

Adult Sibling Relationships With Brothers and Sisters With Severe Disabilities

Research and Practice for Persons
with Severe Disabilities
1–18

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Abstract

The purpose of this qualitative study was to examine perceptions of adult sibling relationships with a brother or sister with severe disabilities and the contexts affecting the relationships. Adult siblings without disabilities ($N = 79$) from 19 to 72 years of age completed an online survey with four open-ended questions about their relationship with their brother or sister with intellectual and developmental disabilities (IDD) and extensive or pervasive support needs. Inductive analysis yielded findings related to perceptions of the sibling relationship and contexts that influence the sibling relationship. More than half of the relationships were described as being close. The emotional impact of the relationships included feelings of guilt and joy, as well as frustration and stress that were often related to current caregiving and future planning responsibilities. The contextual factors influencing relationship development included several characteristics of their brother or sister with IDD related to his or her disability, as well as sibling proximity. Implications for research and practice related to sibling relationships are provided for professionals, families, and the siblings themselves.

Keywords

severe disabilities, intellectual disabilities, siblings, sibling relationships

Siblings play a unique role in the structure of familial and social lives in that they are more akin to peers compared with parents and guardians, though they still share a family bond in contrast with chosen friendships. Siblings spend more time together as children than they do with parents or guardians and peers, resulting in significant formative impact on social and emotional development (L. Kramer & Conger, 2009). Sibling relationships are likely to be the longest of people's lives (Cicirelli, 1994).

Sibling relationships that involve an individual with intellectual and developmental disabilities (IDD) are similar to sibling relationships between those without disabilities but may include a variety of unique interactions and circumstances that affect the nature of the relationship (Doody, Hastings, O'Neill, & Grey, 2010). For example, individuals with severe intellectual disability (ID) and greater support needs were less likely to live in their own home and to experience choice in their lives compared with those with mild ID (Neely-Barnes, Marcenko, & Weber, 2008). These circumstances may affect the dynamics of these relationships, which is part of the reason for focusing on the population in this study.

Sibling relationships are also of interest related to caregiving and other responsibilities. Recent demographic data point to an increased caregiving need for adults with IDD. Individuals with ID are living

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longer (Coppus, 2013), and in the United States more than 75% of people with IDD live at home with aging parent caregivers (Braddock, Hemp, & Rizzolo, 2008). There will be an increased need for family caregiving, and siblings can be an important source of support (Heller, Caldwell, & Factor, 2007). Siblings anticipate taking over greater responsibility in their brother or sister's life (Burke, Taylor, Urbano, & Hodapp, 2012; Rawson, 2009) and often become involved in some capacity as the primary caregiver or as a team member overseeing direct supports when parents can no longer do so (Heller & Kramer, 2009; Hodapp, Urbano, & Burke, 2010).

Despite sibling anticipation and expectation of future caregiving, many families had not planned or did not include siblings in the planning of these arrangements (Heller & Kramer, 2009; Holl & Morano, 2014). Knox and Bigby (2007) emphasized that future planning affects, and thus should include, the entire family. Adult siblings want specific supports related to the sibling role, including information on how to navigate the adult service system, improved service delivery systems overall, and more funding and respite (Arnold, Heller, & Kramer, 2012; Holl & Morano, 2014). Rawson (2009) similarly found that siblings needed greater support for their future caregiving but suggested that age and readiness of the siblings be taken into consideration.

Research on siblings has focused on the development and adaptation of siblings without disabilities, usually with samples of adolescent siblings. This research has shown mixed but generally neutral or positive results (Heller & Arnold, 2010; Heller et al., 2008; Meadan, Stoner, & Angell, 2010). In their meta-analysis of 25 published studies from 1972 to 1999, Rossiter and Sharpe (2001) found a small negative effect on sibling psychological development as a result of having a brother or sister with ID. The authors added that the "magnitude of this negative effect . . . suggests the generalized concern about the social and psychological development of the siblings of individuals with [ID] has been overstated" (Rossiter & Sharpe, 2001, p. 76). Orsmond and Seltzer (2007b), in their review of the literature on siblings with a brother or sister with an autism spectrum disorder (ASD), described both positive and negative aspects of the relationships. Findler and Vardi (2009) found that siblings of brothers and sisters with ID not only adjusted positively to the situation but reported benefits in responsibility, sensitivity to others, and other social/emotional skills. The quality of sibling relationships involving children with IDD has been compared favorably with that of sibling relationships between children without disabilities (Stoneman, 2005). In their review of 23 published studies from 1970 to 2008, Heller and Arnold (2010) found mixed but positive psychosocial outcomes, close relationships enduring over time, and the expectation of future caregiving roles. Adult siblings of individuals with IDD reported close personal relationships and psychological benefits (Hodapp et al., 2010; Seltzer, Greenberg, Orsmond, & Lounds, 2005), as well as, for female siblings, higher levels of volunteerism and experiences in helping professions (Taylor & Shivers, 2011).

There is a need for research examining the nature of relationships between adults with severe disabilities and their siblings (Doody et al., 2010; Floyd, Purcell, Richardson, & Kupersmidt, 2009; Hodapp, Glidden, & Kaiser, 2005; Orsmond & Seltzer, 2007b). Extant research has focused on sibling experiences and outcomes in childhood and adolescence but little about the adult experience (Rossiter & Sharpe, 2001; Stoneman, 2005). In addition, studies were conducted that focused either on a particular category of disability, such as ASD (e.g., Moyson & Roeyers, 2011; Orsmond, Kuo, & Seltzer, 2009) or Down syndrome (e.g., Cuskelly & Gunn, 2006; Pollard, Barry, Freedman, & Kotchick, 2013). Other studies focused on a sample of individuals with IDD who had moderate (i.e., intermittent or limited) support needs (e.g., Findler & Vardi, 2009; Floyd et al., 2009). To date, few studies have focused specifically on adult siblings with brothers or sisters with severe disabilities.

