ORIGINAL ARTICLE

The roles of adult siblings in the lives of people with severe intellectual and developmental disabilities

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Background: Siblings of people with intellectual and developmental disabilities (IDD) often assume key roles to support their brothers and sisters. For people with more significant support needs, siblings may undertake additional roles and responsibilities throughout their lives. The purpose of the present study was to identify and describe the roles of adult siblings who have a brother or sister with severe IDD.

Method: Seventy-nine adult siblings from 19 to 72 years of age completed an online survey with open-ended questions about the roles they play in their relationships with their brother or sister.

Results: Thematic analysis resulted in identification of several roles including caregiver, friend (social partner), advocate, legal representative, sibling (teacher/role model), leisure planner and informal service coordinator.

Conclusion: Siblings assume key roles in the lives of people with IDD and need support from family and professionals to perform these roles.

KEYWORDS
developmental disabilities, intellectual disabilities, sibling roles, siblings

1 | INTRODUCTION

Siblings of people with intellectual and developmental disabilities (IDD) support their brothers and sisters with a variety of emotional, physical and practical help throughout their lives. Most siblings have close contact and positive sibling relationships with their brothers and sisters with IDD (Hodapp, Urbano, & Burke, 2010). Siblings have the longest life relationship, can share unique insights and perspectives and are able to provide a continuum of supports (Heller et al., 2008). The relationships between siblings, when one has IDD, are similar to typical sibling relationships in many ways but may include a variety of unique interactions that influence the roles and responsibilities of each sibling (Doody, Hastings, O'Neill, & Grey, 2010). Many studies have examined experiences and outcomes for siblings in childhood and adolescence. Very few studies have examined the roles that siblings assume, particularly in adulthood. There is a need to understand the roles of adult siblings to inform the practice of professionals and assist in future planning. Therefore, the purpose of this study was to identify and describe the perceived roles of adult siblings in their relationship with their brothers and sisters with IDD.

1.1 | The adult sibling relationship

Adult siblings tend to have close relationships with their brothers and sisters with IDD and anticipate taking on a greater role to support them in the future (Heller & Arnold, 2010). The majority of siblings expect to perform significant roles, such as advocate or guardian, to support their brother or sister for the rest of their lives (Rawson, 2009). When parents are no longer able to care for their child with IDD, siblings frequently become the primary caregivers (Arnold, Heller, & Kramer, 2012; Heller & Kramer, 2009). Siblings are needed to assume high levels of caregiving in the United States because of the inadequacy of the adult systems of caregiving, including large waiting lists for services and inadequate supports and services that families depend on (Burke, Taylor, Urbano, & Hodapp, 2012). Burke et al. (2012) surveyed 757 adult siblings of brothers and sisters with IDD about factors related to future caregiving expectations. Those siblings expected to provide greater care in the future if they had no siblings other than their brother or sister with IDD, experienced a close emotional relationship and lived in close proximity to them.

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The type of their brothers and sisters' disabilities also affects their relationship and how involved siblings become. Orsmond and Seltzer (2007) collected survey data from 77 adult siblings of brothers and sisters with autism spectrum disorder (ASD) and 77 adult siblings of brothers and sisters with Down syndrome about the sibling relationship. They found that siblings had less contact with their brothers and sisters with ASD, felt less emotional closeness and were more pessimistic about the future than the siblings of brothers and sisters with Down syndrome.

1.2 | Lifelong involvement of siblings

Throughout adulthood, siblings' relationships with their brothers and sisters with IDD may change in response to their personal situations, characteristics and supports. Adult siblings face multiple challenges during middle age including the death of family members, the health of their ageing parents and the inclusion of new family members such as in-laws and grandchildren (Knox & Bigby, 2007). During this time, they have their own needs for services and support to assist them in balancing care for their brother or sister, parents and own family (Hodapp et al., 2010). Throughout the lifespan, siblings experience changing roles and an increase or decrease in the intensity of each role related to their siblings.

Involvement in future planning may help siblings identify new or changing roles in the lives of their brothers and sisters with IDD, but many families do not discuss future plans or include siblings. Davys, Mitchell, and Haigh (2010) surveyed 21 adult siblings of brothers and sisters with disabilities about future planning. Twelve (57%) siblings reported that their family had no clear future plan for their brothers and sisters with disabilities. The siblings worried about their future responsibilities and how they will prioritize their sibling's needs against those of their own family. Future planning is important to allow siblings to prepare and learn about their future roles. For example, Burke et al. (2012) found that siblings expect to become advocates for their brothers and sisters with IDD but did not feel prepared and were unaware of legal and financial information. Knox and Bigby (2007) stress that future planning is an issue for the whole family. It is important to identify the future roles of siblings so they may prepare and identify their own supports to help them enact those roles.

1.3 | Support provided through sibling roles

Although individuals with severe IDD have similar desires as other people, they typically need more extensive supports from family and staff throughout their lives. In particular, individuals with profound multiple disabilities have the same participation, relationship, physical well-being, emotional well-being and choice-making needs as other people; they just require more intense supports to meet those needs (Petry & Maes, 2007). For example, individuals with profound multiple disabilities may need more support to communicate their wants and needs. Communication is seen as a process between the individual and the people who support them. Thus, the choices of individuals with profound multiple disabilities may be

interpreted through an indirect manner (e.g., body language, facial expressions and vocalizations) as well as a direct manner. As siblings have the longest life relationship, they may have a better understanding of how to support their brothers and sisters with IDD and provide individualized support in communication, as well as behaviour, social adaptation and daily life activities throughout their lives. In addition to practical support, siblings may provide social support for people with severe IDD. In a study about the structure of informal networks, Kamstra, van der Putten, and Vlaskamp (2015) found that 70.7% of 205 individuals with profound intellectual and multiple disabilities (PIMD) had contact with a brother or sister with an average of 13.65 interactions, including phone calls and visits, in the past year. They found that the informal social networks of individuals with PIMD were small in number and consisted mostly of family members. This study highlighted the number of informal contacts, as well as the relationship of the person to the individual with PIMD, but this does not tell us the actual roles held by each person. Additional research is needed to identify the type of roles siblings hold that provide both practical and social support.

