Sroufe et al., 2005).

Sibling relationships can also be different based on the ‘type’ of siblings; for example, from the same set of parents, a half-sibling, or a sibling with a disability (Aldrich, 2021; Howe et al., 2019). As it can be expected, each of these sibling combinations will develop unique relationships and connections (Aldrich, 2021). Although the connection may differ, siblings will still share genetics, characteristics, environments, childhood experiences, to name a few influencing factors (Her et al., 2021; McHale et al., 2012). Through experiences, such as play or conflicts, siblings will develop social understanding and a knowledge of their unique relationships. This in turn may influence their long-term companionship (Dirks et al., 2015).

Through these experiences, siblings develop companionship that influences and shapes each other's behavior, development, and adjustment, which in turn, helps them develop emotional understanding and problem-solving skills (McHale et al., 2012). It is known that some sibling relationships may be hostile and lack compassion. This is often associated with lower well-being, behavior difficulties, emotional challenges, hyperactivity, and peer problems, such as being considerate of other's feelings, sharing with other children, and fighting with others (Emerson & Giallo, 2014). Due to the various types of sibling relationships, differences in age, family dynamics, and the ever-changing relationships as children age, each sibling relationship will be different (Campione-Barr, 2017). This is further convoluted when comparing families who have children with disabilities (Dervishalaj & Murati, 2014).

Siblings of individuals with disabilities, more specifically, those with high-intensity needs, have historically been a forgotten area in research; yet in recent years, it has become an area of interest (Rossetti et al., 2018). These siblings with high-intensity needs are those that require various supports in their adaptive behavior skills (Westling et al., 2022). This may include, but not limited to, individuals with intellectual disability (e.g., Down syndrome), autism spectrum disorder, or cerebral palsy. Due to their high-intensity needs, siblings become increasingly important to their siblings with a disability (Hayden et al., 2023). In fact, it has been suggested that some siblings have described their roles as caregivers or protectors (Hall & Rossetti, 2018). During the lifespan, these roles may change. For example, the role may begin as a protector during the earlier years, and as these individuals age, the typically developing sibling steps into more of the caregiving role (Travers et al., 2020). The role change, unfortunately, has led to concerns

in the future caregiving of the sibling with disabilities; as it may increase the stressors if the sibling with disability presents behaviors challenges, such as aggression (Leedham et al., 2020).

It is critical to understand the impact these role changes may have on sibling relationships, as the life expectancy for individuals with disabilities has varied over the past 40 years (Coppus et al., 2013), and many of these individuals are beginning to outlive their parents (Kamstra et al., 2017). Because of this, typically developing siblings have begun to assume the caretaking role for their sibling (Lee & Burke, 2018). The added responsibility may present physical, financial, and emotional challenges as the sibling without disabilities also have to cope with other aging family members and finding services for their sibling with a disability (Lee & Burke, 2018). Even before siblings take on the caregiving role, they often maintain a higher level of responsibility in their families than those with siblings without a disability (Barr & McLeod, 2010). It is not surprising that often, these siblings put the needs of their sibling with a disability before their own (Leane, 2019), and they carry the burden of changing others' perspectives about people with disabilities (Paul et al., 2022). The differences in the responsibilities that these siblings undertake, has been suggested to have an impact on their social life (Moyson & Roeyers, 2012), forcing them to miss out on things they would otherwise be able to do, such as social activities (Dervishaliaj & Murati, 2014). Some even reported feeling that their caretaking was not a choice, but rather something they were forced to do (Leane, 2019). Due to the differences in demands, siblings of individuals with disabilities often have characteristics of forbearance, which has led to difficulty expressing feelings (Moyson & Roeyers, 2011). In fact, it has been suggested

that siblings of individuals with disabilities have more mental health challenges, and therefore, utilize mental health services more frequently (Neely-Barnes & Graff, 2011).

The specific characteristics of the individual's disability also have an impact on sibling relationships (Elsakka et al., 2022; Gorjy et al., 2017; Pollard et al., 2013). For example, siblings with Down syndrome were not found to have any differences related to adjustment compared to siblings of typically developing siblings (Cuskelly & Gunn, 2011). Whereas siblings of individuals with cerebral palsy, were found to have higher rates of depression and anxiety when compared to other groups (Elsakka et al., 2022). Similarly, siblings of children with autism were found to have much less participation in extracurricular activities than the comparison group, and had lower levels of social relationships, lower school performance (Barak-Levy et al., 2010), and higher levels of anxiety (Pollard et al., 2013). Furthermore, it has been reported that when siblings of an individual with autism reaches adolescent years, they feel stress, have self-blame, and present challenges in dealing with their sibling's anger or physical aggression (Gorjy et al., 2017); which in turn, will have a higher impact on the sibling's stress and anxiety levels, when compared to other groups (Leedham et al., 2020). Altogether, the characteristic of the disability may have an influence and long-term effect on the sibling. Specifically, there may be impacts on their psychosocial and mental health (Neely-Barnes & Graff, 2011; Tsai et al., 2016), on the use of negative coping or unhealthy habits to deal with their emotions, and on their satisfaction with life (Tsai et al., 2016).

Interestingly, evidence suggests that siblings of individuals with high-intensity needs acknowledged a greater need for social support when dealing with the emotions associated with having a sibling with a disability (Gorjy et al., 2017; Moyson & Roeyers,

2012). In fact, the impact, for some, may be lifelong. For example, Hodapp et al. (2010) indicated that females with a sibling with disabilities were less likely to get married and have children when compared to other females who have typically-developing siblings. Similarly, Haukeland and colleagues (2015) found that siblings of individuals with disabilities described themselves as feeling resentful of the changes in their family dynamic due to their sibling's disability.

Due to the various factors that may impact the sibling of an individual with disabilities, supports are necessary for *all* siblings. The level of stress experienced by these siblings, specifically from people not understanding and appreciating the disability community, has also had a negative impact (Paul et al., 2022), which has led to siblings feeling invisible and not being able to address their emotions (Hanvey et al., 2022). Although studies have looked at sibling needs and adjustment from the parental perspective (Moyson & Roeyers, 2012), only a few have analyzed the sibling's perspective. For example, Chase and McGill (2019) found that adult siblings reported impacts on their career, positive personal characteristics, struggles and challenges, differences in their sibling relationship, responsibilities, maturing at a young age, feeling neglected by their parents, and an ongoing need for support. Whereas some siblings indicated a significant impact from the lack of support and identifying the need for social supports from family or from people outside the family (Moyson & Roeyers, 2012).