In the current study, we conducted qualitative research to better understand adult sibling perspectives on their relationships with brothers and sisters with severe disabilities. Findings from the current study will provide more information on the dynamics of sibling relationships that may be useful in supporting individuals with severe disabilities, their siblings, and their families. Meadan et al. (2010) raised the importance of hearing from siblings themselves about their experiences and needs. We collected adult siblings' perspectives to examine their views on these relationships and the contextual components that affected relationship quality. The questions guiding the research were as follows:

Research Question 1: How do adults without disabilities perceive and experience sibling relationships with a brother or sister with severe disabilities?

Research Question 2: What are the impactful factors influencing these adult sibling relationships?

Method

A qualitative research design matched the exploratory goal of the study. We were interested in examining how adult siblings themselves perceived their relationships with brothers or sisters with severe disabilities. The participants were viewed as the experts, and understanding their perspectives and experiences was central to answering the research questions (Bogdan & Biklen, 2003). The research design was shaped by our perspective on disability, which we viewed as simply one dimension of human difference with its meaning rooted in particular social contexts (Broderick, Mehta-Parekh, & Reid, 2005). As such, we sought to explore how siblings experienced and understood their relationships in their own words.

The research was also influenced by our personal experiences as siblings with brothers with IDD. The first author has a younger brother who is very outgoing and has pervasive support needs due to cerebral palsy (CP; spastic quadriplegia). The second author's older brother is gentle and empathetic and has been diagnosed with multiple disabilities such as autism, CP, Down syndrome, and severe ID. We each are in the midst of navigating futures planning with our respective families and redefining our sibling relationships from greater distances than during earlier times in our lives. These social locations allowed us practical insight into sibling experiences that benefited data analysis in this study.

Participants

Participants were recruited through listserv emails and Facebook posts by sibling organizations at the national (i.e., Sibling Leadership Network) and state (e.g., Ohio Special Initiatives by Brothers and Sisters [SIBS], Massachusetts Sibling Support Network) levels and by organizations supporting individuals with IDD and their families locally (e.g., Massachusetts Down Syndrome Congress) and nationally (American Association on Intellectual and Developmental Disabilities). To clarify what constituted IDD, we provided examples of specific disabilities under the umbrella of IDD on the flyer. These included ID, autism, Asperger's syndrome, Down syndrome, CP, epilepsy, Rett syndrome, Fragile X syndrome, Angelman syndrome, Turner syndrome, Prader-Willi syndrome, Williams syndrome, and Spina Bifida. According to the criteria used in this study, participants needed to be 18 years of age or older and to have at least one sibling with an IDD. For the present study, we defined *severe disability* as a severe to profound IDD (i.e., extensive to pervasive support needs). This was indicated by sibling report on the demographic section of the survey. Siblings were asked the following questions:

- a. What disability/disabilities does your sibling have (open-ended response)?
- b. How significant is your sibling's ID? Mild (needs intermittent supports), moderate (needs limited supports), severe (needs extensive supports), profound (needs pervasive supports), or my sibling does not have an ID.

Participants in the current study were 79 adult siblings (siblings) who had a brother or sister with severe to profound IDD (brother or sister). There were 17 (21.5%) male and 62 (78.5%) female siblings from 19 to 72 years of age ($M = 39.56$ years, $SD = 14.69$ years). There were 59 (74.7%) siblings older than their brother or sister, 19 (24.1%) younger, and 1 (1.2%) the same age. The siblings wrote about their relationships with a total of 50 (63.3%) brothers and 29 (36.7%) sisters who ranged from 14 to 72 years old ($M = 36.66$ years, $SD = 14.43$ years). The most common disabilities listed were ID (etiology unspecified or other than Down syndrome, 55.7%), ASD (29.1%), Down syndrome (20.3%), and CP (16.5%). Refer to Table 1 for additional demographic information.

Table 1. Participant Demographics.

	Adult siblings		Brothers and sisters with severe disabilities	
	<i>n</i>	%	<i>n</i>	%
Sex				
Female	62	78.5	29	36.7
Male	17	21.5	50	63.3
Race/ethnicity				
White/Caucasian	75	95	75	95
Black/African American	1	1.25	1	1.25
Asian or Pacific Islander	3	3.75	3	3.75
Native American ^a	—	—	1	1.25
Highest level of education				
Some high school	—	—	51	64.4
High school graduate/GED	2	2.5	23	29.1
Some college	9	11.4	3	3.8
College graduate	34	43.05	—	—
Graduate degree	33	41.8	1	1.25
No response	1	1.25	1	1.25
Marital status				
Single/never married	31	39.2	78	98.75
Married	40	50.7	1	1.25
Separated/divorced	6	7.6	—	—
Widowed	2	2.5	—	—
Disability diagnosis ^b				
ID	—	—	44	55.7
ASD	—	—	23	29.1
Down syndrome	—	—	16	20.3
CP	—	—	13	16.5
Significance of ID/level of support needs				
Moderate/severe	—	—	4	5.1
Severe	—	—	58	73.4
Severe/profound	—	—	2	2.5
Profound	—	—	15	19.0

Note. GED = General Educational Development; ID = intellectual disability; ASD = autism spectrum disorder; CP = cerebral palsy.
^aOne participant indicated that her brother identified as both White/Caucasian and Native American, thus race/ethnicity percentages add up to more than 100.

^bSome brothers and sisters ($n = 18$) had a combination of diagnoses (e.g., ID-CP, ID-ASD), thus disability percentages do not add up to 100.

Procedures

Approval to conduct the current study was provided by the institutional review board at each of the authors' universities. The recruitment flyer directed those interested in participating to an online survey or to contact us for alternate formats if they did not have access to a computer. We were not contacted about alternate formats. The first page of the survey contained the informed consent description, and beginning the survey constituted provision of consent.