1.4 | Importance of understanding sibling roles

Previous studies identify the importance of ongoing research to better understand the relationships of siblings and the roles that adult siblings assume in the lives of their brothers and sisters with IDD (Floyd, Purcell, Richardson, & Kupersmidt, 2009). Research with siblings across the lifespan is necessary to better understand families and see how their relationships and needs may change over time (Burke et al., 2012; Heller & Arnold, 2010). The identification and description of the roles of siblings who have brothers and sisters with severe IDD are also important to raise awareness and inform the practice of professionals. Direct support professionals can learn from siblings about how to work with people with IDD (Nijs, Vlaskamp, & Maes, 2016). When agencies are aware of siblings' adult roles, they may provide support or services to siblings even before they assume those roles (Burke et al., 2012). Family treatment plans may include strategies to maintain sibling relationships and support a future caregiving role (Smith, Elder, Storch, & Rowe, 2015). By understanding the roles of adult siblings, families and professionals will be able to better support siblings as they assume increased responsibilities and new roles to support their brothers and sisters with severe IDD. Therefore, the purpose of this study was to identify and describe the roles of adults in their relationship with their brothers and sisters with severe IDD. The research questions were as follows: What roles do siblings have in their relationship with their brothers and sisters with IDD? How do siblings enact their roles in their relationship with their brothers and sisters with IDD?

2 | METHOD

Qualitative research methods were utilized to explore the perceived roles of adult siblings who have brothers and sisters with severe IDD.

A social model perspective on disability shaped the study, namely that disability is simply one dimension of human difference with its meaning stemming from society's response to individuals with disabilities (Mertens, 2003). The research was also influenced by the authors' advocacy stance, which aims to give a voice to participants on an important issue yielding an action plan for change (Creswell, 2013).

2.1 | Participants

Criterion sampling was used in this study. For the purpose of this study, participants had to be 18 years of age or older and have at least one sibling with an IDD. Recruitment occurred through listserv emails and Facebook posts by sibling organizations (e.g., Sibling Leadership Network, Ohio SIBS—Special Initiatives by Brothers and Sisters) and by organizations supporting individuals with IDD and their families (e.g., Massachusetts Down Syndrome Congress). A flyer, short announcement for email and Facebook options and link to the survey were sent to the contact person of each organization. For this study, the present authors were interested in the responses of siblings who had a brother or sister with severe IDD. To identify these participants, the present authors selected a subgroup of siblings from our larger sample who indicated on the demographic section of the survey that their brother or sister had a severe IDD or had extensive to pervasive support needs. Disability information was indicated by sibling report on the survey in response to the following two questions:

1. What disability/disabilities does your brother or sister have?
2. How significant is your brother or sister's IDD? Mild (intermittent supports), Moderate (limited supports), Severe (extensive supports), Profound (pervasive supports) or My sibling does not have an IDD.

Seventy-nine siblings from 19 to 72 years of age (M = 39.56, SD = 14.69) who had a brother or sister with severe IDD participated in this study (see Table 1). Over three-fourths (78.5%) of the siblings were female (n = 62), and about three-fourths (74.7%) were older than their brothers and sisters with IDD (n = 59). The participants wrote about 50 brothers and 29 sisters who ranged from 14 to 72 years old (M = 36.66, SD = 14.43). The most common disabilities amongst the brothers and sisters were intellectual disability (ID; n = 44), ASD (n = 23), Down syndrome (n = 16) and cerebral palsy (n = 13). Over three-fourths (78.5%) of the siblings (n = 62) indicated by self-report that their brothers and sisters had a severe IDD. The remaining siblings (n = 17) indicated by self-report that their brothers and sisters had a profound IDD.

2.2 | Data collection

Data were collected from the participants through an online survey hosted by Survey Monkey. The present authors chose to use a survey in order to yield a larger sample of siblings and to efficiently collect common data from them. All study procedures were approved by the authors' Institutional Review Boards. The first page of the online survey contained the participant informed consent form. If they agreed

TABLE 1 Participant demographics

	Adult siblings (N = 79)		Brothers and sisters with severe disabilities (N = 79)	
	n	Percentage	n	Percentage
Sex				
Female	62	78.5	29	36.7
Male	17	21.5	50	63.3
Sibling order				
Older than brother or sister	59	74.7		
Younger than brother or sister	19	24.1		
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
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]				
Intellectual disability			44	55.7
Autism spectrum disorder			23	29.1
Down syndrome			16	20.3
Cerebral palsy			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

[a]One participant indicated that her brother identified as both White/Caucasian and Native American, thus race/ethnicity percentages add up to more than 100.
[b]Some 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.

to participate, they were directed to the survey questions. There was no incentive for participation. All surveys were completed electronically; there was no paper option. Participants provided demographic information about themselves and their brother or sister with IDD including their age, gender, race/ethnicity and educational level. They also indicated their brother or sister's disability/disabilities and significance of IDD or support needs. The participants then responded to four open-ended questions about their relationship with their brother or sister with IDD and the roles they play in the relationship:

1. Describe your current relationship with your sibling who has a disability. (What do you do together? What impacts your relationship with him/her? How do you feel when you are with or away from your sibling? How do you and your sibling support each other?)
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? (They could be formal or informal roles such as guardian, advocate, friend, teammate, caregiver, driver and confidant.)
4. Please describe any changes that would improve your relationship with your sibling.

The present authors received 212 surveys in our initial database. There were 41 incomplete surveys that we did not include. This article reports findings from the 79 completed surveys (of the remaining 171 surveys) from siblings who indicated that their brothers and sisters had a severe IDD. There was no character limit for responses in the survey. The responses to the open-ended questions ranged from one single-spaced line of data (e.g., several words describing roles assumed without further description) to two pages of single-spaced data. Most (*n* = 70) were between 15 single-spaced lines of data (about half a page) to 30 single-spaced lines of data (about a full page).