As the number of individuals with disabilities continues to grow, so does the number of siblings that will need to assume caretaking roles (Lee & Burke, 2018). Because much of the current supports are targeted to the parents (Wofford & Carlson, 2017) or the family (Vanegas & Abdelrahim, 2016), the purpose of this study was to

gather the views of adult siblings on their childhood and teenage experiences while growing up with a sibling with a disability. The goal was to better understand the supports needed for siblings, based on their perspectives. Specifically, this study aims to answer (a) to what extent did adult siblings indicate needing support during their childhood or teenage years; and (b) what supports did adult siblings indicate wanting during their childhood years?

CHAPTER II

METHODS

Research Design

A cross-sectional survey was used to gain information from responses to an open-ended question from adult participants of a sibling with disabilities (Kesmodel, 2018). Specifically, the survey was used to understand the impact participants' demographic information may have on their perspectives of their experiences (Pandis, 2014). Data were collected through participant's demographic information and open-ended responses.

Participants

Adult siblings of individuals with disabilities were recruited to participate in this study. To be included in the study, participants had to: (a) be an adult sibling of an individual with a disability; and (b) answer all demographic information and the open-ended question. For this study, only participants of siblings with autism spectrum disorder, cerebral palsy, Down syndrome, and intellectual disability, were included.

Survey Instrument

The survey was developed by a small group of individuals ($n = 10$), which included: siblings of individuals with disabilities, experts in the field of sibling research, and the National Sibling Research Consortium. Institutional Review Board was obtained

prior to recruitment and survey distribution. The survey was created and distributed using SurveyGold, an online platform for creation, distribution, survey storage (Golden Hills Software, Inc., 2022). The survey could only be completed one time by each participant (based on IP address). The survey consisted of 163 questions divided into 17 sections. Sections asked participants yes or no questions, categorical questions (i.e., gender), Likert-scale questions, and open-ended. For this study, only questions from Section 1, About you ($n = 11$); Section 2, About the sibling with the disability ($n = 4$); Section 5, About your parents ($n = 1$); and one of the open-ended questions from Section 17, Reflections, was used for analysis. The open-ended questions addressed was *'what would have helped you growing up as a sibling of a child with disabilities?'* The complete survey took approximately 20-25 minutes to complete. The main landing of the survey included a statement describing the study, that participation was anonymous and voluntary, and collected participants consent. At the end of the survey a message was provided indicating the completion of the survey, and request for submission.

Procedures

Participants were recruited through websites such as, the Association of University Centers on Disability, in collaboration with the Vanderbilt Kennedy Center, and the Arc's dissemination networks. The Arc also included information on the study on *InSight*, the national newsletter of the Arc (sent to 90,000+ subscribers). The announcement was sent to the Association of University Centers on Disability website, Don Meyer's Sibnet Network, several state Developmental Disability Networks and newsletters publicized the survey May of 2006. The organizations involved in the recruitment process were not provided any payments.

Participants were offered the possibility to complete the survey on a computer or through a paper version of the survey. The websites that posted the survey provided a toll-free phone number and email for potential participants to wanted to complete the paper copy version. Over 100 printed surveys were requested via phone or email. An additional, 250 copies were sent to collaborating organization that were supporting the project's recruitment efforts. Post recruitment, 80 completed paper surveys were received, and their responses were entered in by a research assistant to SurveyGold. Participants information (from mail-in survey) was inputted using a number code so that all information remain anonymous.

Sampling Size and Response Rate

As efforts were made to collect information from across the United States, it was not feasible to reach all adult sibling of an individual with a disability. Therefore, response rate was unable to be determined. The final sample size ($n = 446$) for this study was a subset of those who completed the entire survey ($N = 1,116$).

Data Analysis

After all responses were collected, completed surveys were downloaded into Statistical Package for the Social Sciences (SPSS; version 29). Participants demographic information and of their sibling were inputted into SPSS. Participants open-ended responses were exported into a Microsoft Excel® spreadsheet. Participants were removed if they did not provide responses to the open-ended questions (i.e., blank, "n/a"). Thematic analysis was used to code open-ended responses, and correlates were used to compare the identified themes to participants' demographic information.

Thematic Analysis

A codebook was created by the research team to analyze participants' responses. Operational definitions were outlined with examples and non-examples for each identified theme. Themes were identified by interpreting participants responses and coding them based on key content addressed within each response (Braun & Clark, 2021). The first 89 (19.96%) responses were coded as a team. The remaining responses were coded by the first author. To determine coding reliability, one member of the research team independently coded a random selection of 30% ($n = 109$) of the responses. Reliability was calculated using Cohen's Kappa (1960), $\kappa = 0.9785$, with 'almost perfect agreement' between the two coders.

Descriptive Statistics and Correlates

Descriptive statistics (frequencies and percentages) were calculated on participants and sibling demographic information (i.e., age, gender, state, ethnicity, education, employment, marital status, living status, and number children). Parent's ability to care for the sibling with the disability was also utilized in analysis. Pearson Chi-square tests (p value set at $p < .05$) were used as univariate analyses to determine if participant responses after thematic analysis had relation to demographic information. Independent sample t -tests were used to determine relationships between participants demographic information that had two or more levels when compared to themed open-ended responses.

CHAPTER III

RESULTS

Participants

As represented in Table 1 and 2, a total of 446 individuals completed the survey. This included those who fully completed all demographic information and responded to the target open-ended question. Participants were predominantly White (91.03%) females (78.70%), between the ages of 20-29 (38.34%). Most of the participants were college graduates (64.13%) and full-time employees (59.87%). Almost half were married (46.64%), lived with their spouse or significant other (52.69%), and did not have children (61.66%). Close to three-quarters of the participants (74.22%) were the older sibling of an Individual with autism (28.92%), cerebral palsy (23.54%), and Down syndrome (47.53%). Most of the siblings with disabilities were male (61.66%), living in their family home with their parents or another relative (54.93%), and based on the participants' perspectives, parents had 'moderate to excellent' abilities to take care of their sibling with disabilities (72.65%).

Thematic Analysis

Thematic analyses were conducted on participant's responses to the open-ended question with the purpose to identify what supports did adult siblings received and thought were helpful during childhood or teenage years (RQ1), and what supports they

Table 1

Participants' Demographics

Participant	<i>N</i>	<i>n</i>	%
Age	446		
16-19		40	8.97%
20-29		171	38.34%
30-39		88	19.73%
40-49		61	13.68%
50+		86	19.28%
Birth order	446		
Older		331	74.22%
Younger		115	25.78%
Gender	446		
Male		95	21.30%
Female		351	78.70%
Ethnicity	446		
White Non-Hispanic		406	91.03%
Other		40	8.97%
Level of education	446		
Some high school/high school degree		123	27.58%
Some college		37	8.30%
¹ College		170	38.12%
² Graduate education		116	26.01%
Schooling status	446		
Not a student		299	67.04%
Currently a student		147	32.96%
Employment	446		
No employment		75	16.82%
Employed full-time		267	59.87%
Employed part-time/seasonally or temporarily		104	23.32%
Marital status			
Never married	446		
Married		203	45.52%
Separated/Divorced/Widowed		208	46.64%
Living status	446		
No one else		58	13.00%
Spouse/significant other		235	52.69%
Parents/Other relative(s)/Non-relative(s)		153	34.30%
Parental status	446		
Do not have children		275	61.66%
Have children		171	38.34%

Note. College = college degree earned (e.g., B.S, B.A.); graduate education = Master's degree or Doctoral degree.

