

Patterns of Adult Sibling Role Involvement with Brothers and Sisters with Intellectual and Developmental Disabilities

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Abstract Adult siblings of individuals with intellectual and developmental disabilities (IDD) are increasingly involved in family care, yet, adult siblings consistently report needing more information and support to engage in these roles. Knowing more about which roles siblings are likely to assume may help address this need. Thus, we further examined the most common roles assumed by adult siblings ($N = 171$), the demographic variables related to an increased likelihood of assuming specific roles, and the potential clusters in patterns of role assumption. We transformed qualitative data from an online survey with four open-ended questions about sibling relationships and roles into quantitative presence data for role-related codes in order to examine relationships between assumed roles and demographic variables. The most common roles assumed by adult siblings were friend, advocate, caregiver, and sibling. Key demographic variables related to role assumption included disability severity, emotional closeness, and age of the brother or sister with IDD. Cluster analyses indicated five potential categories of adult sibling role involvement: Companion, Least Involved, Highly

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Involved, Needs Focused, and Professional. Implications and future areas of research are shared.

Keywords Siblings · Sibling roles · Intellectual disabilities · Developmental disabilities

Research on the experiences of adult siblings when one brother or sister experiences intellectual and developmental disabilities (IDD) is critical in light of recent demographic trends. The majority of people with disabilities in the US live at home, including 75–84% of those with IDD (Fujiura 2014). Individuals with IDD are also living longer (Braddock et al. 2015; Coppus 2013), resulting in greater caregiving needs over a longer period for a population of people who already rely on daily support (Fujiura 2014). Moreover, 60% of individuals with IDD living at home reside with aging (i.e., aged 60+) or middle-aged (i.e., aged 41–59) caregivers (Braddock et al. 2015). Thus, there has been a substantially increased need for family caregiving over a longer period. Adult siblings can be an important source of support in responding to this need since sibling relationships are likely to be the longest in people’s lives (Heller et al. 2007, 2008).

Indeed, siblings anticipate taking over greater responsibility in their brothers and sisters’ lives, and they 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 and Arnold 2010; Heller and Kramer 2009; Hodapp et al. 2010; Rawson 2009). Siblings of those with IDD frequently assume significant roles in their brothers and sisters’ lives as caregivers (Burke et al. 2015b; Heller and Arnold 2010), advocates (Burke et al. 2015a; Kramer et al. 2013), and teachers (Tsao et al. 2012; Tzurriel and Hanuka-Levy 2014). Despite the prevalence of current and anticipated future involvement in their brothers and sisters’ lives, adult siblings continue to indicate a need for more information about adult supports and services, and a desire to engage in networking with other adult siblings (Arnold et al. 2012; Heller and Kramer 2009; Holl and Morano 2014). In order to better support adult siblings, it is important to understand how they may be involved with their brothers and sisters with IDD. This study adds to the body of research examining and emphasizing the experiences of adult siblings. We focused on the patterns of involvement by adult siblings without disabilities with their brothers and sisters with IDD through the roles they assume within the context of their sibling relationship.

In particular, sibling involvement in caregiving can be a critical component in the lives of adults with IDD, thus there is a need to further examine it in research (Saxena 2015). Prior research has shown that future caregiving is more common for women, lone siblings, siblings in emotionally close relationships with their brothers and sisters with IDD, and siblings who live in close proximity to their brothers and sisters with IDD (Burke et al. 2012; Heller and Kramer 2009). It is also important to examine other roles adult siblings may assume in order to better prepare them for such role assumption. Additionally, there is a need to examine the factors that may be related to the likelihood that adult siblings assume specific roles in order to identify which siblings need which supports. Based on results from Burke et al. (2012) regarding predictors of the caregiving role, in this study we examined similar variables including sibling gender, emotional closeness, and residential proximity, though for multiple roles.

We were also interested in the effects of the brother or sister’s disability, among other demographic factors (e.g., age), on the likelihood of siblings assuming specific roles.

The extant research on siblings has yet to explore the effects of the wide range of developmental, behavioral, and social/emotional patterns encompassed by a disability diagnosis on sibling relationships and roles (Stoneman 2005). In particular, extant research has focused on siblings of individuals with moderate IDD and intermittent or limited support needs (e.g., Findler and Vardi 2009; Floyd et al. 2009). However, we anticipated that sibling roles may differ with brothers and sisters with severe to profound IDD and extensive or pervasive support needs because their adult outcomes are often different from those with less intensive support needs. For example, compared to those with mild intellectual disability, adults with severe intellectual disability were less likely to live in their own home and to experience choice in their lives, and they had lower rates of paid employment and community inclusion (Davies and Beamish 2009; Gray et al. 2014; Neely-Barnes et al. 2008). Such experiences typically require both agency services and family support.

