

Title: Social Connections Among Siblings with and without Intellectual Disability or Autism

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### **Acknowledgments**

The work reflected in this manuscript has been accepted as an oral presentation to be given at the TASH 2018 annual conference. The work reported in this article was supported in part by a leadership grant from the Office of Special Education Programs, U.S. Department of Education, through Grant H325K140201 to Vanderbilt University. Vanderbilt University IRB approvals were obtained and followed.

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**Abstract**

Although the significance of sibling relationships is widely affirmed, little is known about these relationships in young adulthood. In this study, we examined the experiences and perspectives of 155 siblings (ages 18-30) of individuals with intellectual disability or autism. Our focus was on how young adults spend time with their brother or sister with a disability, the ways in which they view their relationship, and the expectations they hold for the future. We found that most siblings spent time together engaging in a wide range of activities, described their relationships as of high quality, and held varied expectations regarding their brother's or sister's future. Several factors were associated with more time spent together and higher quality relationships. We address implications for practice and suggest future directions for research.

*Keywords:* siblings, young adults, relationships, families, community inclusion, expectations

Sibling relationships are generally the longest lasting relationships in a person's life. Siblings can have a strong and persistent influence over one another's development, life choices, outcomes, and functioning (McHale, Updegraff, & Whiteman, 2012). Interactions between brothers and sisters provide ongoing opportunities to socialize and experience sharing, companionship, rivalry, and a range of other emotions and experiences (Turnbull, Turnbull, Erwin, & Soodak, 2006). This influence is also evident for sibling pairs that include an individual with intellectual disability or autism. Siblings can be significant companions and friends for their brother or sister with disabilities throughout their lives (Gallagher, Powell, & Rhodes, 2006). As individuals with disabilities live longer, siblings may assume a primary caregiver role when parents can no longer do so (Coyle, Kramer, & Mutchler, 2014; Greenberg, Seltzer, Orsmond, & Krauss, 1999). In both companionship and caretaking roles, siblings can help foster community and social inclusion for their brother or sister with disabilities (Kramer, Hall, & Heller, 2013). The longevity of the sibling relationship highlights the importance of understanding the impact individuals with intellectual disability or autism can have on their brothers and sisters.

Sibling relationships—whether or not they include someone with a disability—can change across the lifespan. Both life cycle research (Goetting, 1986) and family systems theory (Caspi, 2012) suggest the nature of sibling relationships changes between adolescence and early adulthood. During childhood, siblings are highly involved together in a wide range of relationship tasks that include companionship and emotional support, caretaking and teaching, and aid and direct assistance. In early adulthood parental direct supervision often decreases, accompanied by an increase in contact and companionship filled by sibling relationships and relationships outside the home (McHale, Updegraff, & Whiteman, 2012). At the same time, older

siblings often move away from the family home and begin a family and career of their own (Goetting, 1986). Although the broader sibling research has addressed this distinctive window of early adulthood, there has been limited focus on sibling dyads in which one member has an intellectual disability or autism (Ferraioli & Harris, 2009).

One facet of sibling relationships requiring more research is the way in which siblings spend time together. Prior studies addressing the amount of time siblings spend together have had mixed results (Seltzer, Greenberg, Orsmond, & Lounds, 2005). For example, in an early study that combined observations of adult siblings (ages 23-60) who had mild intellectual disability and interviews with their siblings, Zetlin (1986) found that most siblings without disabilities reported limited contact and minimal feelings of intimacy toward their sibling with ID. In contrast, a longitudinal study by Floyd, Costigan, and Richardson (2016) found that siblings with and without intellectual disability became closer from adolescence (18 years old and younger) to young adulthood (22 years old or older). Similarly, a longitudinal study by Orsmond and Seltzer (2000) found that adult siblings of individuals with intellectual disability reported increases in both involvement and positive affect over time. Yet, these studies give limited attention to the types of activities siblings do together and who else is involved (e.g. other family members, friends). Knowing how much time siblings spend together, and further, the specific activities they participate in together, could inform the development of resources and community supports that enable siblings to spend more time together in a wider range of activities.