Table 2*Participants Siblings' Demographics*

Sibling	<i>N</i>	<i>n</i>	%
Disability	446		
Autism spectrum disorder		129	28.92%
Down syndrome		212	47.53%
Cerebral palsy		105	23.54%
Age	446		
1-18		95	21.30%
19-29		136	30.49%
30-39		75	16.82%
40-49		89	19.96%
50+		51	11.43%
Gender	446		
Male		275	61.66%
Female		171	38.34%
Living status	446		
Family home with parents/another relative		245	54.93%
Your home		34	7.62%
Group home/large facility/residential school/other		115	25.78%
Supervised apartment		31	6.95%
With spouse/significant other/friend/by self		21	4.71%
Parents ability to care for sibling	446		
Deceased, poor, or fair		122	27.35%
Moderate, good, or excellent		324	72.65%

thought could have been helpful (RQ2). Results indicate that 81.39% of the participants *did not* receive the supports needed, and only 18.61% felt that they *did* receive the supports they needed while growing up with sibling with disabilities.

From participants' responses, a total of six themes were identified, including that 'effective supports and guidance [were] provided' (18.61%; theme 1) while growing up, that they 'did not know' (4.17%; theme 2) what could have been helpful; and the remaining four themes represented participants request for wanting specific support while growing up (77.22%). Specifically, participants indicated needing 'supports for

themselves' (28.17%; theme 3) such as programs for siblings or knowing others growing up with a sibling with disability who they could talk to. Siblings also indicated that it would have been helpful having 'disability awareness' (23.13%; theme 4) by better understanding their sibling's disability and that society was more knowledgeable about the needs of individuals, and families of, an individual with disabilities. Another request stated by siblings, was that it would have been helpful having 'supports in the home' (13.57%; theme 5), such as receiving attention from family members; and more specifically, having 'family supports' (12.35%; theme 6), that could benefit their sibling with a disability and family, overall. A total of 575 responses were coded. Responses were coded under one theme ($n = 341$; 76.46%) and across multiple themes ($n = 105$; 23.54%). Statistical analyses were conducted on participants' open-ended responses and the demographic information they provided to determine any influencing factors.

Supports Needed (RQ1)

Even though the majority of the participants reported on what could have been helpful, 18.61% felt that 'effective supports and guidance [were] provided' (theme 1) during their childhood. In the words of Participant 1602, "I wouldn't change a thing now. The good and the bad have made me the person I am today, and I think I am a pretty good person." When analyzing this theme for potential influencing factors, male siblings were more likely to report 'receiving effective supports and guidance' than female siblings, $X^2(1, N = 446) = 6.220, p = 0.013$. Sibling's type of disability was also found to be an influencing factor. Specifically, those with siblings with Down syndrome (15.47%) reported 'effective supports and guidance [were] provided' more frequently than siblings with autism or cerebral palsy, $X^2(2, N = 446) = 17.699, p < 0.001$. Furthermore,

participants whose siblings lived in their family home with their parents or another relative (17.04%) reported receiving effective supports more than siblings who lived elsewhere, $\chi^2(5, N = 446) = 18.754, p = 0.002$. Participants perceived their parents' ability to care for their sibling as 'moderately,' 'good,' or 'excellent' (20.85%) were also likely to report this theme, $\chi^2(1, N = 446) = 14.426, p < 0.001$. Similarly, parents' ability to care for their sibling was found to have significant differences in their means, with those caring 'moderately,' 'good,' or 'excellent' ($M = 1.87, SD = 0.34$) to those who were deceased, cared 'poorly' or 'fairly' ($M = 1.68, SD = 0.47$); $t(446) = -4.544, p < 0.001$, e.s. = small, Cohen's $d = -0.427$.

Type of Supports (RQ2)

Most of the participants (81.39%) indicated that they would have liked to have received supports while growing up with a sibling with disabilities. When analyzing the reflections of siblings, it is important to acknowledge that 5.13% of the participants indicated that they 'did not know' what would have been helpful (theme 2). Interestingly, siblings older than the individual with disability (4.93%) were more likely to respond that they 'did not know' what could have been helpful, $\chi^2(1, N = 446) = 4.040, p = 0.045$. An example of this sentiment can be captured by Participant 2428 who indicated, "I am not sure anything would have helped. It is what it is, you just have to deal with what you have been given." Although some participants were unclear, the remaining participants (77.22%) provided explicit response to what type of supports would have been beneficial growing up as a sibling of an individual with a disability.

For the 77.22% of siblings who indicated that they would have liked to have supports, the most identified request was 'supports for themselves' (34.62%; theme 3).

More explicitly, participants suggested the need for acknowledgement, specifically that they wanted to know others that had a sibling with a disability (43.21%). And that they would have liked to receive acknowledgment from others about the impact of having a sibling with a disability has on their lives (16.05%). Under this same theme, participants shared their beliefs on the importance of supports related to their role and responsibilities. For example, having less responsibility in the care of their sibling (12.96%), that would have liked supports to help guide their relationship with their sibling (16.05%), and having available counseling services to help navigate having a sibling with a disability (11.73%). Participant 967 summarized this theme by stating that they wanted “to know that it wasn’t something to be ashamed of, to know that I was not alone, to meet other siblings, to meet other people with disabilities with behavioral issues.” Statistical analysis indicated that there were no demographic factors as influencing factors in participants requesting ‘supports for themselves.’

Participants also suggested that there was a need for ‘disability awareness’ (theme 4). These responses indicated the desire for more knowledge in relation to disability, for themselves and others (28.42%). This theme was well represented by the statement made by Participant 1698 who indicated that “having more community acceptance and understanding. Having people look beyond the Down syndrome and see my sister as a person first, not her diagnosis. Also have more information on what it meant to have a sister with Down syndrome.” The majority of the responses (53.38%) within this theme were related to wanting knowledge on the sibling’s disability, following with wanting society to be more knowledge about and acceptance of people with disabilities (33.08%), and awareness of potential disability specific or helpful resources (13.53%). Interestingly,

participants who were younger than their sibling with a disability (9.19%) were more likely to report wanting ‘disability awareness’ than older siblings, $X^2(1, N = 446) = 6.027, p = 0.014$.