Despite greater support needs, which siblings could help provide, the behavioral challenges of those with IDD may negatively affect the sibling relationship (Saxena 2015). Increased support needs, as manifested by social, communication, and behavioral challenges, were frequently cited by adult siblings as perceived barriers to closer sibling relationships (Rossetti and Hall 2015). Past research suggests that siblings with brothers or sisters with autism spectrum disorder (ASD) may have lesser relationship quality than siblings of brothers or sisters with Down syndrome (Hodapp and Urbano 2007; Orsmond and Seltzer 2007; Pollard et al. 2013). This difference related to the presence of maladaptive behaviors, which siblings perceived as the most challenging barrier to closer relationships with brothers or sisters with ASD (Angell et al. 2012; Orsmond et al. 2009; Ross and Cuskelly 2006). Thus, there is a need to specifically examine sibling involvement in relation to the severity of their brother and sisters' disability and level of support needs.

This study addresses a growing need in family care related to the experiences of adult siblings with a brother or sister with IDD. Findings from this study can help guide intervention to better prepare adult siblings in the roles they may assume with their brother or sister with IDD. We examined the demographic variables related to an increased likelihood of siblings assuming specific roles, and potential clusters in patterns of role assumption. The research questions were:

- 1) How many roles are adult siblings likely to assume?
- 2) What variables relate to the probability that adult siblings assume specific roles?
- 3) What attributes are similar or different across potential clusters in the patterns of role assumption?

Method

We previously reported qualitative findings regarding the roles adult siblings described assuming in their relationships with brothers and sisters with IDD and how they enacted those roles (Hall and Rossetti 2017). In the prior study, we identified seven roles assumed by adult siblings, but we noted that over half of the siblings assumed multiple roles. We saw this as an opportunity to further study additional variables related to adult siblings assuming certain roles and patterns of role assumption. Thus, we conducted

this secondary, exploratory analysis of our original qualitative data to examine variables related to the probability that adult siblings do or do not assume specific roles. Taking the responding sample as the specific group for a case study, relationships were examined for this group. Initially, we utilized a qualitative approach to examine the roles that adult siblings described assuming in their relationships with their brother or sister with IDD (Creswell 2013). We then systematically transformed the qualitative data into quantitative presence data (i.e., dichotomous indicator) to examine relationships between the assumed roles and demographic variables (Mertens 2003).

Participants

This study included 171 adult siblings between the ages of 18 and 72 who had a brother or sister with mild, moderate, severe, or profound IDD. Over 80% were female ($n = 140$) and about 70% were older than their brother or sister with IDD ($n = 119$). Among the participants who reported data about their parents ($N = 141$), over two thirds ($n = 99$) had parents who were still involved in caregiving, while under one third ($n = 42$) had parents who were deceased or aging and less involved with caregiving. Of the participants who reported data about their residential proximity to their brother or sister with IDD ($N = 165$), over 60% ($n = 102$) lived greater than two hours away. Among those who lived within two hours, 16 siblings resided with their brother or sister with IDD. Table 1 includes additional demographic information.

The participants wrote about 108 brothers and 63 sisters between the ages of 7 and 72 with, most frequently, intellectual disability ($n = 75$), Down syndrome ($n = 52$), autism spectrum disorder ($n = 44$), and cerebral palsy ($n = 22$). Disability information was indicated by sibling report on the survey in response to the following two questions:

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

Procedures

Participant Selection In the initial study, we used criterion sampling to recruit participants who were 18 years of age or older and had at least one brother or sister with mild, moderate, severe, or profound 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, script for email and Facebook options, and link to the survey were sent to the contact person of each organization. Participants elected to contact us voluntarily. There were no incentives for participation.

Data Collection New data were not collected as part of this study. In the initial study, data were collected through an online survey. We conducted an extensive literature

Table 1 Participant demographics ($N = 171$)