The factors that might influence the occurrence of these shared activities also should be considered. Orsmond and Seltzer (2007) found that the functional abilities of a brother or sister with intellectual disability or autism were positively correlated with the number of shared sibling

activities among adults (ages 21-56). In a study comparing older adult (ages 30+) sibling relationships between sibling pairs that included an individual with Down syndrome and sibling pairs that included an individual with autism, siblings of individuals with autism had less frequent contacts with their brother or sister (Hodapp & Urbano, 2007). Other factors such as speech/communication challenges, shared or separate residence, and the presence of challenging behaviors are all factors that could impact whether and how siblings spend time together. Such information could inform the development of supports or interventions that could be used to assist particular sibling dyads in spending more time together. More research is needed to explore factors that may account for variability in the range of activities siblings with and without disabilities participate in together as adults.

Knowing how siblings feel about their relationship with their brother or sister with disabilities is also important. As individuals with intellectual disability and autism age, siblings may transition into a caregiving role. Higher quality sibling relationships may allow for smoother transitions into this new role. Past research indicates sibling relationships between individuals with and without developmental disabilities are generally positive (Floyd, Purcell, Richardson, & Kupersmidt, 2009; Hodapp & Urbano, 2007; Hodapp, Urbano, & Burke, 2010; Stoneman, 2005); however, some heterogeneity may exist. For example, Roeyers and Mycke (1995) found that siblings reported levels of support and acceptance that were similar to average levels among sibling pairs that did not include an individual with disabilities. Within the group of siblings with a brother or sister with autism, however, there was a positive association between the sibling's knowledge of autism and the quality of their relationship with their brother or sister. Hodapp and Urbano (2007) found that siblings of individuals with Down syndrome had closer and warmer sibling relationships than siblings of individuals with autism. Finally, in a study conducted by

Tomeny, Ellis, Rankin, and Barry (2017), siblings of individuals with ASD reported less positive attitudes towards their siblings compared to siblings of individuals with ID. Despite this past research, little is known about the quality of relationships during early adulthood specifically. Future work should focus on how young adult siblings perceive the quality of their relationship with their brother or sister with disabilities and the factors that may be associated with higher quality relationships during this particular developmental window.

Finally, the expectations siblings hold for their brother's or sister's future are important to consider. Expectations held by parents of individuals with disabilities are significant predictors of a range of post-school outcomes (Carter, Austin, & Trainor, 2012; Doren, Gau, & Lindstrom, 2012). For siblings who may transition into parent-surrogate roles, sibling specific expectations related to whether their brother or sister will attend a post-secondary education program, live independently, have a paid job, or get married may also be associated with later outcomes. Yet, the expectations individuals hold for their siblings with disabilities has yet to be explored. Instead, research is limited to expectations of what the role as a future caregiver might look like (Heller & Kramer, 2009).

The purpose of the present study was to explore the perspectives of young adults on their relationship with their sibling with intellectual disability or autism. We sought to answer the following research questions: How do young adult siblings spend time with their brother or sister with disabilities? What factors are associated with the variety and number of activities siblings engage in together? How do siblings perceive the quality of their relationship? What future expectations do siblings hold for their brother or sister with disabilities? This study extends the extant literature by focusing specifically on the experiences and perspectives of young adults

(ages 18-30) who have siblings with intellectual disability or autism. Limitations and implications for practice are discussed.

## Method

### Participants

Participants included 155 siblings of individuals with an intellectual disability or autism. To be included, their brother or sister must have had an intellectual disability and/or autism. The sibling must also have been between the ages of 18 and 30 years at the time of the study ( $M = 23.2$  years,  $SD = 3.8$ ). The majority of siblings (78.7%,  $n = 122$ ) identified themselves as a sister, 21.3% ( $n = 33$ ) as a brother. Most participants identified as White/Non-Hispanic (88.4%,  $n = 137$ ) and single (76.1%,  $n = 118$ ). Additional demographic information for the siblings (e.g., highest level of education, number of children) is displayed in Table 1.