‘Supports in the home’ (theme 5) was another reflection provided by participants (16.67%). Participants’ responses coded under this theme, suggested the need for referred parents or other family members attention (58.97%) as the main request. For example, “more patience; some quality alone time with my mother; older brother/sister” (Participant 2409). However, other participants views were related to having another sibling without a disability (21.79%), such as “Having another sibling about my age that understood what it was like to have a sibling with disabilities, and what we face every day...” (Participants 481). A stable home environment (19.23%) was another common perspective shared by participants. An example of this view was,

Having a father there. I feel a father figure would have helped out alot [a lot] with the boys especially. My mom has done the absolute best that she can be shes [she is] only one person and she can’t hold every position (Participant 2554).

Statistical analysis indicated that there were no demographic characteristics that were influencing factors for participants requesting ‘supports in the home.’

The need for ‘family supports’ (theme 6) was another identified sentiment provided participants. Specifically, they suggested that supports would have been beneficial to the family (15.17%) such as, being involvement in various organizations, more respite care hours, or early intervention services. An example of this request was made by Participant 783 who suggested that “respite care for my parents would have helped all of us. Also, having more services, educational, medical, physical, speech and occupational therapy and teachers who actually knew what they were doing would have

made all the difference.” Under this theme, the request made by participants reflect supports the need for supports to be provided by the school and communities (66.20%), and for respite care services to be available or having the opportunity for an increase in hours (33.80%). Interestingly various influencing factors were identified when comparing participants demographic characteristics with the need for ‘family supports.’

Specifically, participants who were 40+ years old (7.39%) were more likely to report that it would have been helpful, growing up, having additional ‘family supports’ than those ≤ 39 years of age, $X^2(4, N = 446) = 14.336, p = 0.006$. Further analysis suggests a small effect size (Cohen’s $d = -0.352$) with those aged 38.72 ($SD = 14.61$) requesting ‘family supports’ when compared those with ≤ 33.94 ($SD = 13.25$); $t(446) = -2.429, p = 0.009$. Similarly, significant differences were found between the ages of the participants siblings. Specifically, those with siblings’ age of 34.73 ($SD = 14.95$) were more likely to suggest the need for ‘family supports’ than those with siblings ≤ 30.41 ($SD = 13.72$); $t(446) = -2.168, p = 0.017$, e.s. = small, Cohen’s $d = -0.311$. Significant differences were also found in relation to the sibling’s living status, where siblings who lived in the sibling’s home (1.35%), a group home, a large facility for individuals with special needs such as residential school (4.48%), or a supervised apartment (1.35%) reported the need for ‘family supports’ more often than other living arrangements, $X^2(5, N = 446) = 11.897, p = 0.036$. Parents ability to care was also an area of statistical significance. Those with parents who were deceased or reported ‘poorly’ or ‘fairly’ (6.50%) caring for their sibling with disabilities, suggested the need for ‘family supports’ more frequently than those with parents who were rated ‘moderate’ to ‘excellent’ caregivers, $X^2(1, N = 446) = 12.127, p < 0.001$. Participants’ parents’ ability to care for

their sibling was also found to have differences in means, between parents who had deceased or cared 'poorly' or 'fairly' ($M = 1.55, SD = 0.50$) to those who cared 'moderately,' 'good,' or 'excellent' ($M = 1.76, SD = 0.43$); $t(446) = 3.55, p = 0.002$, e.s. = small, Cohen's $d = 0.476$.

Table 3

Comparisons of Participants' Demographics and Identified Themes

Participant demographic N = 446	Identified Themes											
	Supports for themselves		Disability awareness		Supports in the home		Family supports		Did not know		Effective supports	
	<i>X</i> ²	<i>p</i>	<i>X</i> ²	<i>p</i>	<i>X</i> ²	<i>p</i>	<i>X</i> ²	<i>p</i>	<i>X</i> ²	<i>p</i>	<i>X</i> ²	<i>p</i>
Age	2.567	0.633	0.832	0.934	3.211	0.523	14.329	0.006*	5.142	0.273	8.001	0.092
Birth order	0.192	0.661	6.027	0.014*	0.231	0.631	0.214	0.644	4.040	0.045*	0.022	0.881
Gender	1.708	0.191	0.013	0.909	0.373	0.541	1.436	0.231	2.544	0.111	6.220	0.013*
Ethnicity	0.410	0.522	0.699	0.403	0.104	0.748	0.122	0.727	2.499	0.114	1.015	0.314
Level of ed.	1.259	0.739	2.616	0.455	5.126	0.163	0.420	0.936	2.772	0.428	5.510	0.138
¹ Schooling	0.110	0.74	0.309	0.578	1.329	0.249	3.066	0.080	1.688	0.194	1.829	0.176
Employment	3.701	0.157	3.166	0.205	3.546	0.170	1.937	0.380	3.649	0.161	0.885	0.643
¹ Marital	0.351	0.839	1.073	0.585	5.114	0.078	5.039	0.080	2.817	0.244	1.215	0.545
¹ Living	1.762	0.414	0.056	0.972	5.893	0.053	2.916	0.233	4.246	0.120	0.007	0.996
¹ Parental	0.485	0.486	1.201	0.273	2.246	0.134	2.302	0.129	2.687	0.101	0.842	0.359

Note. Significant at $p < 0.05$; ¹ = refers to participants' status; level of ed. = level of education.

Table 4

Comparisons of Participants Siblings' Demographics and Identified Themes

Participant demographic <i>N</i> = 446	Identified Themes											
	Supports for themselves		Disability awareness		Supports in the home		Family supports		Did not know		Effective supports	
	<i>X</i> ²	<i>p</i>	<i>X</i> ²	<i>p</i>	<i>X</i> ²	<i>p</i>	<i>X</i> ²	<i>p</i>	<i>X</i> ²	<i>p</i>	<i>X</i> ²	<i>p</i>
Disability	1.016	0.602	5.051	0.080	0.027	0.986	4.837	0.089	0.039	0.981	17.699	<0.001*
Age	3.537	0.472	3.654	0.455	1.021	0.907	9.428	0.051	1.504	0.826	8.637	0.071
Gender	1.365	0.243	3.093	0.079	0.515	0.473	2.202	0.129	0.119	0.730	0.460	0.497
Living status	2.346	0.672	7.318	0.120	4.187	0.381	11.847	0.019*	2.277	0.685	17.322	0.002*
Parental care	0.163	0.686	0.578	0.447	1.622	0.203	12.127	<0.001	0.456	0.499	14.426	<0.001*

Note. Significant at $p = <0.05$; parental care = parent ability to care.