Data collection. Data were collected via an online survey that we developed based on the previously stated gaps in the extant research and the goals of the study as specified by the research questions. Participants were asked to provide the following demographic information about themselves and their brother or sister:

age, gender, race/ethnicity, highest level of education completed, and marital status. They were also asked to list their brother or sister's disability diagnosis (or diagnoses) and to indicate the significance of the disability (i.e., mild, moderate, severe, profound) in relation to support needs (i.e., intermittent, limited, extensive, pervasive). The participants then were asked to respond to four open-ended questions that were designed to examine the relationship, how it may have changed over time, roles they may have played within it, and possible improvements to it:

1. Describe your current relationship with your sibling who has a disability.
2. Has your relationship changed from when you were young? If so, how?
3. What roles do you have as a sibling of a brother/sister with a disability?
4. Please describe any changes that would improve your relationship with your sibling.

We received 122 surveys in our initial database. Two were completed by the authors as trial runs of the online format; these were not included in the study. There were 41 surveys with only demographic information completed that also were not included. Of these, there were no discernible patterns as there was a similar sample of gender, age, education, and disability to the others. This article reports findings from the 79 surveys with both the demographic and open-ended questions completed. The responses to the open-ended questions ranged from 4 surveys with five or fewer single-spaced lines of data to five with two pages of single-spaced data. Most (i.e., the remaining 70) were between 15 single-spaced lines of data (about half a page) to 30 single-spaced lines of data (about a full page). There was no character limit.

Data analysis. We analyzed the data using a multi-stage process of open, axial, and then selective coding guided by the constant comparative method (Creswell, 2013; Strauss & Corbin, 1990). This structured the inductive process of data analysis to be systematic and rigorous. Each author independently open coded the first 24 (30%) surveys, marking data units with key words or phrases to highlight and organize topics related to the research questions, those that were frequently repeated, and those that suggested a unique participant perspective (Bogdan & Biklen, 2003). We shared and discussed the codes until agreement, ultimately creating a codebook with 20 codes (e.g., closeness, distance, family dynamics, caregiver) by comparing, combining, and renaming the initial codes. Then we coded the first 24 surveys again to check for the accuracy of the codes and intercoder reliability. We achieved 78.1% agreement (number of agreements divided by total number of coded data units \times 100) overall and 88.1% on the final third of the surveys in this group. After making clarifications to the definition of codes, we completed the coding process with the remaining surveys.

During the axial coding stage, we looked for patterns and relationships in the coded data units and compared them across each survey, ultimately resulting in primary and secondary codes. For example, the *individual's characteristics* code (referring to the brother or sister with severe disabilities) was analyzed and expanded to include secondary codes of *social difficulties*, *communication*, and *behavior*. We identified emerging themes by focusing on connections between the primary and secondary codes, developing categories, and examining relationships among categories. The selective coding stage included identifying a core theme, perspectives on relationship quality, around which the other categories and codes were structured to strengthen the theoretical framework and aid in presentation of findings.

Trustworthiness. We engaged in several commonly accepted credibility measures for qualitative research, including investigator triangulation, researcher reflexivity, and particularizability (Brantlinger, Jimenez, Klingner, Pugach, & Richardson, 2005). Investigator triangulation included the close collaboration of the two authors through all stages of the research process, and discussions of the findings with an external auditor. During the entire coding process, we wrote research memos about the process and the emerging themes and discussed these frequently. As siblings ourselves, we engaged in researcher reflexivity by discussing our experiences and beliefs at all stages of this research. We designed the questions to be as open ended as possible to capture the siblings' perceptions and stories. We also worked carefully to limit assumptions about the sibling experience and to ground the analysis in the participants' words. For example, to help us

focus on participant perspectives, it was useful to remember that although we are siblings who work in the field of special education, most are not and thus do not have access to some of the strategies and approaches we do. Last, we included as many participant quotes and descriptions as possible to help readers recognize common situations and the degree to which the findings may apply to their own situations.

Findings

In response to the first research question about the participants' perceptions and experiences, the siblings described a range of relationship development and quality. Overall, 57% of the participants ($n = 45$) described their relationships as being close. A smaller subset of the close relationships ($n = 10$) were described as being close now but not when the siblings were younger (i.e., growing up together). Of the relationships that were not close ($n = 27$), a smaller subset ($n = 12$) were described as being close when they were younger but not currently. The siblings also described the emotional impact of their relationships, most frequently citing feelings of guilt and joy, as well as frustration and stress in their relationships. Examples of coded data units for all of these findings and for the findings related to the second research question are included in Table 2 along with code frequencies and representativeness.

Perceptions of the Sibling Relationship

Closeness of the relationship. More than half of the siblings indicated that they had a close relationship with their brother or sister. A woman in her late 40s emphasized that the relationship with her younger brother with Down syndrome has always been close: "We have a close relationship that began when he was born." Similarly, a 20-year-old woman stated of her younger brother with autism, "I have always adored him even when we were little. We have always been the closest of all my siblings." Many siblings described closeness despite recognized difficulties, such as a woman in her mid-50s with a brother with ID and bipolar disorder: "Although he is intense, I enjoy him very much."

Of those with close relationships with their brother or sister, some of the participants described meaningful connections. A woman in her 20s stated of her younger sister, "My sibling is my whole world." A woman in her 40s described the impact of her relationship with her younger brother with autism and hearing impairment:

Mike and I are best friends . . . Nothing impacts my relationship with Mike. He is my first priority. His happiness is the first factor in every decision I make . . . I went three and a half hours away to college and could have moved seven hours away to start my career, but my need to be near him and make sure he is well cared for was my deciding factor to come home and stay home. When I'm away I feel the way I imagine a parent would feel being away from their child.