Each sibling provided information about their brother or sister with disabilities. Brothers and sisters with disabilities ranged in age from 3.0 to 46.0 years ( $M = 20.7$  year,  $SD = 6.5$ ); the majority ( $n = 98$ , 63.2%) was male. Differences in age between siblings and their brother or sister with disabilities ranged from 16 years younger to 19 years older. Specifically, 14% of siblings were within 1 year of their brother or sister with disabilities, 57% of siblings were more than 1 year older than their brother or sister with disabilities, and 29% were more than 1 year younger than their brother or sister with disabilities. Almost half (49.7%) of the siblings reported their brother or sister had autism ( $n = 77$ ) and 97 (62.6%) reported intellectual disability; 19 (12.3%) of the brothers or sisters were identified as having both autism and intellectual disability. Additional co-occurring disabilities could also be noted (see Table 2); however, we did not ask participants to identify which disabilities were considered primary or secondary. The majority of the brothers and sisters with disabilities (77.4%) used speech as their primary mode

of communication, 13.5% used speech with limited words, 1.9% used a communication device, and 7.1% were nonverbal. Approximately half of all siblings (50.9%) said their brother or sister with disabilities *never* or *rarely* engaged in challenging behavior; the remainder indicated such behaviors occurred *sometimes* or *often*.

### **Recruitment**

After receiving IRB approval, we solicited recruitment assistance from organizations serving individuals with intellectual disability or autism in Tennessee (e.g., Arcs, Autism societies, Down syndrome associations, Special Olympics chapters, and smaller organizations). These organizations were asked to pass along our study invitation to families and individuals who had a brother or sister with an intellectual disability or autism. Fifty-nine organizations distributed information about the study: 38 sent out emails, 14 added information to a newsletter (electronic or paper), 11 shared it on social media (e.g., Facebook), 4 posted information on their website, and 3 organizations handed out information directly to family members (through a support group network or to families they worked with that qualified). [Methods of distribution add up to over 59 because some organizations shared the information through multiple mediums.] All invitations included a description of the study with instructions on how to take the online survey.

### **Instrument**

We asked siblings to complete a set of measures addressing (a) information about themselves and their brother or sister with disabilities, (b) the activities they do with their brother or sister with disabilities, (c) the strengths of their brother or sister with disabilities, (d) their expectations for their brother or sister with disabilities' future, and (e) the quality of their relationship with their brother or sister with disabilities. Data addressing sibling views of



strengths are reported elsewhere (Masked, 2018). The instrument was piloted with three siblings of individuals with intellectual disability or autism; minor revisions were made to survey items and general formatting.

**Demographics.** We asked siblings to report their age, sex, race/ethnicity, highest level of education, marital status, and number of children (if any). We also asked them to report the age, sex, and disabilities of their brother or sister. More than one disability category could be selected from a list of the 13 disability categories covered under the Individuals with Disabilities Education Improvement Act (2014); however, we did not request primary and secondary categories as we anticipated siblings would not know these distinctions. We asked siblings to report how their brother or sister with disabilities gets around (i.e., walking, wheelchair without assistance, wheelchair with assistance) and their primary mode of communication (i.e., speech, limited language, a communication device, or nonverbal). Siblings reported how often their brother or sister with disabilities “exhibits challenging behaviors (such as aggression, self-injury)” using a 4-point, Likert-type scale (i.e., *never, rarely, sometimes, often*). Finally, we asked if siblings currently lived with their brother or sister with disabilities and, if not, how far away they lived (i.e., 30 min, 30-60 min, 1-2 hrs, over 2 hrs).