2.3 | Data analysis

The surveys were downloaded from SurveyMonkey and saved in Word and Excel documents to prepare the data for analysis. The two authors analysed all four open-ended questions in each survey using a multi-stage process of open and axial coding guided by the constant comparative method (Creswell, 2013; Strauss & Corbin, 1990). The present authors adhered to a broad application of the constant comparative method, specifically comparing all data to emerging codes and organizing them into categories (Creswell, 2013). This allowed the inductive process of the data analysis to be systematic and rigorous. Using qualitative analysis software, we independently coded the first 24 surveys (30%) to identify initial codes and created a codebook by comparing, combining and renaming the initial codes. The codebook included 20 codes with definitions, examples and non-examples for each to guide implementation. Codes included *Family Dynamics*, *Closeness* and *Communication*, and each of the roles reported in the Findings. The present authors recoded the first 24 surveys using the codebook to check for accuracy of the codes and collect inter-rater reliability data. They did not add or delete any of the 20 codes. The present authors achieved 78.1% agreement (number of agreements divided by total number of coded data units) overall and 88.1% on the final third of the surveys in this group. After each round of coding, the present authors systematically discussed codes until they reached agreement, and then independently coded the remaining surveys. During axial coding, they identified primary and secondary codes by exploring categorical relationships in the data and comparing them across each survey. The present authors then identified themes that reflected the categories and the connections between primary and secondary codes.

Within the overall total of 20 codes, eight codes directly related to the roles assumed by adult siblings of brothers and sisters with severe IDD. These included *Caregiver*, *Friend*, *Advocate*, *Legal Representative*, *Sibling*, *Leisure Planner*, *Informal Service Coordinator* and *No Role*. The first seven emerged from the data as the roles the participants described assuming. Data units were coded with these roles when participants explicitly stated assuming them either by listing the roles they assumed in their response to question 3 or by describing assumption of a role in responses to one of the other question. The authors' discussions about coding refined these definitions and the distinctions amongst the roles. Data units could be coded with multiple role codes, such as the following, which was coded with *Friend* and *Sibling*: "Our relationship always was and always will be as best friends and sisters!"

2.3.1 | Credibility measures

The present authors engaged in several commonly accepted credibility measures for qualitative research, including investigator triangulation, researcher reflexivity and particularizability (Brantlinger, Jiminez, Klingner, Pugach, & Richardson, 2005). Investigator triangulation included collaboration and discussion by the authors throughout the study, especially writing and discussing research memos about the connections within and between codes and categories during analysis. As siblings the authors engaged in researcher reflexivity by discussing their experiences and beliefs at all stages of this research. For example, the authors identified and defined in writing the roles they assumed in their relationships with their brothers and diligently worked to understand how the participants defined these roles for themselves in their contexts. Lastly, the authors included as many participant perspectives as possible to help readers recognize commonalities and the degree to which the findings may apply to their own situations.

3 | FINDINGS

The adult siblings described assuming a variety of roles in their relationships with their brothers and sisters with severe IDD. The roles were directly assigned to them by their parents, indirectly assumed by the family, taken on as the sibling's choice or developed from the needs that arose from their family's circumstances. Siblings took on formal and informal roles to support their brother or sister with IDD with varying levels of involvement. Siblings assumed the specific and distinct roles of caregiver, friend (social partner), advocate, legal representative, sibling (teacher/role model), leisure planner and informal service coordinator (see Table 2). Almost half (48.1%) of the siblings (*n* = 38) indicated that they assumed four or more of these seven roles. Two siblings did not describe assuming any role (i.e., no response to question 3 about roles), and their responses to other questions in the survey indicated they had no involvement in their brother or sister's life. Within each of these roles, the siblings served many functions, such as advisor, cheerleader, driver, cook, behaviour specialist, interpreter, activities director, financial manager and

TABLE 2 Sibling roles: code definitions

Role	Definition
Caregiver	Sibling provides direct care to their brother or sister with IDD. Includes the following: primary/secondary caregiver, respite provider, bather, laundress, chef, shopper and physical support (e.g., help getting dressed or eating).
Friend	Sibling interacts with brother or sister as a social partner sharing activities and talking together in a reciprocal manner. Includes the following: companion, confidant, partner at a meal (in a social capacity) and regular social contact (e.g., phone, email).
Advocate	Sibling protects and/or speaks up for their brother or sister with IDD. Includes the following: attending meetings, standing up to bullies, representing brother or sister's intentions or interests and conveying high expectations.
Legal Representative	Sibling is legally responsible for brother or sister and his or her affairs. Includes the following: current or future (legally identified) guardian, co-guardian, co-conservator, power of attorney, trust manager and emergency contact.
Sibling	Sibling emphasizes the sibling role as critical to their relationship. Includes the following: acting as "typical siblings do," providing guidance or encouragement, role reversal (i.e., younger sibling acting as mentor) and sibling as parent/surrogate parent. *Note—Sibling interactions are distinguished from Friend interactions by being hierarchical or unilateral compared to reciprocal.
Leisure Planner	Sibling provides support or plans for brother or sister's recreational and leisure activities. Includes the following: vacation planner, activities director, entertainer and volunteer for events; also, providing encouragement or support for brother or sister to be active in the community. *Note—Going on vacation together or sharing in activities is coded as Friend.
Informal Service Coordinator	Sibling supervises or coordinates services and supports for brother or sister. Includes the following: financial advisor, health advisor, trains or monitors direct support providers, monitors medication, checks in on brother or sister, discusses services with case manager and works with parents to plan for the future.
No Role	Sibling indicates that they do not assume any roles and/or are not involved with their brother or sister.

legal guardian. For many siblings, these roles and the more specific functions within them changed over time. All participant names are pseudonyms (Table 3).