Table 5

Comparisons of Continuous Demographics and Identified Themes

Themes	Age of participant				Age of sibling				Parent ability to care			
	<i>M</i>	<i>SD</i>	<i>t</i>	<i>p</i>	<i>M</i>	<i>SD</i>	<i>t</i>	<i>p</i>	<i>M</i>	<i>SD</i>	<i>t</i>	<i>p</i>
Supports for themselves	1.50	0.50	0.695	0.488	1.50	0.50	-0.429	0.668	1.71	0.453	0.400	0.345
Disability awareness	1.51	0.50	0.475	0.636	1.48	0.50	-0.033	0.974	1.70	4.60	0.745	0.457
Supports in the home	1.51	0.50	0.382	0.703	1.48	0.50	0.039	0.969	1.67	0.48	1.211	0.229
Family supports	1.59	0.50	-1.165	0.247	1.61	0.49	-2.233	0.028*	1.55	0.50	3.155	0.002*
Did not know	1.67	0.48	-1.459	0.157	1.54	0.51	-0.590	0.560	1.67	0.48	0.628	0.536
Effective supports	1.49	0.50	0.968	0.334	1.36	0.48	2.861	0.005*	1.87	0.33	-4.533	<0.001*

Note. Significant at $p = <.005$; effective supports = effective supports and guidance provided; sibling supports = supports for the sibling.

CHAPTER IV

DISCUSSION AND CONCLUSION

This study aimed to answer the research questions of (a) to what extent did adult siblings indicate needing support during their childhood or teenage years, and (b) what supports did adult siblings indicate wanting during their childhood or teenage years? Based on the views of siblings of individuals with autism, cerebral palsy, and Down syndrome, a total of six themes were identified. These themes were: (a) ‘effective supports and guidance provided;’ (b) ‘does not know;’ (c) ‘supports for the sibling;’ (d) ‘disability awareness;’ (e) ‘supports in the home;’ and (f) ‘family supports.’ Implications are discussed as they related to the research questions.

The Need for Support (RQ1)

Understanding sibling perspectives is critical to determine what supports siblings may need while growing up. Yet, much of the current available research has focused on the parental perspectives (Hodapp et al., 2017; Moyson & Roeyers, 2012). The limited evidence that exists on sibling perspectives have suggested that adult siblings have reported the need for ongoing support (Chase & McGill, 2019) and specifically, a need for social support (Gorjy et al., 2017). The impact of having a sibling with a disability will lifelong (Haukeland et al., 2015; Hodapp et al., 2010); which in turn, emphasize the importance in identifying the supports needed for these siblings across their lifespan.

Although findings from this study indicated that some participants (18.61%) reported that they had received ‘effective supports and guidance’ during their childhood, most of the participants (81.39%) indicated that there is a need for supports for siblings of a child with disabilities. These findings are similar to Chase and McGill (2019), who indicated participant dissatisfaction with the supports they received during childhood. Similar findings were also found by Arnold and colleagues (2012) who suggested that siblings needed to be exposed to disability-related information, support in how to best manage their caregiving role, and how to address the needs of their siblings.

Findings from this study resemble previous findings as siblings indicated that, “Not feeling guilty, ashamed, embarrassed, selfish, and often confused would have helped. At times it was extremely difficult because his disability was a new experience for all of us and we were all trying to learn to get through this together...” (Participant 1422). Even though most participants’ views suggest a need for supports (81.39%), there was a small number of participants (18.61%) who indicated that they “I [they] had a lot of support growing up and I [they] can’t think of any additional support that I [they] would have needed... I [they] had supportive parents...” (Participant 449). Interestingly, participants who shared this sentiment, were more often male siblings. Based on findings from Hoddap and colleagues (2017), male siblings were much less likely to be caregivers for their sibling with a disability, and female siblings were more likely to be involved in the caregiving of their sibling with disabilities. There also seems to be a difference between the level of pressure female siblings are exposed to. For example, evidence suggests that female siblings are more likely to have higher levels of stress, depression, and are

more prone to developing socio-emotional difficulties (Hamama & Gaber, 2021). Male siblings may have had less involvement in the lives of their siblings (Hodapp et al, 2010); and therefore, had less adjustment problems and fewer needs for support (Hamama & Gaber, 2021).

Participants who had siblings with Down syndrome were also more likely to report ‘effective supports and guidance provided.’ These findings are consistent with previous research where siblings of individuals with Down syndrome reported warmer relationships and lower levels of conflict (Cuskelly, 2016), and less stress than siblings with autism (Shivers et al., 2019). Furthermore, participants were likely to report that they had ‘effective supports and guidance’ if their sibling currently lived in their family home with parents or another relative. Where the sibling lives may have an impact on feeling satisfied with supports received. These findings relate to those found by Burke and colleagues (2012), where participants whose siblings lived with another family members had decreased levels of stress associated with caregiving, finances, and scheduling. The location where the sibling with the disability lives may relate to less responsibility for the care of their sibling as the caregiving is placed on another family member, thus, having less concerns for the care and supports needed (Burke et al., 2012).

Advocating for Supports (RQ2)

Although the majority of participants indicated that they wanted support (81.39%), 4.17% of these siblings indicated that they ‘did not know’ what would have been helpful to them. An example of this sentiment can be summarized by Participant 1099 who indicated, “I don’t know. We did what we had to do. We always took care of him.” The lack of knowing what could have been helpful, was found to be linked to the

siblings' birth order. Participants who were older may have been an influencing factor, due to the fact that older siblings are often considered more of a leader, and beginning from a young age, they grow accustomed to helping their younger sibling with a disability, and caregiving becomes a skilled that they gain (Saxena & Adamsons, 2012). Interestingly, evidence also suggest that younger siblings of those with disabilities often assume the 'older sibling' role (Hall & Rossetti, 2018). This role switch may create some challenges in the sibling dynamics (Hall & Rossetti, 2018). Specifically, that the younger sibling rather than receive 'mentorship' by their older sibling, they become the mentor (Diener et al., 2015). The role changes may have an impact on not only the typically developing sibling, but also the sibling with the disability, who may crave to take on the role as the older sibling but are limited in doing so due to their disability (Meltzer, 2018). Furthermore, the birth order has been suggested to have an impact on the emotional and behavioral adjustments of the siblings, in that older siblings seem to be better adjusted than younger siblings (Petalas et al., 2009).

Siblings' perspectives also indicated a request for support related to 'supports for the sibling;' 'disability awareness;' 'supports in the home;' and 'family supports.' 'Supports for the sibling' were often related to a request for "a support group; knowing that I [they] was [were] not alone and having a place to share my [their] thoughts, fears, concerns..." (Participants 2315). Although no statistical significance was found, the request for supports for the siblings was the most reported. Findings from Arnold and colleagues (2012) suggest that supports for siblings continue to be an area of need, with a desire for connection through things such as 'knowing others' who had siblings with disabilities and 'acknowledgement.' Chase and McGill (2019) also suggested that the

lack of support for siblings reciprocated the need for more support due to the impact it has on them. It is evident that having a sibling with a disability has a significant impact on the sibling (Moyson & Roeyers, 2012). As such there is a need for systems to be in place to effectively support siblings (Chase & McGill, 2019) and guide them through the process of growing up (Barr & McLeod, 2010), identifying and advocating for services for their sibling (Burke et al., 2012), and leading the caregiving of their sibling with disabilities later in life (Lee & Burke, 2018).