**Shared activities.** We asked siblings to report on shared activities with their brother or sister with disabilities. This measure was adapted from prior studies focused on the community involvement of adolescents with severe disabilities (e.g., Carter et al., 2010). We listed 16 activities (e.g., going to the movies, going to the mall, volunteering; see Table 3) and asked siblings how many times they had participated in each activity with their brother or sister with disabilities during the past year. Two “other activity” options were included to account for unlisted activities. Siblings were not asked to write in a description of any other activities;

however, they could indicate how frequently they participated in the unnamed activity and with whom they participated. Response options for each activity item were 0 times, 1 time, 2 times, 3 times, 4 times, or 5 or more times. Cronbach's alpha for our sample was  $\alpha = .75$ . In addition, we asked siblings who else participated in each activity: just the two of us, with family, with friends, or with others (see Table 4). When participating in the same activity more than one time, the siblings could indicate as many of these fellow participants as was appropriate. For example, if a sibling went to the movies five times with their brother or sister, they could indicate this had happened with family only and also with friends, but never with others. From this information, we determined the total number of different activities siblings had done (a) alone with their brother or sister with disabilities, (b) done together with other family members, (c) done together with friends, and/or (d) done with others also present.

**Relationship quality.** We asked siblings a series of questions addressing the quality of their relationship with their brother or sister with disabilities (see Table 5 for specific survey questions). This measure was derived from the Positive Affect Index of relationship quality (Bengston & Black, 1973) and has been used to measure sibling relationships between siblings with and without disabilities (Hodapp & Urbano, 2007; Hodapp et al., 2010). Siblings rated the degree to which they understood, trusted, respected, loved, felt close to, and felt positive toward their brother or sister with disabilities (Cronbach's  $\alpha = .91$ ). Responses were provided on a 6-point Likert-type scale (1 = *not at all*, 2 = *not much*, 3 = *somewhat*, 4 = *pretty much*, 5 = *very much*, 6 = *extremely*). Cronbach's alpha for our sample was  $\alpha = .88$ .

**Expectations.** We asked siblings a series of eight questions addressing their expectations regarding their brother or sister with disabilities' future in the areas of living arrangements, postsecondary education, work, and relationships (see Table 6). Items were drawn from prior

studies addressing family expectations (e.g., Carter, Trainor, Ditchman, Swedeen, & Owens, 2011; Chambers, Hughes, & Carter, 2004; Griffin, McMillan, & Hodapp, 2010). Each item was rated on a 4-point Likert-type scale: 1 = *definitely no*, 2 = *probably no*, 3 = *probably yes*, 4 = *definitely yes*. If the expectation item was already met (i.e., the sibling with disabilities was currently living with family members), the sibling recorded 5 = *currently is*. Each of the five response options were mutually exclusive, so siblings who indicated their sibling *currently is* for any of the listed expectation items were not able to provide additional information about future expectations. Cronbach's alpha for our sample was  $\alpha = .61$ .

We placed the final survey online using a secure survey platform (REDCap; Harris et al., 2009). We estimated it took approximately 15-20 min to complete all measures. After submitting the survey, siblings were redirected to a separate survey in which they were given the option to fill out their name, address, phone number, and email address. Siblings could choose whether they wanted to be entered into a drawing for one of twenty \$25 gift cards and to receive a summary of the study findings. All contact information was kept separate from the actual survey to maintain confidentiality.

### **Data Analysis**

Once all data were exported from REDCap, we removed siblings who took the survey, but did not meet our inclusion criteria for this study (i.e., between ages 18-30 years old, had a brother or sister with an intellectual disability and/or autism). We also removed 34 surveys from siblings who did not complete any of the shared activity, relationship quality, and expectations sections. Missing data on the remaining 155 surveys was minimal (i.e., no items were skipped on the shared activities measure, no more than 2 participants skipped any item on the relationship quality measure, and no items were skipped on the expectations measure).