3.1 | Caregiver

About 65% (*n* = 51) of the siblings indicated that they were a caregiver to their brother or sister with IDD. The caregiver role was enacted through a large range of specific roles and responsibilities, but the common element was providing direct care to their brother or sister with IDD. The siblings indicated that they provided respite care, transportation, advice, personal care, cooking and cleaning services, financial assistance and behavioural supports. The specific tasks and amount of time siblings spent in caregiving changed throughout their lives, and many siblings spent a significant amount of time in this role. As one sister (P12) of a brother with ASD and ID confirmed, "I spent a good deal of my late childhood, adolescence and early adult years (in college) providing child/respite care for my brother." When siblings

grew older, the amount of caregiving they provided depended on family dynamics such as the support from other family members and service providers, their siblings' abilities and their own willingness to participate. One woman (P59) shared, "As I grew older I would help with her dressing, eating, and toileting," and another sibling changed diapers and fed her brother more often as she got older.

The intense amount of caregiving a few of the siblings provided became the defining element of their relationship. As one woman (P50) wrote, "Our relationship is mostly that of caregiver/care recipient." Several participants indicated that they perceived the sibling relationship to include predominantly caregiving due to their brother or sister's lack of functional communication limiting other interactions. Although there are siblings who do not want to be a caregiver, others were drawn to the role (P19): "It's something that has always resonated with me since I was very young." There were siblings who were the primary caregiver and two siblings (P25 and P32) who were paid service providers, such as a home health care provider, for their brother or sister with IDD.

TABLE 3 Sibling (*N* = 79) roles: frequencies and examples

Role	Frequency % (*n*)	Examples
Caregiver	64.6% (51)	• "As I grew older I would help with her dressing, eating, and toileting." • "I find myself helping her more so my parents can interact with our family."
Friend	64.6% (51)	• "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." • "I am really one of the only real friends he has."
Advocate	62.0% (49)	• "I am extremely protective of my sister especially when we are in public." • "As our parents are growing older, I've begun attending meetings with her support coordinators along with my mother in preparation for the time when I will be her primary advocate."
Legal Representative	54.4% (43)	• "I am her guardian and spend about 15 hours a week either with her or managing her affairs." • "I am the manager of present and future trusts set up with my brother's future needs in mind."
Sibling	51.9% (41)	• "As a sibling my first role is to be his sister and love and enjoy his company." • "I was always the 'older' brother even though I am four years younger, and I always took that role very seriously."
Leisure Planner	34.2% (27)	• "I keep her socially active. We visit family and friends, attend community events, and go on vacations." • "I set up a Facebook account so he can connect with old friends."
Informal Service Coordinator	19.0% (15)	• "I monitor his medications and work very close with staff regarding his appearance, hygiene, diet and review once a year." • "I have gotten him a Medicaid service coordinator, participation in a day program, respite, and 24/7 overnight care and am trying to get him into a group residence."
No role	2.5% (2)	

Although some families had members who did not participate in caregiving, other families shared the tasks of caregiving amongst all family members (P53): "When we were young, we all pitched in to help care for him. This included babysitting him, feeding him, changing his diapers, and even bathing him." In another family, the siblings supported their parents by feeding their brother and keeping an eye on him while their parents ran errands. As one woman (P10) explained, "He doesn't speak or communicate effectively, so my sister and I both help our parents in caring for him." In another family, there were few options for respite when the siblings were young. One woman (P43), whose brother had ASD and a hearing impairment, "had to babysit when both parents worked because no one else could/would be left alone with him." Many of the siblings provided care when their parents worked or ran errands. Caregiving was also highlighted during family gatherings (P32): "I find myself helping her more so my parents can interact with our family." The siblings seemed aware of both the needs of their brother or sister with IDD and the support needs of their parents.

The responsibilities of siblings in the caregiver role were tailored to the abilities of their brother or sister with IDD. For her sister, one woman (P57) became a "clothing consultant and shopping assistant, home decorating assistant, driver, travel companion, financial advisor and bill payer, health care manager." Another sister required constant care and supervision, so her sibling (P79) acted as a "caregiver, driver, shopper, chef, bather, laundress, taker to doctors and dentist, etc." The caregiver role was shaped by their brothers and sisters' support needs (P48): "I was at times caring for her while she was having a seizure. She needed bathing, changing of clothes, changing her diaper, eating, drinking, giving medication for seizure disorder, getting her in and out of her wheel chair, lifting her on and off of her school bus while my mother was still at work." Another 27-year-old man (P25) had a brother with ID, cerebral palsy, ASD, epilepsy and Crohn's disease. He worked as a paid caregiver for his brother and supported him with physical activities: "Because I am a lot more physically capable I often look at myself as his 'body.' I try to do for him what he cannot do for himself."

3.2 | Friend

For many of the siblings, the sibling bond grew into the role of a friend or social partner. The distinguishing characteristics of this role were being primarily social in nature and being enacted reciprocally, such

as sharing activities together as opposed to the interaction occurring to provide care or support in a hierarchical (e.g., mentoring) manner. Although 64.6% (n = 51) of siblings indicated that they were a friend to their brother or sister with IDD, the intensity and experience of friendship were as different as each sibling pair. The friendship between siblings was important because many of their brothers and sisters with IDD had few relationships outside of the family. As one sibling (P65) explained, "I am really one of the only real friends he has." The importance of having friends influenced one brother (P11) to focus most of his energy on that role: "I'm John's friend. He doesn't have many and that seems to be the role he needs most in his life…it always seems like being his friend is what matters most."

Being a confidant often indicated the siblings' friendship. There were sibling pairs who confided in each other and pairs where only the brother or sister with IDD confided in his or her sibling. One sibling (P16) made an effort to create an open environment where her brother would feel comfortable to talk with her: "I let him know that he can call me anytime, and when he does I do take the time to chat with him no matter what I am doing. I don't really confide anything with my brother, but when I am home alone or stuck in traffic I give him a call." Throughout the lifespan, some friendships stayed the same while other siblings grew closer or became distant (P22): "For a while I was still a confidant for my sister, but I don't think this is true anymore." Siblings connected with each other differently than with their parents (P15): "Sometimes he will confide in me about his own relationships when he won't talk to my parents."