Other siblings described that their relationships remained strong or unaffected by the changes that occurred as they aged together. A man in his early 70s stated of his younger brother with Down syndrome, "As we grew older we stayed very close." Other siblings mentioned situations that affected the quantity of interactions with their brother or sister, though they felt that the relationships remained strong. For example, a woman in her mid-50s stated of her brother with ID and bipolar disorder, "We are close even though he lives in a group home." Similarly, a man in his late 20s stated of his younger brother with ID, "Now that I'm older I see my brother less often, but our relationship has not changed even a little bit."

Some siblings described that their relationships improved over time and were closer than they had been. For example, a woman in her 50s described being as close as ever with her younger brother with CP and ID:

My relationship with my brother has changed over the years. When I was very young we always got along. The last four years my relationship with my brother has grown to a loving, caring, and friendly relationship. Over our lives I went from lots of contact to no contact to now actually learning to appreciate him for who he is.

Such sustained relationships over time led to benefits such as awareness, advocacy, and appreciation for many siblings.

Table 2. Code Frequencies (Primary Codes) and Participant Representativeness (Secondary Codes).

Primary/secondary codes	Frequency	Representativeness (n, %)	Example
Perceptions of the sibling relationship			
Closeness of the relationship	118		
Close relationship		35 (44.3%)	"We still are very close. I recently got married, and he was a groomsman in the wedding."
Closer when older		10 (12.7%)	"We have become closer, and I have become more aware of the disability and more protective of him."
Closer when younger		12 (15.2%)	"Since I have become an adult I feel less connected to my brother. We no longer live together, and he is nonverbal, so it's difficult to keep in touch in any meaningful way."
Not close		17 (21.5%)	"I have a pretty distant relationship with my brother, both geographically and emotionally."
No indication		5 (6.3%)	
Emotional impact of the relationship			
Guilt	116	28 (35.4%)	"I feel guilty that we don't spend more time with him. I am always happy to see him, and he seems happy to be with us."
Joy		25 (31.6%)	"He doesn't speak much, but when he sees me he is very happy! We enjoy doing what we can together."
Frustration		18 (22.8%)	"I get frustrated with her in ways that I did not when she was a child, which puts a strain on us."
Stress		17 (21.5%)	"Having a full-time job and a family of my own on top of the need to be vigilant and engaged in advocacy often leads to lots of stress, and this stress and lack of time affects all my relationships."
Contexts that influence the sibling relationship			
Brother's or sister's characteristics	103		
Diagnosis of ASD		23 (29.1%)	"He has many special interests and lacks social norms. These can get in the way of our relationship."
Social difficulties		38 (48.1%)	"They like to talk to death whatever their current interest is."
Communication needs		35 (44.3%)	"My brother is mostly nonverbal and rarely communicates via his assistive technology, so that has a significant impact on our relationship."
Behavioral challenges		23 (29.1%)	"If something were changed or if something happened that she did not want, she would throw a horrible temper tantrum."
Time/distance	93/84		
Sibling proximity		25 (31.6%)	"Living closer would be a huge improvement."

Note. ASD = autism spectrum disorder.

Other relationships transformed from lacking in a strong connection to being more vibrant and reciprocal over time. For example, a woman in her early 40s stated of her older brother with ID, "I feel much closer to my brother now than in the past. He asks for me when he comes to my mother's house which makes me feel good." Similarly, a woman in her mid-20s stated of her older sister with ID, "I feel that we get along much better now. I feel so guilty saying the following, but it was all so difficult growing up." A woman in her 50s stated of her younger brother with Down syndrome, "I now know my brother vastly better than I did as he was growing up, and I enjoy his company, sense of humor, and friendship as well." These siblings had experienced a difficult family dynamic or lack of opportunity to bond with their brother or sister, often resulting in some degree of embarrassment or resentment while growing up. Due to time apart, the resolution of certain family dynamics, or the necessity of providing support, these siblings reconnected and became closer with their brothers or sisters as adults.

As a second type of perceived changes, some relationships were described as becoming more challenging or distant over time. A woman in her early 20s stated of her younger brother with autism, "My brother and I don't do as many activities together as we used to." A woman in her late 20s stated of her younger sister with ID and visual impairment, "For a while I was still a confidant for my sister, but I don't think this is true anymore." A man in his 40s wrote of his younger brother with autism, "I'm a much smaller character in my brother's life than I was as a child and we shared a roof. There's not a lot of emotional need that either of us fills for the other." This theme of being happier when younger included implications of siblings moving out of the family home. In addition, some of the changes over time were due to declining health:

I feel that my brother and I have worked on developing a positive and supportive relationship throughout our lives. Because of his declining health, my relationship with him is changing. I can no longer include him in certain areas of my daily life because of his increased level of dependence and need. This restricts our abilities to interact as we once did and it is painful for both of us. Our relationship will continue to grow and change as time passes.

Some siblings were hoping and working for improvements in the relationship; others had accepted the current status.

Finally, some siblings described infrequent interactions and strained associations with their brother or sister. A woman in her late 20s stated of her younger brother with Fragile X syndrome, "My brother and I have a limited relationship. I didn't like my brother when I was growing up. I told my mom that I wished I had a 'real brother.'" A woman in her early 20s explained of her younger brother with autism, "My brother and I haven't been close since we were kids. He spends most of his time alone or with our mom. There was a point in time where he didn't like me and we couldn't figure out why." Other siblings described specific reasons for the state of the relationship. For example, a 30-year-old man wrote about his younger brother with autism,

Our relationship has changed, but there's a very clear power structure that has always been in place. He relies on me much more than I rely on him. I wish it wasn't so one-sided, but I know that isn't likely to change.