	Adult siblings		Brothers/sisters with IDD	
	<i>n</i>	Percentage	<i>n</i>	Percentage
Sex				
Female	140	81.9%	63	36.8%
Male	31	18.1%	108	63.2%
Sibling order				
Older than brother/sister	119	69.6%		
Younger than brother/sister	52	30.4%		
Race				
White/Caucasian	163	95.3%	163	95.3%
Asian or Pacific Islander	5	2.9%	5	2.9%
Black/African American	3	1.8%	3	1.8%
Native American*	–	–	1	0.6%
Highest level of education				
Some High School	1	0.6%	70	40.9%
High school graduate/GED	7	4.1%	79	46.2%
Some college	16	9.4%	17	9.9%
College graduate	79	46.2%	3	1.8%
Graduate degree	68	39.8%	1	0.6%
No response	–	–	1	0.6%
Marital status				
Single/Never married	71	41.5%	166	97.1%
Married	87	50.9%	3	1.8%
Separated/Divorced	11	6.4%	2	1.2%
Widowed	2	1.2%	–	–
Disability diagnosis**				
Intellectual Disability			75	43.9%
Down syndrome			52	30.4%
Autism Spectrum Disorder			44	25.7%
Cerebral palsy			22	12.9%
Level of ID/Support needs				
Mild			21	12.3%
Moderate			71	41.5%
Severe			61	35.7%
Profound			18	10.5%

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

search (e.g., Saxena 2015; Stoneman 2005) and then developed the survey based on the gaps in the extant research (e.g., other sibling roles besides caregiving) and the goals of the study. The authors' Institutional Review Boards approved all study procedures.

After participants indicated agreement to participate, they provided demographic information about themselves and their brother or sister with IDD (i.e., age, gender, race/ethnicity, marital status, and educational level). They also indicated their brother or sister's disability/ies and level of support needs. They then answered four open-ended questions about their sibling relationship:

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 212 surveys in our initial database. There were 41 surveys with only demographic information provided that we did not include. Of these, there was a similar sample of gender, age, education, and disability to the completed surveys we included. This article reports findings from the 171 completed surveys. Due to missing data on some of the demographic survey data, 18 participants were excluded from some analyses (indicated below). 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 identifying roles assumed without further description) to two pages of single-spaced data. Most responses were between 15 single-spaced lines of data to 30 single-spaced lines of data.

Data Analysis In the initial study, the first and third authors utilized a multi-stage process of open and axial coding to analyze the responses to the four open-ended survey questions. We developed a codebook, achieved 88.1% inter-rater agreement (number of agreements divided by total number of coded data units) on 10% of the surveys, independently coded each survey, and discussed the coding until agreement. This process resulted in the sibling role data utilized in this study (i.e., seven roles participants described assuming). Indication of assumption of a given role was recorded if evidence was volunteered in any of the open-ended questions, and indicators were dichotomous (not count data). Thus, the unit of analysis for an assigned code was the entirety of the four-question response.

In this study, the quantitative data set consisted of demographic and categorical information from the survey, and data that were systematically transformed from the open-ended question responses into specific variables. To prepare the quantitative data for analysis, we developed a coding system to transform the qualitative data into quantitative presence data. To ensure that the transformation of data was valid and reliable, we developed and applied a codebook with code titles, descriptions, and examples and non-examples as application criteria. The first and third authors independently coded each survey and systematically discussed coding until agreement. This process included coding for variables that were not specifically solicited by survey questions (e.g., residential proximity, emotional closeness). Thus, we coded explicit statements of these spontaneous contributions. For example, when a sibling described that he has always had a close relationship with his brother we coded this with *Close*

Always. When a sibling indicated she lived in the same town as her sister, we coded this with *Proximity*; when a sibling indicated he lived across the country from his sister, we coded this with *No Proximity*. Those that did not explicitly state this were not coded, thus resulting in possible missing data.

The following analyses examined the siblings' self-reporting of assuming specific roles (that emerged from the data) in their relationships with brothers and sisters with IDD. When missing data was removed from the demographic info in the data set, it reduced the total sample size from 171 to 153. As it is possible that a sibling had assumed a given role though did not specifically mention it in her/his response, it is imperative to note that these quantitative variables are interpreted as a willingness to indicate assumption of a given role, as opposed to evidence of having assumed a given role. The dependent variable list included the following seven sibling roles (based on the coding of the qualitative data): caregiver, friend, advocate, legal representative, sibling, leisure planner, and informal service coordinator. The dependent variables were dichotomous, indicating serving in that role or not. The other key demographic variables included: age, education, and gender of siblings and their brothers and sisters with IDD; severity of disability (i.e., mild, moderate, severe, profound); residential proximity; emotional closeness of the relationship (categorized into an ordinal scale: never close, close only in the past, close only recently, always close); and, assumption of other roles.

To assess possible relationships between self-identified roles and other key demographic variables, relationships were examined using the appropriate correlation. For two dichotomous variables (e.g., gender, role engagement), the phi-coefficient was used; for dichotomous and ordinal variables (e.g., severity, emotional closeness), Cramer's V was used (though in all cases, comparable findings were obtained when using Spearman's rho); and for dichotomous and scalar variables (e.g., age, education), Spearman's rho was used. To assess for statistically significant differences while controlling for Type I errors, the Holms-Bonferonni algorithm was used.