As friends, the siblings talked, laughed, teased and fought with their brothers and sisters in multiple ways. The communication methods and needs of the brothers and sisters with IDD often structured or determined these social conversations and interactions. Thus, the availability and mode of communication between siblings affected assumption and enactment of roles. One woman (P41) saw her brother once a month and called him between visits: "I talk and sing on the phone to him weekly." Many of the siblings who could not see their brother or sister regularly would make time to talk on the phone or Skype. For siblings who had brothers or sisters with limited verbal abilities, it was easier to use Skype because they could read nonverbal gestures and show visuals to communicate. When they were together, the siblings who described themselves as friends took the time to just have fun. As one 57-year-old man (P68) described, "We usually have a playfully joking way of hanging out together," and another 59-year-old woman (P72) shared, "We like to laugh and tease each other." The siblings spent time with each other at family gatherings, going out to eat, shopping, attending events in the community, watching television and talking or playing games. The types of activities siblings do together may or may not change as they get older (P54): "The things she likes to do now are not very different from the things she enjoyed as a child, and we continue to do those things." One young man (P24), whose brother is 23, wrote: "We especially love going for a car ride and just singing songs (Sesame Street, almost always)." The interactions siblings have were often specific to their brother or sister's abilities and personalities (P23): "When we hang out we play a lot of games together that involve her signing and pointing at things and me describing what she is signing in a funny voice, and very animated so that she cackles." These interactions were unique to the sibling pair and reflected the closeness they shared as social partners who mutually chose to spend time together and reciprocally enjoyed their companionship.

3.3 | Advocate

Of the adult siblings, 62% (n = 49) identified as either an informal or formal advocate for their brothers and sisters with IDD. The advocate role primarily included the sibling acting as a protector and/or representing their brother or sister's interests. As an example of formal advocacy, one sibling (P12) with a 17-year-old brother stated, "I attend his IEP (individualized education program) meetings and regularly discuss with my parents plans for his education and ways that we might work with his IEP team plan for a successful transition from school to adulthood." Another sibling (P54) was preparing for the future when her parents would no longer be able to advocate: "As our parents are growing older, I've begun attending meetings with her support coordinators along with my mother in preparation for the time when I will be her primary advocate." The siblings used their knowledge of their brother or sister with IDD and their personal expertise to advocate. As a special education teacher (P38), one sibling helped to ensure her sister's individualized education programme was appropriate. Many of the siblings attended meetings for their brothers and sisters as family support or in the role of a legal guardian or an authorized representative. One man (P57) noted that through his role as an advocate for his brother with Down syndrome, he also helped his brother advocate for himself.

The siblings also acted as informal advocates for their brothers and sisters with IDD. As one sister (P65) confirmed, "I am currently his strongest advocate." The siblings affirmed that they watched out for their brother or sister, stood up for them and spoke up when needed. The home environment was a safe space for some families, but they were wary of people in the community. As one sibling (P17) shared, "I am extremely protective of my sister especially when we are in public." In the school environment, siblings stood up to their peers for their brothers and sisters (P51): "I noticed the other kids at school picking on them. I one time had to whack a kid on the head while loading the school bus to make him move over for my brother who had nowhere else to sit." Other siblings focused their advocacy efforts within the family. For example, one woman (P29) wrote about how she felt her brother with ASD would benefit from moving out of his parent's home and advocated for that transition: "I try to represent what I think are important issues in his life." Another young man (P46) wanted to make sure his sister's future was planned for and that steps were taken by his mother to prepare for when she was no longer around. As he stated, "It took 10 straight years of me fighting until she finally got a will drawn up." Another woman (P75) described her involvement when her brother with an ID fell and went through a year of hospitalizations and rehabilitation: "Advocating for him through that period of illness and recovery was exhausting." Siblings advocated for their brothers and sisters with IDD within the family, at school, with professionals and in the community.

3.4 | Legal representative

Of the adult siblings, 54.4% (*n* = 43) indicated that they had assumed or were preparing for a role as a legal representative in which they would be responsible for their brother or sister with IDD and his or her affairs. The specific responsibilities of each sibling depended on the abilities of their brother or sister with IDD. For example, one woman (P71) identified herself as the authorized representative for her brother. Another woman stated, "I am his representative in all legal matters." One man (P68) had the sole responsibility of being the representative payee (to receive federal benefits for someone who cannot independently manage them) for his brother with Down syndrome, and another man shared that he was the "manager of present and future trusts set up with my brother's future needs in mind."

Many siblings were preparing for or were already their brother or sister's legal guardian (P58): "I am her guardian and spend about 15 hours a week either with her or managing her affairs." Another woman (P43) described, "I helped mom get guardianship of Luke and I am named as her choice of guardian in her will." However, siblings and their parents did not always agree on whether the sibling should become a legal guardian. As shared by one woman (P33), "I wanted to apply for guardianship for him but my parents weren't on board." In another situation, a woman (P39) explained, "My mother won't give me any guardianship because my sister refuses to listen to me." The siblings were more likely to be a guardian later in life, when their parents were not able to continue this role (P73): "I became her guardian when my parents became elderly and eventually passed." A few siblings shared the responsibility with other family members when the need arose. As one woman (P55) explained, "I am co-guardian of my brother along with my parents since he was diagnosed with Alzheimer's. Prior to that, he was his own guardian, capable of making his own life decisions with support of his family and caseworkers."

Siblings felt the weight and importance of their future roles as legal guardians. As one 55-year-old woman (P63) reflected on her future role as a guardian, she commented, "This will evolve into a new relationship as we will be called upon to make some bigger decisions. I don't know how that will look." Another woman (P48) shared, "I only hope that in the event of their death or inability to care for her, I can provide for her the same care that they have been providing for her all these years." As a sibling, she was willing to step into the role as a guardian to ensure her sister with severe developmental disabilities, who used a wheelchair and had limited functional communication, continued to experience quality care in her life.