To determine how siblings spent time with their brother or sister with disabilities, we used descriptive statistics to summarize ratings on the shared activities measure. We computed a total activities rating based on the number of activities siblings reported they participated in with their brother or sister with disabilities at least one time. We then used this total activities variable to run independent samples *t*-tests to examine the extent to which the total number of activities participated in together differed based on multiple factors: the presence of autism, whether the respondent sibling was male or female, whether the brother or sister with disabilities was male or female, whether the brother or sister with disabilities used speech to communicate, and whether the two siblings lived together. We selected these factors based on prior studies indicating that gender, disability severity, autism diagnosis, and residential proximity can impact different aspects of sibling relationships (Greenberg, Seltzer, Orsmond, & Krauss, 1999; Orsmond, Kuo, & Seltzer, 2009; Orsmond & Seltzer, 2000; Orsmond & Seltzer, 2007; Rimmerman, 2001; Seltzer, Begun, Seltzer, & Krauss, 1991; Zetlin, 1986). To examine factors associated with total number of shared activities, we computed Pearson correlation coefficients to examine the strength of associations between total activities participated in together and continuous variables of interest (i.e., age of sibling respondent, age of brother or sister with disabilities, difference in age between siblings). When examining the correlation between total activities and severity of challenging behavior, we computed Spearman's rank-order correlation. Finally, we examined the correlation between the total number of activities siblings engaged in together and siblings' overall rating of quality of relationship.

## **Results**

### **How Do Siblings Spend Time Together?**

Descriptive statistics for item-level ratings are reported in Table 3. The most common

activities siblings reported doing together at any point in the past year were watching television (94.9%), talking on the phone (82.0%), and doing hobbies (71.6%). These activities tended to be more frequently undertaken than activities that occurred just one or two times (e.g., going to the movies, going to the mall, going to a concert). The least common activities reported by siblings (i.e., those never done together in the last year) included taking art, music, or dance lessons (92.3%); volunteering together (83.2%); and using the public library together (82.6%).

The other persons who joined the siblings when these activities took place varied widely (see Table 4). Overall, most activities tended to involve other persons in addition to the two siblings. For example, for fourteen of the sixteen activities we listed, more than 50% of the siblings reported engaging in the activity with additional family members present. Doing activities with friends or others was far less common. For example, with the exception of the activity hanging out with friends, 50% or fewer siblings reported spending time with their brother or sister with disabilities and additional friends for each of the remaining 15 activity items. With the exception of volunteering together, less than 20% of siblings reported spending time with their brother or sister with disabilities and others for the remaining 15 activity items. The activities most likely to be done between just the sibling and the brother or sister with disabilities were talking on the phone together; taking art, music, or dance lessons together; and other activity (not listed). Of note, only 12 of the 159 participants reported taking art, music, or dance lessons together at any time over the past year.

### **What Factors are Associated with Shared Activities among Siblings?**

Several factors were associated with differences in number of shared activities among siblings. When participating in activities—with or without any additional persons—siblings of brothers or sisters who were able to communicate using speech participated in significantly more

total activities with their brother or sister with disabilities ( $t = 2.77, p < .01$ ). Female siblings also participated in more total activities with their brother or sister with disabilities than male siblings ( $t = 2.18, p < .05$ ). As the difference in age between the sibling and their brother or sister with disabilities increased, sibling pairs participated in fewer activities together ( $r = -.16, p < .05$ ). Finally, siblings participated in fewer total activities with their brothers or sisters with disabilities who exhibited more challenging behavior ( $\rho = -.19, p < .05$ ) and fewer total activities with brothers or sisters who had autism ( $t = -2.35, p < .05$ ). Neither the age of the respondent nor the age of the brother or sister with disabilities were significantly correlated with the total number of activities the siblings participated in together. Likewise, sex of the brother or sister with disabilities, residence, and presence of intellectual disability were not associated with total activities participated in together.