Finally, an agglomerative clustering algorithm was used to group the participants into classes to examine possible shared attributes. With participants ($N = 171$) indicating assumption of a given role (or not) for a set of seven roles, hierarchical cluster analysis using the farthest-neighbor method was applied to a distance matrix obtained using the taxi-cab distance. This combination is appropriate for a vector of dichotomous variables of this nature. First, the distance metric is easily interpretable as the number of discordant role-pairs between a pair of individuals (e.g., a distance of 3 indicates the pair "agreed" on the remaining $7-3=4$ roles—either both assuming or both failing to indicate assumption of those roles). Second, the farthest-neighbor aggregation method combines groups only if the most disparate individuals from each group are "close" to each other. This conceptually results in more uniformity within groups. Finally, this method allows for one additional attribute with dichotomous data: final clusters can be categorized by the maximum number of disagreements occurring between any pair of individuals within a given cluster.

Results

Role Assumption by Adult Siblings

All but four of the adult siblings described assuming at least one of the roles of friend, advocate, caregiver, sibling, legal representative, informal service coordinator, and leisure planner in their relationships with brothers and sisters with IDD. The most common roles assumed by adult siblings were friend, advocate, caregiver, and sibling (see Table 2). The mode (and median) for total number of roles assumed was three across the entire sample, as well as for each subgroup when split into two groups by the brother or sister's disability severity: mild/moderate ($n = 92$) and severe/profound ($n = 79$). For the entire sample, 12.3% ($n = 21$) of participants indicating assuming at most one of the roles, 21.1% ($n = 36$) of participants indicated assuming at least five of the roles, and 5.8% ($n = 10$) of participants indicating assuming all seven of the roles.

Comparing across the two severity groups, 60% of the siblings with a brother or sister in the mild/moderate group indicated that they assumed three or fewer of these seven roles, while almost half (48.1%) of the siblings with a brother or sister in the severe/profound group indicated that they assumed four or more of these seven roles. The four siblings who did not indicate assuming any of the roles were evenly split across the two groups. Higher percentages of siblings with a brother or sister with more intensive needs assumed the roles of legal representative, leisure planner, and caregiver; higher percentages of siblings with a brother or sister with less intensive needs assumed the roles of sibling and informal service coordinator.

Relations between Roles and Demographic Variables

The resulting relationships were flagged as statistically significant (p -values are Holms-Bonferonni-adjusted values). Though such quantification of relationships may serve a predictive purpose statistically, the information provided here is not intended to suggest any form of causal relationship. Results must be interpreted accordingly.

The friend role was related to sibling role, $\chi^2(1) = 10.7$, $\phi = .26$, $p = .015$, with 35.7% assuming only one of the two roles, and 43.3% assuming both of the roles. The friend role was related to emotional closeness, $\chi^2(3) = 40.8$, $V = .50$, $p < .001$, with a trend toward indicating assuming the role the closer the siblings (see Table 3). The sibling role was also related to emotional closeness, $\chi^2(3) = 24.1$, $V = .39$, $p < .001$, with a similar trend as observed for the friend role (see Table 3).

The informal service coordinator role was related to the advocate role, $\chi^2(1) = 10.7$, $\phi = .26$, $p = .016$, with 45.0% assuming only one of the two roles, and 19.3% assuming both of the roles. The informal service coordinator role was related to the age of the brother or sister with IDD, $\rho = .37$, $p < .001$. Specifically, the older the brother or sister with IDD, the more likely adult siblings indicated having assumed the informal service coordinator role.

The legal guardian role was also related to the age of the brother or sister with IDD, $\rho = .26$, $p = .010$. Specifically, the older the brother or sister with IDD, the more likely adult siblings indicated having assumed the legal guardian role.