Findings also suggest that participants wanted to be more aware of their sibling's disability characteristics. This sentiment was related to siblings wanting more knowledge in relation to disability for themselves and for others. An example of this perspective was made by Participant 945 who indicated that, "greater understanding of his [sibling's] disability but also how valued his [sibling's] roles was. That he [his sibling] wasn't just an annoyance but a part of the community." Interestingly, participants who were younger than their sibling with a disability were more likely to report the needs for 'disability awareness.' This finding may be related to the fact that research has indicated that siblings want more education and training opportunities (Arnold et al., 2012; Barr & McLeod, 2010; Hodapp et al., 2017). The desire for 'disability awareness' goes beyond the sibling. More specifically, evidence suggest that siblings want society to become more aware of disabilities (Arnold et al., 2012; Dervishaliai & Murari, 2014; Gorjy et al., 2017). The hope, for siblings, is to decrease the feeling of uncomfortable or embarrassed when their sibling draws attention to themselves in public, and as a result, having others stare or have negative attitudes towards their sibling with a disability (Barr & McLeod, 2010).

‘Supports in the home’ was also a prevalent request made by siblings where they indicated wanting “a little more attention for me” (Participant 766) or “more siblings so that I [they] wouldn’t feel so alone” (Participant 1759). While no participant demographic characteristics were significant, evidence suggest that this is a common theme among siblings of individuals with disabilities (Barr & McLeod, 2010; Dervishaliai & Murari, 2014). For example, Chase and McGill (2019) suggested that when participants reflected upon their childhood, a common theme was ‘compromising attention,’ where their participants indicated they felt neglected by their parents. The lack of attention from parents is prevalent among siblings (Bar & McLeod, 2010) and continues to have long term impacts on their adult lives (Chase & McGill, 2019). In fact, it has been suggested that the lack of attention, has negatively impacted siblings by presenting increased levels of stress, mental health challenges, delayed life choices (i.e., getting married, having children), and other physical, emotional, and financial challenges (Gorjy et al., 2017; Hodapp et al., 2010; Lee & Burke, 2018).

‘Family supports’ such as “in home support services before or after school so siblings were not the primary caregivers during that time” (Participant 1844) was also a request made by 12.35% siblings of individuals with disabilities. More specifically, participants aged 40+ reported wanting ‘family supports,’ more often than others. These findings may be related to Hanvey and colleagues (2022) who found that siblings of individuals with disabilities were likely to repress their experiences during a young age, and later recognizing, as an adult, the challenges they faced as a child. Furthermore, participants whose siblings lived in their personal home, in a supervised apartment, or a group home setting were more likely to suggest the need for ‘family supports.’ For

example, Participant 33 expressed the desire for "...someone else being there to help take care of him while I was in high school to open more opportunities." These findings are supported by Dervishalia and Murati (2014) who suggested that the siblings of their participants needed consistent supervision, and they admitted to having many responsibilities during their childhood.

These additional responsibilities that siblings face as discussed by Dervishalia and Murati (2014) may link directly to their parents' caregiving abilities. This study found that participants who rated their parents 'lowest in their caregiving abilities' wanted 'family supports', possibly due to the additional responsibilities they had to make up for the lack of caregiving from their parents. Perhaps their parents' current low caregiving abilities was also consistent during childhood, where Burke et al. (2012), explained that these individuals have to assume their siblings care in addition to their own health and well-being, which can be anxiety producing. These 'family supports' (i.e., respite care, school and community supports) could have been beneficial to them growing up to make up for their parents' caregiving abilities for their sibling.

Practical Implications

The findings from this study emphasize that siblings of individuals with disabilities, more specifically, siblings of individuals with autism, cerebral palsy, and Down syndrome have been under-supported. To better support these siblings changes are needed to provide sibling support groups, disability awareness, supports in the home, such as more attention from their parents, and family supports, such as respite care. The supports in place currently have been lacking and deemed insufficient based on the perspective of 446 siblings. It is clear that parental supports have been put in place, yet

siblings continue to not feel unsupported.

More specifically, a call for sibling groups, counseling services tailored to siblings of individuals with disabilities, and resources on how to improve their relationship with their sibling, will better support the experiences face by sibling of individuals with disability during childhood and teenage years. Furthermore, there is a need for society to become more knowledgeable and responsive to the unique needs of individuals with disabilities, and their families. Only, by doing so, will society be better prepared to help deal with the needs of siblings, of individuals with disabilities, and specifically, of those with potential challenging behaviors.

A call out also goes out to respite care providers as abundant families are In such need. Schools and communities need to make larger efforts to provide opportunities for the sibling with the disability to grow in their abilities and participate in activities. By providing more, cumulative supports to siblings, they may feel better prepared for the lifelong responsibilities that come with being a sibling to an individual with a disability and can better deal with the emotions they experience throughout childhood.

Limitations and Future Research Questions

Several limitations were identified based on this study. The first limitation of the study is that this study targeted older siblings, so a critical population was not included in this study. It would be beneficial to know what siblings want in the present time as they grow up with a sibling with a disability. This information can provide a better understanding of what supports are necessary at various stages of life. Another limitation is that participants were removed from the study if they did not provide responses to all the demographic data. It would be helpful to require participants to complete each

demographic question prior to advancing to the open-ended question. Because participants were not required to answer demographic questions, these participants open-ended responses to the question were left out of the study, thus potentially not providing a cumulative look into what supports are needed during childhood as a sibling of an individual with a disability. Furthermore, replication is needed of this study to gather information on siblings' explanations on their identified support.

Conclusion

Current supports for family members of individuals with disabilities are targeted towards parents, or the family in general. The purpose of this study was to obtain the views of siblings of individuals with disabilities during their childhood and adolescent years to better understand the support needs for these individuals. The current study highlights the need for support for siblings of individuals with disabilities and support the notion that more research is needed in this area. Unfortunately, findings suggest that most siblings did not feel adequately supported throughout their childhood and teenage years, as such a call out to disability organizations, communities, schools, and society to support families to enhance the respite care and counseling services for these siblings. These supports are imperative to providing pillars to siblings to help them cope with challenging experiences and emotions they face during childhood.