When participating in activities as just a sibling pair (i.e., with no additional family, friends, or others), communication, age difference between the siblings, presence of challenging behavior, and presence of autism continued to be significant factors impacting the total number of activities participated in together. Additionally, as the age of the brother or sister with disabilities increased, the more likely the siblings participated in activities together ( $r = .21, p < .05$ ). The age of the sibling, the sex (of sibling or brother or sister with disabilities), residence, and presence of intellectual disability were not associated with the number of shared activities. When participating in activities with additional family members, the only associated factor with fewer total activities was challenging behavior ( $\rho = -.17, p < .05$ ).

### **How Do Siblings Describe Their Relationships with Their Brothers and Sisters?**

Overall, siblings described their relationships in positive ways. When asked how close they felt in their relationship with their brother or sister with disabilities, more than three quarters

of siblings (79.1%) said *pretty much to extremely*. When asked about the extent to which their relationship was mostly positive, more than four fifths (86.9%) said *pretty much to extremely*. Items addressing how much they could understand, trust, were fair toward, respect, and feel affection for their brother or sister with disabilities were also positive, with more than three quarters of siblings providing these high ratings. Of note, siblings who spent more time together reported more positive quality relationships. Total number of activities participated in together at least once and with any additional person were significantly correlated with each of the 7 quality of relationship survey items (Respect, Affection, Fair, Understand, Trust, Close, Overall positive relationship).

Siblings who reported their brother or sister with disabilities engaged in challenging behavior more frequently reported less positive quality relationships ( $\rho = -.28, p < .01$ ). Additionally, we found that siblings of brothers and sisters with autism reported less positive quality relationships ( $t = -2.54, p < .05$ ) than siblings of brother and sisters with intellectual disability. There were no statistically significant differences in relationship quality between sex (of sibling or brother or sister with disabilities), communication mode, or residence. Likewise, age of sibling, age of brother or sister with disabilities, and sibling age difference were not significantly correlated with relationship quality.

### **What Expectations Do Siblings Hold Regarding Their Brothers' and Sisters' Futures?**

Only 14.8% of all siblings recorded that their brother or sister with disabilities (ages 3-46) currently had a paid job in the community. (For siblings whose brothers or sisters with disabilities were at least age 18 years, 20.8% reported they currently had a paid job in the community.) Among the remaining siblings whose brothers or sisters were not currently working, 56.1% responded with *definitely yes* or *probably yes* when asked if they expected their

brother or sister with disabilities to have a paid job in the community. In terms of having a volunteer job in the community, 7.7% of siblings reported their brother or sister with disabilities currently had this experience. Among the remaining siblings, 51.0% responded with *definitely yes* or *probably yes* when asked whether they expected their brother or sister with disabilities to have a volunteer job in the community in the future. Only 3.9% of brothers or sisters with disabilities currently worked in sheltered workshops. Among the remaining siblings, 21.9% responded with *definitely yes* or *probably yes* when asked whether they expected their brother or sister with disabilities to work in a sheltered workshop in the future. Finally, 3.9% of brothers and sisters with disabilities were currently attending college. Among the remaining siblings, 22.0% responded with *definitely yes* or *probably yes* when asked whether they expected their brother or sister with disabilities to attend college in the future.

Expectations surrounding living arrangements varied. About half (49.7%) of the brothers or sisters with disabilities currently lived with family. Among the remaining siblings, 32.2% responded *definitely yes* or *probably yes* when asked if they expected their brother or sister to live with family members in the future. In terms of other living options, 20.7% of siblings said *definitely yes* or *probably yes* when asked if they expected their brother or sister with disabilities to live independently; 25.8% said *definitely yes* or *probably yes* when asked if they expected their brother or sister with disabilities to live in a group home in the future. Of note, there was no significant correlation between any expectation item and the overall quality of the sibling relationship. However, the expectation for independent living item ( $r = -.22, p < .01$ ) and the expectation for marriage item ( $r = -.20, p < .05$ ) were both significantly negatively correlated with total number of activities participated in together.