The leisure planner role was related to the caregiver role, $\chi^2(1) = 11.3$, $\phi = .27$, $p = .012$, with 43.3% assuming only one of the two roles, and 17.5% assuming both of

Table 2 Sibling roles: frequency and examples

Role	Frequency (<i>N</i> = 171)	Subgroup frequency		Data examples
		M-M (<i>n</i> = 92)	S-P (<i>n</i> = 79)	
Friend	113 (66.1%)	62 (67.4%)	51 (64.6%)	<ul style="list-style-type: none"> • “I am his best friend.” • “He and I have a very open relationship and have talked about any subject important to him at the time.”
Advocate	104 (60.1%)	55 (59.8%)	49 (62.0%)	<ul style="list-style-type: none"> • “Advocate for obtaining the supports she desires.” • “I handled any bullies that came his way.”
Caregiver	98 (57.3%)	47 (51.1%)	51 (64.6%)	<ul style="list-style-type: none"> • “I help get her dressed, take her to the bathroom, and fix food.” • “I find myself helping her more so my parents can interact with our family.”
Sibling	96 (56.1%)	55 (59.8%)	41 (51.9%)	<ul style="list-style-type: none"> • “From the time when our mother first explained his disability when I was six, I have felt responsibility for him and for his education.” • “I was always the ‘older’ brother even though I am 4 years younger, and I always took that role very seriously.”
Legal rep.	62 (36.3%)	20 (21.7%)	42 (53.2%)	<ul style="list-style-type: none"> • “I am her legal guardian as well as her representative payee for Social Security.” • “I have Power of Attorney for my brother.”
Informal service coordinator	39 (22.8%)	24 (26.1%)	15 (19.0%)	<ul style="list-style-type: none"> • “Writing my sister’s plans, scheduling providers, and taking care of her business and financial affairs.” • “I oversee all residential and vocational services.”
Leisure planner	36 (21.1%)	9 (9.8%)	27 (34.2%)	<ul style="list-style-type: none"> • “I try to incorporate something fun into our time together.” • “We have taken her on vacations with us.”
No response	4 (2.3%)	2 (2.2%)	2 (2.5%)	

M-M Mild-Moderate, *S-P* Severe-Profound, *Legal Rep.* Legal Representative

the roles. The leisure planner role was also related to the age of the brother or sister with IDD, $\rho = .27, p = .005$. Specifically, the older the brother or sister with IDD, the more likely adult siblings indicated having assumed the leisure role. The leisure planner role was also related to severity of the brother or sister’s disability, $\chi^2(3) = 19.8, \phi = .34, p = .003$, with a trend toward indicating assuming the role the higher the severity (see Table 4).

Table 3 Relation between emotional closeness and sibling roles

Emotional closeness	Friend role		Sibling role	
	No	Yes	No	Yes
Never close	21 (77.8%)	6 (22.2%)	19 (70.4%)	8 (29.2%)
Close only in past	13 (44.8%)	16 (55.2%)	20 (69.0%)	9 (31.0%)
Close only recently	4 (22.2%)	14 (77.8%)	6 (33.3%)	12 (66.7%)
Always close	13 (14.9%)	74 (85.1%)	25 (28.7%)	62 (71.3%)

Cluster Analysis for Assumption of Given Roles

Exploratory analyses seemed to indicate that a clustering solution with 3–5 total clusters would be appropriate for the data. Consequently, the dendrogram (see Fig. 1) for this analysis indicated three distinct clusters (if at most six roles were allowed to be distinct) or five distinct clusters (if at most five roles were allowed to be distinct). Because the five-cluster solution is relatively easily interpretable, it is presented here. The proportions for each role by cluster are presented in Fig. 2.

The first and largest cluster ($n = 65$) is labeled “Companion,” as individuals in this cluster assumed the close-relational roles of friend (80%) and sibling (58%) more frequently than those in the other clusters. In fact, they showed the highest frequency of assuming the friend role. Those in the Companion cluster were lowest in the roles of informal service coordinator (0%) and legal representative (26%). The siblings in the Companion cluster interacted as social peers, confidants, and mentors.

The second cluster ($n = 52$) is labeled “Least Involved,” as members of this group indicated assuming nearly all of the roles at a lower frequency than members of the other clusters. Those in the Least Involved cluster assumed an average of only two roles. They were the lowest or among the lowest in assumption of the leisure planner (2%), caregiver (10%), and informal service coordinator (4%) roles.

The third cluster ($n = 34$) is labeled “Highly Involved,” as members of this group indicated assuming nearly all of the roles at a higher frequency than those in other clusters. Those in the Highly Involved cluster showed the most frequent assumption of the leisure planner (68%), caregiver (97%), sibling (91%), and advocate (91%) roles. They were also among the most frequent for assumption of the legal representative (88%) and informal service coordinator (53%) roles.