3.5 | Sibling

Just over half (51.9%) of the siblings (*n* = 41) indicated that they assumed the role of a sibling to their brother or sister with IDD, which was an important part of their relationship for many siblings. This was a unique role as all of the participants were siblings of individuals with IDD by nature of the study's inclusion criteria. However, those who had assumed the role of a sibling explicitly emphasized the sibling role as critical to their relationship with their brother or sister.

Despite some potential areas of overlap with other roles (e.g., friend, advocate), the siblings who assumed this role embraced it as a distinct role that held great meaning for them. In this role of a sibling, the participants described a variety of experiences that ranged from what they described as typical sibling relationships to interactions they perceived as unique because they involved a hierarchical teaching or role modelling interaction style, even for younger siblings. The common interactions attributed to siblings without disabilities, such as playing and arguing, were highlighted by multiple siblings. As one sibling (P60) explained, "We tease and joke with him just like all siblings do. We treat him like the younger brother that he is." Siblings are known to be silly and find their way into trouble together, as revealed by one brother (P23): "She has always had a goofy sense of humor that I share, and we were often mischievous together in our younger years." The typical interactions between siblings were also presented to show strength in the sibling relationship (P17): "We are very much sisters and treat each other as sisters. We get into arguments just like sisters and we make up just like sisters." One man (P47) described how he played the "brother" character in his brother's life. He explained that his brother "has certain things that fall into the realm of 'share with brother,' and I get those things." He also realized the importance of knowing his brother throughout their lives: "A unique role I fill is as sort of a shared memory repository, as I'm one of the few people who's known him his whole life." One woman (P18) who had a sister with cerebral palsy shared: "We do everything together the same way I would imagine any two sisters so close in age would be." The descriptions of these "typical sibling interaction" examples manifested a person-first orientation by siblings in which they actively and purposefully emphasized and embraced what they viewed as an ordinary sibling relationship.

Many of the siblings also wrote about the differences between their relationship and the sibling relationships of their friends whose brothers and sisters did not have IDD. One man (P31), who was very close to his sibling, stated, "Our relationship is very unlike the relationship that my friends have with their sibling." The differences in relationships included the ways they communicated with, played with and supported their sibling with IDD. The amount of support they provided depended on their brother or sister's personal needs as well as the involvement of other family members. As one sibling (P31) explained, "There's a very clear power structure that has always been in place. He relies on me much more than I rely on him." To support her brother with ASD and ID, one sibling (P12) actively encouraged her brother to be more self-determined. She would "give him choices and ways to show self-determination rather than simply making decisions for him," and supported him by encouraging his independence.

The other type of sibling role the participants described was when siblings took on greater responsibilities for their brothers and sisters with IDD that many times developed into a secondary parent role. Siblings younger than their brother or sister with IDD experienced a role reversal in which they acted as the older sibling through the supports they provided. The role reversal was evident in one woman's (P13) experience: "I am her big-little sister." Some siblings became overwhelmed with the additional responsibilities, while others were

more prepared for that role (P23): "I was always the 'older' brother even though I am four years younger, and I always took that role very seriously." The intensity of this role depended on the support needs of their sibling with IDD, the support of other family members and the willingness of the sibling to take on more responsibility. For many siblings, the role reversal seemed parental (P13): "I have always been a mini-mother and felt like an older sister to my sibling rather than the five years younger that I truly am." As another sibling (P12) explained, "It definitely felt like a mixture between a sibling and a parenting role for me." Many of the siblings shared that they will continue their responsibilities and interactions with their brother or sister as a sibling throughout their lives. For example, a 58-year-old sister (P69) of a woman with developmental disabilities shared, "I will always be her big sister, who has looked out for her."

3.6 | Leisure planner

Of the siblings, 34.2% (n = 27) described multiple ways they supported and planned for their brothers and sisters with severe IDD to participate more actively in recreational and leisure activities. Siblings supported them by arranging activities, initiating social interactions and encouraging them to interact and participate. As one sister (P45) stated, "I am the activities director now." Another woman (P45) planned holiday activities for both her brother and cousin who had IDD: "I plan activities for both of them like holidays: Easter egg hunts, Halloween make up, masks etc." Another woman (P72) referred to herself as the "vacation-arranger" for her 49-year-old sister with Down syndrome. The leisure support for one woman's (P70) 52-year-old sister with ID included taking her to see their mother and entertaining her: "When I am with my sister I usually play music or sing to her to bring her out of herself." In this context, the interaction of playing music and singing to her sister was a form of encouragement to participate in a leisure activity as opposed to being primarily social in nature and enacted reciprocally, which distinguishes it from the friend role. The siblings encouraged their brother or sister to go out in the community and participate in activities they enjoy and attempted to ensure they "had entertaining things to do" (P32). As one sibling (P73) explained, "I keep her socially active. We visit family and friends, we attend community events, we go on vacations." Siblings also described encouraging and trying to find ways to help their brother or sister maintain friendships. One woman (P65) shared, "I set up a Facebook account so he can connect with old friends." This was important because it was difficult for her brother who had cerebral palsy, ID and depression to communicate with and maintain those relationships on his own. In multiple experiences, the siblings were central in planning and supporting their brothers and sisters with IDD in leisure and recreational activities.

3.7 | Informal service coordinator

Siblings also supported their brothers and sisters with severe IDD by supervising and/or coordinating their services and supports as informal service coordinators (n = 15; 19%). Many siblings worked with their parents to prepare for the future (P43): "I assisted my parents in getting the will created and Luke's special needs trust." Other siblings worked on their own to acquire the funding and set up the services that their brothers and sisters with IDD needed. As one woman (P65) shared, "I have gotten him a Medicaid service coordinator, participation in a day program, respite, 24/7 overnight care and trying to get him into a group residence." Other siblings took their brothers and sisters to medical appointments and advised them or helped keep track of their finances. They attended meetings for their brothers and sisters with their direct service providers and case managers and discussed service provision. As one 58-year-old woman (P70) described, she intervened on her sister's behalf "on everything from clothes to medical issues to inquiring about her mood." Another man (P1) shared, "I monitor his medications and work very close with staff regarding his appearance, hygiene, diet and review once a year." The siblings assumed the role of informal service coordinator because they wanted to ensure that their brothers and sisters were healthy, happy and receiving quality care.