REFERENCES

- Aldrich, L. (2021). The association between sibling type, sibling relationship quality, and mental health from adolescence into young adulthood. *ProQuest Dissertations Publishing*. <https://www.proquest.com/dissertations-theses/association-between-sibling-type-relationship/docview/2553774466/se-2>
- Arnold, C. K., Heller, T., & Kramer, J. (2012). Support needs of siblings of people with developmental disabilities. *Intellectual and Developmental Disabilities*, 50(5), 373–382. <https://doi.org/10.1352/1934-9556-50.5.373>
- Barak-Levy, Y., Goldstein, E., & Weinstock, M. (2010). Adjustment characteristics of healthy siblings of children with autism. *Journal of Family Studies*., 16(2), 155–164. <https://doi.org/10.5172/jfs.16.2.155>
- Barr, J., & McLeod, S. (2010). They never see how hard it is to be me: Siblings' observations of strangers, peers and family. *International Journal of Speech-Language Pathology*., 12(2), 162–171. <https://doi.org/10.3109/17549500903434133>
- Bedford, V. H., & Avioli, P. S. (2012). Sibling relationships from midlife to old age. In R. Blieszner & V. H. Bedford (Eds.), *Handbook of families and aging* (2nd ed., pp. 125-151). Santa Barbara, CA: Praeger.
- Braun, V., & Clarke, V. (2021). *Thematic analysis: A practical guide*. London: Sage.
- Brighouse, H., Swift, A., Swift, A., Brighouse, H., & Swift, A. (2014). Family values : The ethics of parent-child relationships / Harry Brighouse, Adam Swift. (Course Book). Princeton University Press., <https://doi.org/10.1515/9781400852543>
- Burke, M. M., Taylor, J. L., Urbano, R., & Hodapp, R. M. (2012). Predictors of future caregiving by adult siblings of individuals with intellectual and developmental disabilities. *American Journal on Intellectual and Developmental Disabilities*, 117(1), 33–47. <https://doi.org/10.1352/1944-7558-117.1.33>
- Campione-Barr, N. (2017). The changing nature of power, control, and influence in sibling relationships. *New Directions for Child and Adolescent Development*., 2017(156), 7–14. <https://doi.org/10.1002/cad.20202>

- Chase, J., & McGill, P. (2019). The sibling's perspective: experiences of having a sibling with a learning disability and behaviour described as challenging. *Tizard Learning Disability Review*, 24(3), 138–146. <https://doi.org/10.1108/TLDR-11-2018-0032>
- Cohen, J. (1960). A coefficient of agreement for nominal scales. *Educational and Psychological Measurement*, 20(1), 37–46. <https://doi.org/10.1177/001316446002000104>
- Coppus, A. (2013). People with intellectual disability: What do we know about adulthood and life expectancy? *Developmental Disabilities Research Reviews.*, 18(1), 6–16. <https://doi.org/10.1002/ddrr.1123>
- Cox, M. J. (2010). Family systems and sibling relationships. *Child Development Perspectives*, 4(2), 95–96. <https://doi.org/10.1111/j.1750-8606.2010.00124.x>
- Cuskelly, M., & Gunn, P. (2006). Adjustment of children who have a sibling with Down syndrome: perspectives of mothers, fathers and children. *Journal of Intellectual Disability Research : JIDR.*, 50(12), 917–925. <https://doi.org/10.1111/j.1365-2788.2006.00922.x>
- Dervishalij, E., & Murati, E. (2014). Families of children with developmental disabilities: perceptions and experiences of adolescent siblings of children with developmental disabilities. *European Scientific Journal*, 10(2). <https://core.ac.uk/download/pdf/236412976.pdf>
- Diener, M. L., Anderson, L., Wright, C. A., & Dunn, M. L. (2015). Sibling relationships of children with autism spectrum disorder in the context of everyday life and a strength-based program. *Journal of Child and Family Studies*, 24(4), 1060–1072. <https://doi.org/10.1007/s10826-014-9915-6>
- Dirks, M., Persram, R., Recchia, H., & Howe, N. (2015). Sibling relationships as sources of risk and resilience in the development and maintenance of internalizing and externalizing problems during childhood and adolescence. *Clinical Psychology Review*. 2015;42:145-155. <https://doi.org/10.1016/j.cpr.2015.07.003>
- Elsakka, E., Abdelhady, M., & Anwar, S. (2022). Depression and anxiety among siblings of children with cerebral palsy. *Journal of High Institute of Public Health*, 52(1), 24–32. <https://doi.org/10.21608/jhiph.2022.246672>
- Emerson, E., & Giallo, R. (2014). The wellbeing of siblings of children with disabilities. *Research in Developmental Disabilities.*, 35(9), 2085–2092. <https://doi.org/10.1016/j.ridd.2014.05.001>
- Golden Hills Software, Inc. (2022) *SurveyGold*. Available at: <http://surveygoldsolutions.com> (retrieved on 19 June 2023).

- Gorjy, R. S., Fielding, A., & Falkmer, M. (2017). "It's better than it used to be": Perspectives of adolescent siblings of children with an autism spectrum condition. *Child & Family Social Work, 22*(4), 1488–1496. <https://doi.org/10.1111/cfs.12371>
- Hall, S. A., & Rossetti, Z. (2018). The roles of adult siblings in the lives of people with severe intellectual and developmental disabilities. *Journal of Applied Research in Intellectual Disabilities, 31*(3), 423–434. <https://doi.org/10.1111/jar.12421>
- Hamama, L., & Gaber, S. (2021). Seeing the siblings: Gender differences in emerging-adult siblings of individuals with autism spectrum disorder. *Research in Developmental Disabilities, 108*, 103829–103829. <https://doi.org/10.1016/j.ridd.2020.103829>
- Hanvey, I., Malovic, A., & Ntontis, E. (2022). Glass children: The lived experiences of siblings of people with a disability or chronic illness. *Journal of Community & Applied Social Psychology, 32*(5), 936–948. <https://doi.org/10.1002/casp.2602>
- Haukeland, Y. B., Fjermestad, K. W., Mossige, S., & Vatne, T. M. (2015). Emotional experiences among siblings of children with rare disorders. *Journal of Pediatric Psychology, 40*(7), 712–720. <https://doi.org/10.1093/jpepsy/jsv022>
- Hayden, N. K., Hastings, R. P., Kassa, C., & Danylec, F. (2023). Subjective poverty moderates the association between carer status and psychological outcomes of adult siblings of people with intellectual and developmental disabilities. *Journal of Autism and Developmental Disorders, 53*(3), 987–999. <https://doi.org/10.1007/s10803-022-05520-3>
- Her, Y., Batur, Z. Z., Vergauwen, J., & Mortelmans, D. (2021). Siblings' similarities and dissimilarities: A review of theoretical perspectives and empirical insights. *Journal of Family Theory & Review, 13*(4), 447–462. <https://doi.org/10.1111/jftr.12436>
- Hindle, D. (2018). *Sibling matters: a psychoanalytic, developmental, and systemic approach / Debbie Hindle. (First edition.). Taylor and Francis.*
<https://doi.org/10.4324/9780429480195>
- Hodapp, R. M., Urbano, R. C., & Burke, M. M. (2010). Adult female and male siblings of persons with disabilities: Findings from a national survey. *Intellectual and Developmental Disabilities, 48*(1), 52–62. <https://doi.org/10.1352/1934-9556-48.1.52>
- Hodapp, R. M., Sanderson, K. A., Meskis, S. A., & Casale, E. G. (2017). Adult siblings of persons with intellectual disabilities: Past, present, and future (Vol. 53, pp. 163–202). *Elsevier.* <https://doi.org/10.1016/bs.irrdd.2017.08.001>
- Howe, N., Persram, R. J., & Bergeron, C. (2019). Sibling relationships in adolescence. *The encyclopedia of child and adolescent development, 1-14.*
<https://doi.org/10.1002/9781119171492.wecad410>