Table 4 Relation between disability severity and sibling roles

Disability severity	Leisure planner role	
	No	Yes
Mild	19 (90.5%)	2 (9.5%)
Moderate	64 (90.1%)	7 (9.9%)
Severe	44 (71.0%)	18 (29.0%)
Profound	8 (47.1%)	9 (52.9%)

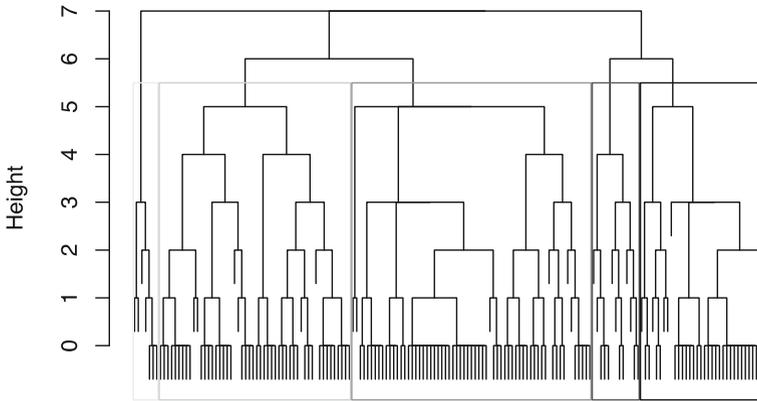


Fig. 1 Cluster dendrogram

The fourth cluster ($n = 13$) is labeled “Needs-Focused,” as individuals in this cluster assumed the supportive roles of caregiver (77%), advocate (77%), and informal service coordinator (100%) more frequently than those in other clusters. They also assumed the sibling (0%), leisure planner (8%), and legal representative (38%) roles at a lower frequency compared to those in other clusters. Thus, their role involvement centered directly on providing necessary and appropriate services and supports related to their brothers and sisters’ needs.

The fifth cluster ($n = 7$) is labeled “Professional,” as members of this group appeared to be most involved in their brothers and sisters’ lives in the legal representative (100%, highest for all clusters), advocate (86%), and informal service coordinator (86%) roles. They were the lowest in assumption of the caregiver and friend roles (both 0%), and among the lowest in assumption of the leisure planner (29%) and sibling (43%) roles. Thus, their role involvement reflected formal and legal rather than social or supportive orientations in their relationships with their brothers and sisters with IDD.

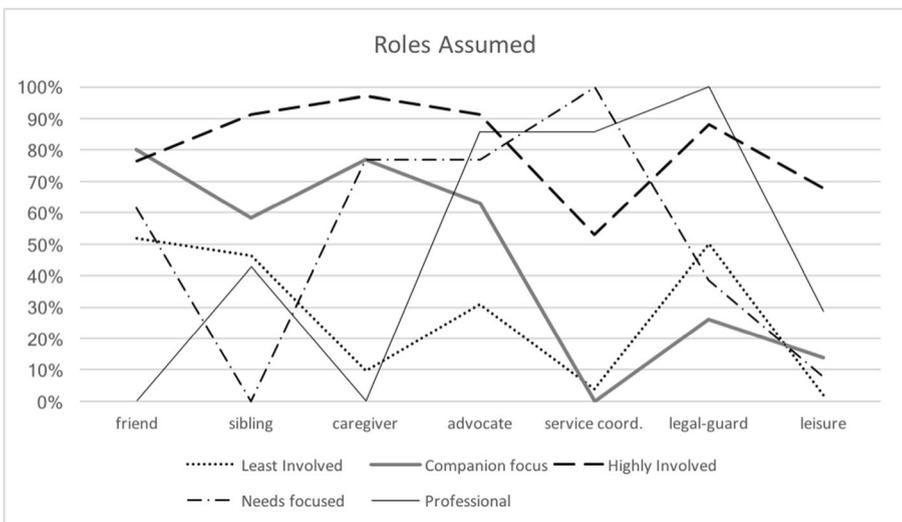


Fig. 2 Cluster patterns of assumed roles by adult siblings

These trends are most evident in Fig. 2. As would be expected, ANOVA run with the roles as the dependent variables by cluster membership indicated significant differences for all analyses. As a further exploration of the plausible validity of these clusters, chi-square tests of independence were run for the demographic variables in relation to the clusters (see Fig. 2). There was a clear relationship in the roles assumed and all possible measures of closeness, both emotional closeness of the relationship (all $p < .001$) and physical proximity (e.g., proximity, $p = .005$). There was also a relationship with the sex of the sibling and the assumed roles ($p = .03$). All other relationships were non-significant (sex, gender-match, birth-order, and education).

Discussion

This study examined the number of roles that adult siblings without disabilities voluntarily indicated assuming in their relationship with brothers and sisters with IDD, the demographic variables related to an increased likelihood of siblings assuming specific roles, and the patterns of shared roles for similar clusters of adult siblings.