4 | DISCUSSION

Siblings typically have the longest relationship with their brothers and sisters with IDD and may assume important roles in their lives. As individuals with IDD are living longer and beginning to outlive their parents (Fujiura, 2010), siblings may be expected to fulfil caregiving and other related roles (Burke et al., 2012; Orsmond & Seltzer, 2007). In this study, the present authors examined the roles adult siblings described that they assume in their relationship with their brothers and sisters with severe IDD. The findings are discussed under three headings.

4.1 | Sibling roles

Adult siblings of brothers and sisters with severe IDD took on formal and informal roles with varying levels of involvement. All but two siblings assumed at least one role, and the majority of siblings assumed multiple roles. They assumed the roles of caregiver, friend, advocate, legal representative, sibling, leisure planner and informal service coordinator. Within each role, siblings had diverse responsibilities specific to their brother or sister's functional abilities and support needs. Their level of involvement reflected their family dynamics (e.g., parent involvement, availability of other siblings), the availability of outside supports and their personal desires within relationships that ranged in terms of closeness and were affected by proximity (Rossetti & Hall, 2015). Regarding the enactment of some of the specific roles assumed by siblings, several additional findings stand out as contributing to extant research and are described below.

Many participants described assuming the two distinct roles of friend and sibling. Clearly, all of the participants were siblings by birth in their families, which was inclusion criteria for the study. That they emphasized assuming the role of a sibling beyond being born into it revealed its meaning for them. There was some overlap across the roles of friend and sibling in that they broadly reflected the social interactions,

emotional connection and support and instruction in social and practical skills that siblings may provide to their brothers and sisters with severe IDD. However, the siblings indicated that these were separate and distinct roles with the role of a friend being that of a social partner and the role of a sibling including instruction, mentoring and/or role modelling. To be clear, the friend role was enacted horizontally (i.e., same level, reciprocal) while the sibling role was often enacted vertically (i.e., hierarchical, unilateral support). Regardless of whether these sibling relationships would meet the common criteria for friendships, such as mutuality, transcending context and intimacy/trust (Matheson, Olsen, & Weisner, 2007), siblings assumed the role of a friend when they recognized that their brother or sister did not have anyone else in their social network. In the role of a friend, siblings acted as confidants who engaged in regular communication and shared activities and fun times together. Most siblings described that these social experiences were enacted differently than filial interactions with parents and sibling interactions with their other brothers and sisters. That these social experiences are significant because siblings may be the only ones in their brothers and sisters' social networks is consistent with prior research (Rimmerman & Raif, 2001).

In contrast, the sibling role in particular was described within a framework of varied relationship symmetries. Some siblings described that they interacted in what they perceived to be similar to typical sibling interactions. It was meaningful to the siblings that they actively embraced such a role and emphasized the typicality of it when their brothers and sisters experienced what were often visible disabilities and significant support needs. When the siblings acquired another supportive role (e.g., caregiver) or recognized an unbalanced dynamic in their interactions with their brothers and sisters (e.g., brother/sister is more reliant on sibling), the siblings viewed themselves as a secondary parent or the "older sibling" even though they may have been younger by age, thus manifesting relationship asymmetries (Stoneman, 2005). Although prior research examines the roles of friend and sibling for children and adolescents (Aksoy & Bercinyildirm, 2008; Floyd et al., 2009; Knott, Lewis, & Williams, 2007), the findings in the present study add to the literature by expanding consideration of these roles to the experiences of adult siblings.

The participants also described assuming the role of an advocate for their brothers and sisters with IDD. Their advocacy consisted primarily of providing protection, giving voice and representing the intentions and interests of their brothers and sisters. This is consistent with case advocacy focused on one individual, but not with cause advocacy focused on policy change for a group of people (Burke, Arnold, & Owen, 2015). Additionally, siblings assumed the related role of legal representative, which raised the issue of including siblings in future planning. The siblings had varied levels of involvement in future planning. Consistent with prior research, it was difficult for some siblings to plan ahead because of the resistance they received from their parents who did not want to talk about the future or make preparations for the sibling to be the next legal guardian (Heller & Kramer, 2009). Broadly, and consistent with prior research, siblings were enacting or preparing to enact this role, although they described needing additional education, training and support to do so (Arnold et al., 2012).

Finally, some of the participants assumed the role of leisure planner, which emerged as a unique finding. For some siblings, this entailed planning vacations and making arrangements so their brother or sister could fully participate in recreational and leisure activities. Other siblings planned special activities during holidays and family gatherings. The majority of siblings entertained their brother or sister whenever they were together. They planned and provided encouragement to their brothers and sisters to engage more regularly in activities such as taking a walk, eating out, going shopping, watching a movie or participating in community events. The siblings who assumed this role were motivated and satisfied to do so because they viewed such community participation as important to their brother or sister's quality of life.

4.2 | Sibling roles across the life course

Taken as a whole, the perspectives of siblings from 19 to 72 years of age revealed that sibling roles will most likely change across the life course. Some relationships became closer while others grew more distant, resulting in related changes in roles. How roles change will depend on family dynamics and life situations, but the majority of siblings indicated change. In particular, prior research has examined siblings in the caregiver role from youth through adulthood (Burke, Fish, & Lawton, 2015; Burke et al., 2012; Dew, Llewellyn, & Balandin, 2004). Our findings indicate how this role may change throughout a sibling's life. Some siblings assumed intense caregiving responsibilities when they were children and adolescents (i.e., respite, home care/monitoring), but when they moved out of their parents' home as adults and began college, careers and/or their own families, they either had no responsibilities or only assumed them when they visited their brothers and sisters. Later in life, one clear pattern of change consisted of increased sibling responsibility related to their brother or sister, especially as parents (as the primary caregivers or legal representatives) aged. Increased responsibilities resulted from filling needed roles as parents aged out of them and dealing with medical complications as their brothers and sisters aged. This trajectory of changes in the caregiving and related roles reflects characteristics of the sibling relationship across the life course (Dew, Balandin, & Llewellyn, 2011). The siblings also described how their family dynamics impacted the caregiving role they assumed. Critical factors included parental involvement and perspective of how much each sibling should help, shared responsibilities amongst family members, the number of siblings and the support given by immediate and extended family members.