The siblings often mentioned the influence of distance on their strained relationships. For example, a woman in her late 50s stated of her younger sister with Down syndrome, "I think that if we lived closer, that would allow us to see each other more often and probably improve the relationship in that way."

Emotional impact of the relationship. Whether the siblings' relationships with their brothers and sisters were close or not quite as they would prefer them to be, the siblings described the profound emotional impact of these relationships, and especially of their brother or sister's personal influence upon them. The emotional impact of these relationships included feelings of guilt, joy, frustration, and stress (see Table 2).

Guilt. Many siblings in the study described experiencing *guilt*. Feelings of guilt often related to not seeing one's brother or sister as much as one had in the past. A woman in her 60s described the dual difficulties in her relationship with her brother with Down syndrome: "Distance impacts my relationship; guilt impacts my relationship." Others articulated the guilt of not sharing time together: "I feel sad that my brother and I

can't have a typical relationship. I also feel guilty when I miss his weekend activities." A 30-year-old man with a younger brother with autism described guilt due to thinking of his own needs:

I feel guilty having to push him to the side at times, but I recognize that my relationship with him can't dominate my time and thoughts as much as it has in the past. When we're together, especially without our parents there, it can feel stressful. He's very needy, very dependent, and being with him is a full-time job, especially when he's out of his comfort zone (visiting me, for example).

Despite the challenges and the guilt, this sibling and his brother continued to work through them to maintain a close relationship. A woman in her late 20s felt guilty for perceived absences in both her sister's and mother's lives: "When we're away sometimes I feel guilty, both for not calling her, and for leaving my mom alone to take care of her so much." A man in his late 20s who worked as a direct service provider for his younger brother with CP and ID described his unique form of guilt:

I routinely feel angry, frustrated, defeated, hopeless, and emotionally vacant. Not because I don't care, but because most of the time there isn't anything I can do to make him "better." But more than all of these feelings is the guilt that I feel every time my shift is over. Every time I get to go home and forget about working with him, and do the things that I enjoy doing without him. I feel guilty for looking forward to my days off. It is one thing to look forward to the weekend when you work a desk job, and quite another to look forward to days off when your job is taking care of another living person.

Finally, guilt was tied to the dynamics of the sibling relationship itself, especially in processing past feelings of embarrassment, frustration, or shame. For example, a woman in her 40s with a younger brother with ID explained, "I was humiliated by him and angry that he broke my toys and drooled on my stuff. I came to realize how loving and generous he is, and to forgive myself for resenting him." A woman in her late 20s stated of her younger brother with ID,

I feel guilty that I had so much dislike for my brother. I now want to be in his life as much as possible. I am so proud of all his accomplishments. Although he still [has] behavior problems, they aren't frequent.

A woman in her early 30s with a younger sister with autism described feelings of guilt that were part of family dynamics:

There are times I visit and she is so happy to see me that she is laughing. That warms my heart. She is closest to those she sees every day. I feel guilty that I do not live closer to her, but I also feel almost like I ran away. I kind of missed out on a childhood since my sister demanded so much care, too much for my mom to handle on her own. I never found out who I was outside of that and I almost needed the distance to figure it out.

Joy. In addition to guilt, the other most frequently mentioned emotional response was *joy*. The siblings described happiness being together with their brothers and sisters. For example, a woman in her late 50s wrote of her younger sister with Down syndrome, "We are happy when we have a chance to get together. We like to laugh and tease each other. I worry sometimes that I'm not closer in case something happens and she needs me." It was usually in joy that the siblings perceived reciprocity in the relationship, as described by a woman in her 20s with a younger sister with IDD:

Although people claim I take care of her all the time, most people have no idea how much she supports me more than most people in my life. Just seeing her smile can make my day a million times better.

A woman in her 40s described how recognition of the difficulties intensified the joy:

Mike does not talk or acknowledge hearing others. He is OCD to an extreme, he does not maintain eye contact, and he is tactile defensive so he does not hug, or even like to be touched. With all of that, when he does look me in the eyes or let me hug him, my heart soars.

These joyful moments mitigated ongoing challenges and provided motivation to continue to put effort into the relationship. A woman in her 20s described a combination of joy and stress related to her younger brother with autism:

I typically feel very happy spending time with him at home now. When we are out and about, I am always a little nervous that he might get upset or have a meltdown and I won't be able to effectively manage the situation and we will both feel out of control. I miss him when I am away from him for longer than a week or so.

Within a relationship that did bring joy, she commonly considered the adequacy of her behavioral supports and worried about his behaviors in various contexts. This example of experiencing multiple emotional responses was common to most of the siblings.

Frustration. As the third emotional response, some siblings experienced *frustration*, usually related to actual difficulties in the relationship or with the current caregiving situation. Some siblings described ongoing issues that were connected to childhood difficulties such as the following by a woman in her 50s with a younger brother with ID:

I did have to care for him often when we all were kids at home since I was the oldest sister. I never had much patience with him and it is strained for me to be around him much now.

Some siblings shared frustrations related to perceptions of the relationship. For example, a man in his mid-40s described, "When I'm not with them, specifically, when I'm watching an interaction between other 'normal' siblings, I am saddened because I don't have that kind of relationship with my brothers. I would like to know what that's like." Last, some siblings were frustrated that their brother or sister remained at home. For example, a woman in her mid-50s stated of her younger brother with CP and ID, "When I am with my brother, I sometimes feel really sad that he is so isolated living with my mother. Even though he goes to a day program, he needs to be on his own with supports."

Stress. The fourth emotional response was *stress*. This often reflected the demands of increased responsibility, as a woman in her late 50s described of her younger sister with ID: "I get to enjoy my sister's sense of humor now and she mine. But also I feel the burden of responsibility toward my sister in a way I did not feel before now, even before I took over guardianship." For others, the stress resulted from trying to balance these responsibilities with the demands of one's own life. For example, a woman in her early 50s described of her older sister with ID, "I love my sister dearly. Sometimes the management of her life and business clouds the carefree nature of our sister relationship. The demands of her care are many and have affected many facets of my life."