In response to the first research question, the majority of adult siblings in this study reported assuming multiple roles. The most frequently assumed roles by adult siblings were friend (social partner), advocate, caregiver, and sibling (mentor/teacher). These results largely confirm prior findings indicating that siblings currently assumed and/or planned to assume advocacy, caregiving, and teaching roles in the future (Burke et al. 2015a, b; Heller and Arnold 2010; Kramer et al. 2013; Tsao et al. 2012; Tzuriel and Hanuka-Levy 2014). The remaining role of being a friend has been studied predominantly among younger siblings with emphasis on the likelihood that siblings are their brother or sister's first, and sometimes only, social partner (Aksoy and Yildirim 2008; Floyd et al. 2009; Knott et al. 2007; Rimmerman and Raif 2001). These results expand the assumption of the friend, or social partner, role to adult siblings. Better preparing adult siblings to assume this role could result in enhanced quality of life outcomes. For example, with specific training and information, siblings in the friend role could better understand how to support their brother or sister's self-determination (Wehmeyer 2005) and how to emphasize meaningfulness in their social activities (Rossetti et al. 2015).

The second research question inquired about the demographic variables related to an increased likelihood of siblings indicating the assumption of specific roles. We were especially interested in the effects of the brothers and sisters' disability on sibling involvement as indicated by roles assumed. Our results showed that the brothers and sisters' disability severity predicted sibling assumption of the leisure planner role. Siblings of brothers and sisters with severe or profound IDD were more likely than those of brothers and sisters with mild or moderate IDD to assume the leisure planner role. That siblings of brothers and sisters with severe or profound IDD were more likely to indicate assumption of the leisure planner role reflects both the opportunity and need to include them in leisure and recreational activities. Individuals with severe to profound IDD who typically have extensive to pervasive support needs tend to have few friends, and their social networks include mainly family members and paid support staff (Amado et al. 2013; Kamstra et al. 2015). Additionally, Taylor and Hodapp (2012) found that individuals with IDD who did not have daytime educational and vocational activities were more likely to have intensive support needs manifested by greater

functional and behavioral problems, as well as fewer agency services and less parental support. They also found that siblings of those without daytime activities were more likely to have negative health outcomes than siblings of those with daytime activities. Thus, agencies and service delivery systems should focus on increasing activities for individuals with severe or profound IDD, and on providing information and support to help siblings who have assumed, or have the opportunity to assume, the leisure planner role.

Additional variables affecting role assumption included the sibling-reported perceptions of the emotional closeness of their relationships with brothers and sisters with IDD, as well as the age of brothers and sisters with IDD. Though inconsistent with previous studies linking sibling emotional closeness to the caregiving role (Burke et al. 2012), perceptions of sibling emotional closeness were related to both the friend and the sibling roles. The other demographic variable that was related to adult sibling role assumption was the age of the individuals with IDD. In particular, the older the brother or sister with IDD, the more likely adult siblings indicated having assumed the informal service coordinator role, the legal guardian role, and the leisure planner role. It seems likely that the parents of these older brothers and sisters with IDD were also aging and thus transitioning out of their prior roles with adult siblings stepping in to assume these roles. These findings support the importance of including adult siblings in future planning for individuals with IDD since they are likely to assume these roles (Arnold et al. 2012; Heller and Kramer 2009; Holl and Morano 2014). These findings extend the literature by emphasizing not only providing adult siblings with information about formal systems of support for adults with IDD (e.g., informal service coordinator, legal guardian roles) but also considerations related to meaningful activities and social belonging (e.g., leisure planner, friend roles).

Our third research question inquired about the potential clusters of patterns of sibling role assumption. These findings suggest that assumption of certain roles may influence the probability that siblings do or do not assume other specific roles. The cluster analysis revealed five distinct “groupings” of adult sibling roles that can be best described as: Companion, Least Involved, Highly Involved, Needs-Focused, and Professional. The Companion cluster was the largest, as it encompassed the most frequently assumed specific role of friend. The parents of siblings in the Companion cluster tended to still be the primary caregivers and/or guardians for their brothers and sisters, thus there may not have yet been a need for the siblings to assume those other more formal and supportive roles. That so many siblings showed a role assumption pattern of Highly Involved across all roles reflects the value of sibling support and involvement in the lives of individuals with IDD, as well as a need to cultivate knowledge and leadership by siblings in these roles (Heller et al. 2008). Additionally, the Needs-Focused and Professional clusters, while smaller, suggest that siblings fulfill needed roles when parents no longer can.