4.3 | The impact of communication on sibling roles

Although this topic was less explicitly addressed in the Findings, there were multiple examples across the various roles of the impact of communication on sibling role assumption and enactment. Communication skills and supports were important to sustain and strengthen the relationships between siblings, especially when they lived far away and did not see one another often. The siblings described that many of their brothers and sisters with severe IDD had difficulty in communication and needed visual cues, verbal prompts, assistive technology,

encouragement to initiate communication or the very presence of their sibling. Limited functional communication or other communication difficulties experienced by individuals with IDD can become barriers to sibling interactions and relationships (Rossetti & Hall, 2015). Consistent with prior research, siblings believed that using augmentative alternative communication, as well as assistive technology and Skype or email, was critical to maintain regular contact and strengthen sibling relationships as adults (Dew et al., 2011).

5 | IMPLICATIONS

The findings from this study raise several implications for practice. First, siblings who want to continue their involvement should be involved in future planning for their brothers and sisters with IDD due to the various roles they fulfil throughout the lifespan. This may begin within the family when siblings are adolescents by identifying the roles they currently assume and the roles they wish to fulfil in the future. Future plans and sibling roles should remain flexible to the changing situations and desires of the family. Disability service providers and healthcare providers may include siblings in meetings and other forms of communication to inform planning and support siblings in their roles. Siblings could be invited to annual planning meetings not only to learn and become involved, but also to assist service providers in working with their brothers and sisters with IDD. Similar to siblings in childhood, adult siblings may teach direct support providers how to communicate and interact (e.g., nonverbal communication, physical support) with their brothers and sisters with IDD (Nijs et al., 2016).

Siblings fulfil roles to support their brothers and sisters with IDD through advocacy, service coordination and legal representation. Similar to the findings of Burke et al. (2012), many siblings in this study were not aware of the financial and legal information concerning their brothers and sisters with IDD. Thus, siblings need information, training and opportunities for individual support similar to what is provided for parents. Siblings advocated on behalf of their brothers and sisters with IDD to secure appropriate services (Burke, Arnold, et al., 2015; Burke, Fish, et al., 2015). In order to do this, siblings need information about the services available, how to navigate the service system and the rights of their brothers and sisters.

About 65% of the siblings in this study identified that they were a caregiver for their brothers and sisters with IDD to some degree. They enacted the role by providing direct care, transportation, personal care, cooking and cleaning services, financial assistance and behavioural support. Knowing that a majority of siblings intend to fulfil caregiving roles, support should be provided for these siblings. The types of support should reflect the information and assistance already available to parents. Also, as it has been shown for adolescent siblings, healthcare professionals should include adult siblings in family treatment plans and use strategies to foster the caregiver role (Smith et al., 2015). Additional support, such as increased respite, might be needed for middle-aged siblings who may be caring for their own children and their ageing parents as well as their brothers and sisters with IDD. As suggested by Burke et al. (2012), a multigenerational approach to shaping caregiving expectations is needed because of the involvement of multiple family members.

6 | LIMITATIONS AND FUTURE RESEARCH

Limitations include the sampling procedures and the use of an online survey for data collection. Although there were 79 adults who participated, the findings cannot be generalized to all siblings of people with IDD. The siblings reported the disability type and severity of their brothers and sisters on the survey, so we could not verify this information. Future research may request documentation of diagnoses or use an assessment, such as the Supports Intensity Scale, for this determination. The sample was not randomized, and within each sibling relationship, the specific disabilities, sibling personalities, family dynamics and supports received impact the roles that siblings assume. Future research may address the roles of siblings in their relationship with their brothers and sisters with IDD by focusing on a specific disability, major life event or cultural background. Further, the sampling procedures may have limited the number and diversity of siblings who participated in the study. The invitations to participate occurred via listserv emails and Facebook posts 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). Siblings who do not have computer or Internet access may not be represented (Davys et al., 2010). Sampling procedures may be adjusted to expand the diversity of participants by providing paper copies of the recruitment flyer and survey as well as soliciting participation through community organizations with diverse membership. Using a survey to collect data, the present authors were unable to probe for clarifying information as in an individual or focus group interview. Future research should include interview methods to delve deeper into sibling perspectives. One possibility would be to conduct follow-up interviews with a subset of the sample from a survey study such as ours. Additionally, while it was not our focus in this study, only one half of the sibling dyad relationship is represented in this study. Brothers and sisters with IDD should certainly be included in future research to more fully examine sibling roles and relationships.

7 | CONCLUSION

Siblings assume a variety of roles and responsibilities to support their brothers and sisters with severe IDD. Many of the roles unique to siblings of people with severe IDD, such as caregiver or legal representative, take a significant level of commitment and education (Rawson, 2009). Although the majority of siblings would like to be involved in the lives of their brothers and sisters, they need greater opportunities to receive information, network with other siblings and find supports (Heller & Kramer, 2009). Siblings need to be included in discussions with family members and professionals as they prepare for the future

of their brothers and sisters with severe IDD and how they may be involved when their parents can no longer provide care (Heller & Kramer, 2009). They may also receive support from sibling groups as children (e.g., Sibshops) or as adults (e.g., the Sibling Leadership Network). With the benefit of information and planning when they are young, they may be more prepared to take on new and changing roles throughout their lives.

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