- IBM Corp. (2023). IBM SPSS Statistics for Macintosh (Version 29.0) [Computer software].
IBM Corp.
- Kamstra, A., van der Putten, A. A., & Vlaskamp, C. (2017). Efforts to increase social contact in persons with profound intellectual and multiple disabilities: Analysing individual support plans in the Netherlands. *Journal of Intellectual Disabilities, 21*(2), 158–174. <https://doi.org/10.1177/1744629516653037>
- Kesmodel, U. S. (2018). Cross-sectional studies - what are they good for? *Acta Obstetrica et Gynecologica Scandinavica.*, 97(4), 388–393. <https://doi.org/10.1111/aogs.13331>
- Lanjekar, P. D., Joshi, S. H., Lanjekar, P. D., & Wagh, V. (2022). The effect of parenting and the parent-child relationship on a child's cognitive development: A literature review. *Curēus.* <https://doi.org/10.7759/cureus.30574>
- Leane, M. (2019). Siblings caring for siblings with intellectual disabilities: Naming and negotiating emotional tensions. *Social Science & Medicine* (1982), 230, 264–270. <https://doi.org/10.1016/j.socscimed.2019.04.022>
- Lee, C. eun, & 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. <https://doi.org/10.1111/jppi.12246>
- Leedham, A. T., Thompson, A. R., & Freeth, M. (2020). A thematic synthesis of siblings' lived experiences of autism: Distress, responsibilities, compassion and connection. *Research in Developmental Disabilities, 97*, 103547–103547. <https://doi.org/10.1016/j.ridd.2019.103547>
- 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>
- McHale, S. M., Updegraff, K. A., & Whiteman, S. D. (2012). Sibling relationships and influences in childhood and adolescence. *Journal of Marriage and the Family.*, 74(5), 913–930. <https://doi.org/10.1111/j.1741-3737.2012.01011.x>
- Moyson, T., & Roeyers, H. (2011). The quality of life of siblings of children with autism spectrum disorder. *Exceptional Children, 78*(1), 41–55. <https://doi.org/10.1177/001440291107800103>
- Moyson, T., & Roeyers, H. (2012). “The overall quality of my life as a sibling is all right, but of course, it could always be better”. Quality of life of siblings of children with intellectual disability: The siblings' perspectives. *Journal of Intellectual Disability Research : JIDR.*, 56(1), 87–101. <https://doi.org/10.1111/j.1365-2788.2011.01393.x>

- Neely-Barnes, S. L., & Graff, J. C. (2011). Are there adverse consequences to being a sibling of a person with a disability? A propensity score analysis. *Family Relations*, 60(3), 331–341. <https://doi.org/10.1111/j.1741-3729.2011.00652.x>
- Pandis, N. (2014). Cross-sectional studies. *American Journal of Orthodontics and Dentofacial Orthopedics*, 146(1), 127–129. <https://doi.org/10.1016/j.ajodo.2014.05.005>
- 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*, 71(2), 671–685. <https://doi.org/10.1111/fare.12608>
- Petalas, M. A., Hastings, R. P., Nash, S., Lloyd, T., & Dowey, A. (2009). Emotional and behavioural adjustment in siblings of children with intellectual disability with and without autism. *Autism : The International Journal of Research and Practice*, 13(5), 471–483. <https://doi.org/10.1177/1362361309335721>
- 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. <https://doi.org/10.1007/s10826-012-9618-9>
- Magaña, L. C., Myers-Walls, J., A., Love, D., (2014). Provider-parent partnerships. Purdue University, School of Consumer and Family Sciences. *Department of Child Development and Family Studies*. <http://www.ces.purdue.edu/providerparent/index.htm>
- Quintigliano, M., Fortunato, A., Lauriola, M., & Speranza, A. M. (2023). Parent–Child Relationship Scale (P-CRS): A valid and clinically sensitive tool for assessing the parent–child relationship. *Infant Mental Health Journal*, 44(1), 92–99. <https://doi.org/10.1002/imhj.22031>
- Rossetti, Z., Harbaugh, A. G., & Hall, S. A. (2018). Patterns of adult sibling role involvement with brothers and sisters with intellectual and developmental disabilities. *Journal of Developmental and Physical Disabilities*, 30(4), 527–543. <https://doi.org/10.1007/s10882-018-9600-6>
- Saxena, M., & Adamsons, K. (2013). Siblings of individuals with disabilities: Reframing the literature through a bioecological lens: Bioecological framework and siblings. *Journal of Family Theory & Review*, 5(4), 300–316. <https://doi.org/10.1111/jftr.12021>
- Shivers, C. M., McGregor, C., & Hough, A. (2019). Self-reported stress among adolescent siblings of individuals with autism spectrum disorder and Down syndrome. *Autism : the International Journal of Research and Practice*, 23(1), 112–122. <https://doi.org/10.1177/1362361317722432>
- Sroufe, L. A., Egeland, B., Carlson, E. A., & Collins, W. A. (2005). The development of the person. New York: Guilford. http://library.mpib-berlin.mpg.de/toc/ze_2006_1800.pdf

- Travers, H. E., Carlton, M. E., & Carter, E. W. (2020). Social connections among siblings with and without intellectual disability or autism. *Intellectual and Developmental Disabilities*, 58(1), 19–33. <https://doi.org/10.1352/1934-9556-58.1.19>
- Tsai, H.-W. J., Cebula, K., & Fletcher-Watson, S. (2016). Influences on the psychosocial adjustment of siblings of children with autism spectrum disorder in Taiwan and the United Kingdom. *Research in Autism Spectrum Disorders*, 32, 115–129. <https://doi.org/10.1016/j.rasd.2016.09.007>
- Vanegas, S. B., & Abdelrahim, R. (2016). Characterizing the systems of support for families of children with disabilities: A review of the literature. *Journal of Family Social Work*, 19(4), 286–327. <https://doi.org/10.1080/10522158.2016.1218399>
- Westling, D. L., Carter, E. W., Da Fonte, A., & Kurth, J. A. (2022). *Teaching Students with Severe Disabilities*. Pearson.
- 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>