Taken together, these results contribute to the growing body of research on sibling experiences by providing information about sibling involvement with their brothers and sisters with IDD as indicated by the roles that they voluntarily confirmed assuming within their relationships and the variables related to specific role assumption. Overall, the participants were substantially involved with their brothers and sisters with IDD, assuming most frequently the roles of friend, advocate, caregiver, and sibling. Service professionals may support siblings to enact the roles they assume in relation to their

brothers and sisters with IDD. Since it would be too much to prepare for any role, they could focus on the most common roles of friend, advocate, caregiver, and sibling. The friend role in particular may be an effective entry point for intervention as siblings may assume this role first, likely while parents are still involved in providing care. Intervention could comprise information and opportunities related to enacting the friend role. In addition, since siblings of brothers and sisters with severe or profound IDD may more frequently assume the leisure planner role, this could be another effective entry point for their involvement. The leisure planner role by its nature (e.g., planning vacations, occasional visits) may also be an effective way for adult siblings to remain involved with their brothers and sisters with IDD after the adult siblings move away from the family home and begin their own families.

Beyond these entry points for sibling support related to specific roles, siblings could be included in family support systems and family planning for future assumption of additional roles (e.g., legal representative, caregiver). Service professionals may invite siblings to training opportunities already provided for parents about resources in the community, accommodations, how to navigate the developmental disability system, and how to advocate. For example, siblings may benefit from information on person-centered planning and supported decision-making. These services may target siblings who have brothers and sisters with severe/profound IDD since almost half of the participants indicated that they assume four or more roles. Service professionals may also promote the emotional closeness between sibling pairs by identifying ways to stay connected, supporting the person with IDD to reach out and communicate with their sibling, and supporting the sibling in interactions when needed. Finally, service professionals may consider providing information and support to siblings related to service delivery and the other roles that were related to the older ages of their brothers and sisters with IDD.

It is important to acknowledge the study's limitations. First, though the sample was large, the findings cannot be generalized to all adult siblings of individuals with IDD. Our sample was not systematically developed or randomized, and as such, may not be representative of the public. Second, the sampling procedures may have limited the number and diversity of participants. The invitations to participate occurred via listserv emails and Facebook posts by members 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). In addition, siblings who do not have computer or internet access may not be represented (Davys et al. 2010). The sample was predominately white, female, and college graduates. Sampling and recruiting procedures may be adjusted accordingly to expand the diversity of participants in further research.

Additionally, the statistical analyses were conducted on voluntarily proffered indicative data (i.e., verbal indication of a present role) as opposed to directly queried or forced-choice data (i.e., ranking the degree of assumption for a given set of roles or asking to preferentially rate one role over another). This is important for assessing the implications for all inferential statistical findings presented. As such, conclusions drawn from these findings should be considered in this light: likelihood to indicate one role may relate to the likelihood to indicate another role, whereas a different relationship between the actual presence of said roles may exist. As an additional limitation, this

was a statistical analysis of a single case study, and the generalizability of these findings is limited; as an exploration analysis, this work is presented to provide initial findings and evidence to assist future researchers in planning further studies. Furthermore, as some potential key confounding variables were not measured in this study (e.g., other sibling responsibilities, parental involvement, residential care support, etc.), a strictly exploratory (and non-predictive) perspective was assumed. Consequently, no regressions (OLS or logistic) were reported, as this would be more appropriate for a future study that collects a richer set of data (directly measuring more variables and not imputing information from indirect sources) from a more diverse sample.

Despite these limitations, the results provide information and potential guidance in an area of growing need. Demographic trends indicate that individuals with IDD are living longer, predominantly reside in the family home, and receive care from aging or middle-aged parents or guardians (Braddock et al. 2015; Coppus 2013; Fujiura 2014). The adult service delivery system has been unable thus far to respond to this need as indicated by waiting lists for needed services and the ongoing challenge of maintaining a consistent staff of quality direct support providers, among other problems (Burke et al. 2012; Hewitt and Larson 2007; National Council on Disability 2011). Thus, siblings will be relied on to fulfill many of these roles to even greater degrees in the near future (Fujiura 2014; Heller et al. 2008). Greater understanding of sibling involvement in these roles by service agencies and policy makers can guide intervention and resources to better prepare and support siblings in the roles they will certainly assume.

Compliance with Ethical Standards

Funding This was unfunded research.

Ethical Approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

This article does not contain any studies with animals performed by any of the authors.

Informed Consent Informed consent was obtained from all individual participants included in the study.

Conflict of Interest Author A declares that he has no conflict of interest. Author B declares that he has no conflict of interest. Author C declares that she has no conflict of interest.

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