Other stress-inducing concerns were health related and worsened with age, as described by a woman in her early 60s about her younger brother with ID:

Advocating for him through that period of illness and recovery was exhausting . . . Caring for him is more difficult. He is more impulsive/distractible and has swallowing issues. He needs more supervision as he is not quite steady on his feet. As he and I age, I am fearful of the future.

Like her, others worried about planning for future caregiving, including a woman in her 60s with a younger sister with autism and Down syndrome: "In case my little sister out-lives us all; that really concerns me." The dynamic of planning for the future often included a reliance on siblings, as described by a woman in her 40s with an older brother with ID: "Additionally, I worry. I worry because our mother is 78-years-old, and I know at some point their caretaking is going to fall on me." A 28-year-old woman with an older brother with autism described discomfort with the caregiving decision:

I sometimes wish that my family had waited to ask me to take on this role until I was a little bit older. I feel I've needed time to get space from the intense experience of growing up with my brother and have the space to

develop my own separate identity. I do feel a sense of guilt for having created this separation. I worry about my brother's future more than I used to and the role I will need to play in caring for him. I have concerns about how my future care obligations may impact my marriage and the lives of my children (if I have any).

Although she wanted and agreed to take on the larger and formal role, she also shared concerns both personal and related to her brother's care. Finally, some siblings in charge of the daily care of their brother or sister recognized the consequences in their own lives, as noted by a woman in her mid-20s with a younger sister with CP:

To have a way for her to do things she enjoys while still allowing me to have time to myself would be the most helpful thing. I'm happy to do it, but caring for her constantly has made my social and personal life pretty difficult.

This scenario summed up a commonality of sibling experiences in the challenge of supporting and maximizing time with one's brother or sister while maintaining a life of one's own. Regardless of one's decision, the experience included feelings of being pulled in two directions.

Contexts That Influence the Sibling Relationship

In response to the second research question about the contexts affecting the relationships, analysis revealed that several variables related to characteristics of the brothers and sisters affected relationship quality. These included primarily having a diagnosis of ASD and experiencing social difficulties, as well as, having limited communication abilities and engaging in behaviors that challenged others. In addition, distance and time acted as mediators and moderators of frequency of contact and relationship quality.

Brother's or sister's characteristics. In describing the relationships, some of the siblings pointed out certain barriers to interacting with their brother or sister as much as they would like. A man in his 20s with a younger brother with CP, autism, and ID conveyed the extent of these challenges: "There are so many barriers that keep us apart it can be overwhelming at times." The two variables most closely related to relationship quality were having a diagnosis of ASD and experiencing social difficulties. In addition, communication difficulties and behavior challenges were frequently cited as perceived barriers to improved relationships.

Siblings of brothers and sisters with ASD described notable challenges, as a woman in her 20s stated, "My older brother with autism has been difficult to bond with, and making sense of him and our relationship has been a lifelong process." Siblings of brothers and sisters with ASD compared with siblings of brothers and sisters with other types of disabilities were more likely to describe their current relationship as not close. Of the 23 siblings whose brother or sister was diagnosed with ASD, 65% ($n = 13$) described the relationship as being closer when they were younger or not close. Such an outcome for those with ASD seemed due to the presence of the other difficulties cited by siblings as barriers to close relationships. For example, of the 16 brothers and sisters diagnosed with ASD who had data indicating social interaction skills, all but one experienced social difficulties. Of the 15 brothers and sisters with ASD who had data indicating level of communication, the majority ($n = 13$) did not speak or had limited functional communication. And, of the 13 brothers and sisters with ASD who had data indicating behavioral challenges, the majority ($n = 11$) engaged in aggressive behavior or tantrums.

Regardless of disability diagnosis, experiencing social interaction difficulties was also related to sibling relationship quality. Of the 35 siblings whose brother or sister was coded as experiencing social interaction difficulties, almost half ($n = 16$) described the relationship as being closer when they were younger or not close. Social interaction difficulties included sibling descriptions that their brother or sister was shy or anxious in social settings, tended to focus on their special interests during conversations, and did not have any consistent friendships. For example, a 20-year-old woman described of her younger brother with ASD that "the only thing that may benefit us is if his shyness in social situations improved greatly." As all relationships are social in nature, these challenges were frequently cited as barriers to developing closer relationships even for those who described that their relationship was close.

Some siblings described struggling to develop or maintain relationships when their brother or sister did not speak or had limited functional communication. Of the 34 siblings whose brother or sister was coded with communication difficulties, almost half ($n = 16$) described the relationship as being closer when they were younger or not close. For example, a woman in her early 30s stated of her younger sister with ID and ASD, "I find it harder and harder to have a close relationship since she is nonverbal." A woman in her mid-50s with a younger brother with Down syndrome and CP perceived challenges, especially with communication difficulties: "He is dependent for all [activities of daily living]. We see him just to spend time. He does not talk. He is severely handicapped. He is well taken care of in the facility that he lives in."

Communication difficulties were not limited only to those siblings with brothers or sisters who did not speak. For example, one sibling noted a drop in verbal communication due to disability:

We support each other just by being there for each other. Though my brother does not talk a lot because he is depressed he knows that I love him and will always be there for him. When he comes out of his depression it makes me and him really happy.

A woman in her early 60s noted difficulties due to her older sister's limited verbal communication skills: "Our relationship could be improved if her communication skills could be improved. She has great difficulty explaining who, what, where, when and how. I never get the whole story and consequently may not be able to address her concerns."