## **Discussion**



Since the early 1980s there has been a steady growth in the number of published studies focused on siblings of individuals with disabilities (Stoneman, 2005). Our work extends the sibling literature by focusing on the relationships of young adults (ages 18-30) and their brothers and sisters with intellectual disability or autism. Specifically, we sought to understand the specific activities siblings engaged in together, the factors associated with this engagement, how siblings viewed the quality of their relationship with their brother or sister with disabilities, and the expectations siblings hold for their brother or sister with disabilities. We highlight several ways this study extends the sibling literature and offer future directions for research.

First, siblings with and without disabilities spent time together participating in a wide range of activities. Of the 155 young adult siblings, all reported they had participated in at least one of the 16 activity items with their brother or sister. Further, more than half of siblings reported participating in at least 8 of the 16 activity items with their brother or sister with disabilities at least once. This finding is consistent with other studies focused on how siblings with and without disabilities of all ages engage with one another (Abramovitch, Stanhope, Pepler, & Corter, 1987; Lobato, Miller, Barbour, Hall, & Pezzullo, 1991; McHale & Gamble, 1989; Stoneman, Brody, Davis, & Crapps, 1989), reiterating that siblings are a present part of the lives of individuals with intellectual disability or autism.

The combination of shared activities was different for every sibling pair. However, the most common activities were those done in the home (i.e. talking on the phone, watching TV). Conversely, siblings reported spending the least amount of time together participating in activities done in the community (i.e. art, music, or dance lessons; volunteering; public library). It is possible that activity location or context was a factor in how siblings spent time together, as has been suggested in past research (Brody, Stoneman, Davis, & Crapps, 1991; Stoneman et al.,

1989). Additionally, activities in the community might require more planning or take more time. It is also possible that young people are no longer going to the public library or volunteering very often regardless. Further research is needed to understand the types of activities that siblings participate in regularly, independent of time spent with their brother or sister with disabilities.

Second, several factors were associated with spending less time together. The number of different shared activities was lower when the brother or sister had more limited speech and when the brother or sister engaged in challenging behavior more frequently. Characteristics such as limited speech and increased challenging behavior may serve as indicators of disability severity and could make accessing community activities more difficult. The majority of the activity options presented in the survey require supports for a person who is not able to communicate or engages in disruptive or aggressive behavior. With higher support needs, it is possible that siblings do not feel equipped to support their brother or sister independently. For example, siblings were more likely to engage in the activity if additional family members were present for 14 out of the 16 activity options.

In addition, the total number of activities was significantly lower when there was a larger age difference between the siblings, when the sibling of the brother or sister with disabilities was male, and when the brother or sister with disabilities had autism. It is reasonable that a larger difference in age may make it more difficult for siblings to participate in more activities together. As the older sibling ages and moves out of the family home, it is likely that there are less natural opportunities to engage as a sibling pair. Our finding that male siblings are less likely to spend as much time with their brother or sister with disabilities as female siblings (regardless of the brother or sister's sex) is consistent with literature that has found sisters tend to have closer relationships with their sibling with a disability (Greenberg et al., 1999; Hodapp, Urbano, &

Burke 2010; Krauss et al., 1996; Orsmond & Seltzer, 2000; Stoneman, 2001). Finally, our finding that siblings of individuals with autism have less close relationships than siblings of individuals with intellectual disability is consonant with past research (Hodapp & Urbano, 2007; Tomeny et al., 2017).

Third, the majority of siblings viewed their relationships with their brother or sister with disabilities positively. For example, when asked whether their relationship with their brother or sister with disabilities was mostly positive, 86.9% of siblings responded *pretty much*, *very much*, or *extremely*. This portrait is consistent with past studies that have provided evidence of positive views of brother or sisters with disabilities (Hodapp et al., 2010; Kaminsky & Dewey, 2001; McHale, Sloan, & Simeonsson, 1986; Rivers & Stoneman, 2003; Roeyers & Mycke, 1995). However, there were a few factors that were associated with lower quality relationship. Namely, the presence of autism and challenging behaviors. Previous literature has found that siblings of individuals with autism generally report less positive sibling attitudes and poorer quality relationships (Hodapp & Urbano, 2007; Tomeny et al., 2017). This supports our finding of a positive correlation between the total number of activities participated in together and the quality of the sibling relationship. Although we do not know the direction of influence of this correlation, it may be that the relationship is cyclical: with more time spent together relationship quality improves, and as the quality improves, siblings want to spend more time together. More research is needed to further understand this relationship. The quality of the young adult sibling relationship between individuals with and without disabilities is important in considering outcomes for the sibling without disabilities. As individuals with disabilities live longer, many siblings will take on a more active role in the lives of their brother or sister. Understanding the