Some siblings described their brother or sister's behavioral challenges as barriers to further developing and maintaining close relationships. Of the 22 siblings whose brother or sister was coded as engaging in behavioral challenges, more than half ($n = 12$) described the relationship as being closer when they were younger or not close. Behavioral challenges included violent or aggressive actions to self or others and also engagement in tantrums. For example, a woman in her early 20s stated of her younger brother with Down syndrome, "He also has significant behavior problems, and I think if we could find a better way to handle those problems we would be closer." Similarly, a woman in her mid-20s described trying to avoid triggering such behaviors in her younger brother with ASD: "He can have violent tendencies so if I push him too hard he might throw something or try to hit me."

Time and distance. A majority of siblings mentioned time and distance as key factors in how frequently they were able to interact together with their brother or sister with IDD. Time and distance seemed to act as mediators in that close relationships could be developed and maintained when siblings were in close proximity and saw each other consistently. Time and distance seemed to act as moderators in terms of establishing practical limits to relationship development and maintenance. Ultimately, sibling proximity was related to relationship quality. Of the 25 siblings who lived in the same home or within 2 hr of their brother or sister, more than three fourths ($n = 20$) described their relationship as being close or closer when they were older.

Two patterns related to effects of distance during the life cycle were (a) siblings leaving home for the first time as young adults and (b) siblings returning home or moving closer as parent caregivers aged. For example, a woman in her early 20s with a younger brother with autism declared, "I miss him like crazy when I go back to college." A woman in her 60s who moved closer to support her younger brother with ID described,

I love him dearly and I'm in for the long haul, but sometimes I wish my life wasn't so difficult. Fortunately, I am now retired and my children are grown so I am able to be his caregiver and provide the level of care he needs.

In addition to the practical reality of distance, many siblings described not having enough time to share with their brothers and sisters because of the demands of their own families, jobs, or other responsibilities. From a 52-year-old woman with a younger sister with CP and ID, the following was a typical response: "I wish I could spend more time with her, but the demands of my husband, children, and job make it difficult." Similarly, a woman in her late 40s with a younger brother with CP and Down syndrome stated, "I think the biggest impact on our relationship is distance (I am two and a half hours away) and being busy with my own family. It is a 'planned event' when we want to see him."

Discussion

The present study examined adult siblings' perceptions of their relationships with brothers and sisters with severe disabilities and the contextual factors affecting relationship development. By focusing on sibling perspectives, it addressed an imperative to include the voice of siblings in research on their experiences (Arnold et al., 2012; Heller et al., 2008; Meadan et al., 2010). As in previous studies focusing on sibling perspectives and experiences, the participants provided valuable insight into their relationships and needs (Holl & Morano, 2014; Moyson & Roeyers, 2011, 2012; Petalas, Hastings, Nash, Dowey, & Reilly, 2009; Rawson, 2009). These perspectives are vital in the process of improving sibling supports and including siblings in the domain of family supports. Findings included (a) siblings' needs for information and supports related to future planning and caregiving, (b) descriptions of close relationships by more than half of the siblings, (c) several individual characteristics that influenced relationship quality, and (d) several patterns of changes in sibling needs and experiences across the life span.

The study fills several gaps in the extant research on siblings by focusing on adult (as opposed to child or adolescent) sibling relationships and on those involving brothers and sisters with severe (as opposed to moderate) disabilities (Rossiter & Sharpe, 2001). One critical aspect of adult sibling relationships is the emphasis on current or future caregiving and other support-related responsibilities that was most commonly reflected in the participants' feelings of frustration and stress. This confirmed prior research findings related to siblings' needs for information and supports around future planning and caregiving (Arnold et al., 2012; Heller & Arnold, 2010; Holl & Morano, 2014; Rawson, 2009). In addition to the need for information to help navigate service systems and ensure basic caregiving needs, the sibling perspectives also highlighted support needs related to the process and planning for the transition from parent to sibling caregiving or oversight of caregiving. Siblings spoke of being unprepared or otherwise uncomfortable with the transition due to its timing and the toll it took on their own lives in terms of their availability and stress levels.

By focusing on brothers and sisters with severe disabilities, this study helps to shed light on how siblings experience relationships with brothers and sisters with the most significant support needs. One important contribution of this study was that slightly more than half of the relationships were described by siblings as being close or as closer when they were older. Many siblings described strong connections and positive experiences of joy in these relationships. These descriptions contrast findings of less warmth reported by siblings of brothers and sisters with severe compared with those with moderate ID (Doody et al., 2010).

However, many siblings reported that their current relationships were not close, and those with brothers and sisters with ASD did so at a higher rate than the entire sample. Past research has shown that siblings with brothers or sisters with ASD have lesser relationship quality than siblings of brothers or sisters with Down syndrome (Hodapp & Urbano, 2007; Orsmond & Seltzer, 2007a; Pollard et al., 2013). In addition, past research identified the presence of aggressive or maladaptive behaviors as the most challenging barrier to closer relationships with brothers or sisters with ASD (Angell, Meadan, & Stoner, 2012; Orsmond et al., 2009; Ross & Cuskelly, 2006). Siblings in this study also described behavioral challenges as barriers to close relationships; however, social interaction difficulties were more closely related to relationship quality. The siblings also described limited communication skills by their sister or brother as a factor influencing their relationships. This finding is a novel contribution as there is limited extant research on these factors, and prior research found that communication status did not impact closeness of the sibling relationship (Smith, Romski, & Sevcik, 2013).

Finally, the study adds to the growing literature on sibling experiences and needs by focusing on the sibling relationship across the life span (Heller et al., 2008). The participants in the study ranged from 19 to 72 years of age and described the closeness of current relationships, key changes during different life transitions, and various levels of formal and informal involvement with their brothers and sisters. Although age was not related to relationship quality, many of the changes in relationships that the siblings described resulted from progressing through stages (e.g., young adulthood) and transitions (i.e., adjustment periods between stages) within the family life cycle (Carter & McGoldrick, 2005). One common pattern occurred when young adult siblings left home for the first time for college, employment, or adult living, typically resulting in greater distance between siblings, less contact, and feelings of guilt. Another common transition

occurred when siblings, usually in their 30s and 40s, had children of their own that limited time with their brother or sister and typically resulted in feelings of guilt, frustration, or stress. The other common pattern occurred later in life when caregiving responsibilities transitioned from parents to siblings. These findings extend those of other researchers who have found that siblings' support needs changed throughout their lives (Holl & Morano, 2014; Orsmond & Seltzer, 2000, 2007b).

Limitations

Limitations include the qualitative nature of the study, the sampling procedures, several research procedures, and the participation of only one half of the sibling relationship. First, though there were 79 adults who participated, the findings cannot be generalized to all siblings of brothers and sisters with severe disabilities because the sample was not representative. Second, the sampling procedures may have limited the number and diversity of siblings who participated in the study. The invitations to participate were emailed through Listservs and posted on Facebook pages of disability and sibling groups. The findings reflect only the perspectives of siblings who are already a part of these support groups or know someone in the group and may include few siblings who are less involved in the lives of their brothers and sisters (Arnold et al., 2012). Third, because we used an online survey for data collection, siblings who do not have computer or internet access may not be represented (Davys, Mitchell, & Haigh, 2010). Regarding the content of the survey, we did not pilot the questions in this study and we did not collect demographic information on the siblings' geographic location. Another procedural limitation is that we did not identify a response rate and do not know how responders differed from non-responders. Fourth, the participants in the current study included only adult siblings without disabilities, thus just one half of the sibling relationship. Individuals with IDD can and should have a voice in research and policy that affects them (Charlton, 2000).

Implications for Future Research

The findings from the current study raise several implications for future research on sibling relationships. As also recommended by the Sibling Leadership Network, future research should continue to focus on adult siblings and should expand such a focus to include changes in sibling needs and relationships across the life span (Heller et al., 2008). Longitudinal studies (Orsmond & Seltzer, 2007b; Seltzer et al., 2005) can provide information about changes in sibling relationships over time and examine key transition points as siblings and parents age. Second, future research can certainly do more to include the voices and perspectives of individuals with IDD (Doody et al., 2010) by including them in studies examining sibling experiences and by including sibling pairs in research together to examine both perspectives (J. Kramer, Hall, & Heller, 2013). Third, there is a need for research on interventions that may address sibling outcomes such as stress. Research on parental stress related to having a child with a severe disability (e.g., Benson, 2006) and to navigating the special education system (e.g., Burke & Hodapp, 2014) has provided useful findings to guide and improve intervention and support for parents. Future research can examine whether siblings of individuals with severe disabilities experience increased stress compared with siblings of individuals without disabilities.

Implications for Practice

The findings from the current study also raise several implications for practice. First, in response to the findings indicating sibling needs and also experiences of frustration and stress related to future planning and caregiving responsibilities, implications for families and professionals include various strategies to expand information and supports to siblings. Adult siblings would benefit from the information, supports, and programs offered to parents and guardians through parent information centers. In addition, and in response to the patterns of changing needs across the life span, siblings would benefit from planning forms for sibling roles, preparation for changes during various life stages and transitions, and information about future planning (e.g., guardianship, disability trust, and elder health care). For example, Heller and Caldwell's (2006)

future planning intervention for aging caregivers and individuals with developmental disabilities should be applied to siblings of individuals with severe disabilities.

Second, the findings related to relationships that were not close suggest that siblings would benefit from increased and individualized supports related to the sibling relationship itself, especially siblings of brothers and sisters with ASD or those who demonstrate social difficulties, limited communication, and maladaptive behaviors. Such supports can include learning more about the characteristics of the disability, identifying roles to play, initiating conversations (face-to-face, phone, online video conferencing), and scheduling social time together based on shared interests. Some siblings may benefit from suggestions for shared activities and/or behavioral supports to interact with their brother or sister. Sibshops (Meyer & Vadasy, 2007) have provided such supports to young siblings resulting in many positive outcomes such as more positive feelings about their brothers and sisters and the acquisition of coping strategies (Conway & Meyer, 2008). Extending Sibshops to adult siblings could meet these support needs.

Third, and in response to the barriers to close relationships, brothers and sisters with severe disabilities need full access to social skill interventions and opportunities, various methods and modes of augmentative alternative communication, and positive behavior supports to maximize interactions with their brothers and sisters. Although many siblings described difficulties when their brother or sister did not speak, they did not mention use of voice output communication aids or other forms of augmentative alternative communication such as nonverbal communication techniques. Similarly, siblings described social and behavioral challenges but did not describe use of any social or behavioral supports and strategies. The supports provided to siblings should include information about the full range of interventions and approaches related to social skill, communication, and positive behavior supports.

Finally, those with close relationships tended to perceive their brother or sister as a person first and to focus on his or her strengths and gifts. Taunt and Hastings (2002) found that parents reported a range of positive impacts of having a child with developmental disabilities for themselves, siblings, and extended family members. This approach of focusing on the positive to balance negative experiences and perceptions is something that could benefit all siblings. For example, Biklen (2005) described a disconnect between the thoughts and actions of some individuals with autism. In other words, his or her appearance or behavior may not reveal what he or she is thinking. This type of information and support may help siblings better understand or reframe their perceptions of their brother or sister with severe disabilities such that they identify strengths and gifts despite the presence of social difficulties, limited communication, or behavioral challenges.

To conclude, the adult siblings described many experiences and relationships with their brothers and sisters with severe disabilities that profoundly affected them. That so many were positive is promising. It is our hope that these findings help bring more individualized supports to those siblings who need them due to a new life stage or to their brother or sister's social difficulties.

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