relationship quality and closeness of sibling pairs over time could aid in a better transition from sibling to caretaker for both the individual with disabilities as well as the sibling.

Fourth, the future expectations of siblings were moderate and mixed. Most siblings felt their brother or sister with disabilities would obtain a paid job in the community. Previous research on expectations from parents, teachers, and individuals with disabilities themselves have suggested that higher expectations are associated with better outcomes (Doren et al., 2012). Although the impact of sibling expectations has not yet been studied, their expectations may also have an influence on future positive outcomes, particularly if siblings plan on transitioning to a surrogate-parent role over time. On a less positive note, our findings also indicate the majority of siblings did not expect their sibling to get married or go to college (76.7% and 78.4%, respectively). We do not, however, know why siblings felt this way.

### **Limitations**

Several limitations to this study should be considered. First, our recruitment efforts were disseminated primarily through disability organizations and agencies. Siblings who have some level of involvement with these groups may be different from siblings who do not. Second, our sample was limited in geographical and demographic diversity. Siblings were mostly white, single, females from just one state. Older siblings might have offered a different perspective. Third, our survey only captured the perspective of a single sibling. The perspective of one sibling does not give a full picture of family dynamics or reflect the views of all siblings in a family (Hodapp, Glidden, & Kaiser, 2005). Fourth, no exhaustive list of siblings exists, and therefore we cannot discern whether these findings would be representative of all siblings in our state. Fifth, we relied on siblings for descriptions and characteristics of their brother and sisters. It is possible that they did not have accurate knowledge to answer the questions we asked about their

brother or sister with disabilities, including accurate or complete disability categories. Sixth, we do not know how the siblings with disabilities viewed these relationships or whether the views collected by our survey were reciprocated. By excluding the perspective of the individual with disabilities, our findings are limited to statements about quality of relationship from a singular sibling's perspective.

### **Implications for Practice**

Our findings have implications for practice. First, we found that siblings spent a substantial amount of time together (more than 50% of siblings reported participating in at least 8 of the 16 activity items with their brother or sister with disabilities at least once). Moreover, the large majority of siblings in our study felt they had a positive quality relationship with their brother or sister with disabilities. These findings suggest that many siblings may know their brother or sister with disabilities quite well. However, siblings are rarely involved in formal school or service plans. If siblings are going to take on a caregiving role for their brother or sister at some point in their adult lives, it may be valuable to include them in person-centered planning events earlier on. Such involvement may help equip siblings in ways that make them stronger, more knowledgeable advocates for later life decisions.

Second, it is important that siblings have appropriate information about available supports in their community. Parents are often the sole recipients of information about available activities and supports in the community. Further, siblings might be overlooked by the family support service system, particularly if an adult sibling has moved from the family home (Floyd, Costigan, & Richardson, 2016). But siblings, especially older siblings who may have the ability to drive, can be another important person to support community inclusion for the brother or sister with disabilities. Our findings show there is a positive relationship between the number of

activities participated in together and the quality of the sibling relationship. If schools and community programs better equip siblings with information about community resources we may find that siblings are able to improve the quality of their relationship.

### **Future Research**

This study highlights several avenues for future research. First, future studies are needed to assess sibling knowledge of resources and supports that already exist. If siblings knew about agencies or organizations that could help them to participate actively in their community with their brother or sister with disabilities, it is possible we could see a rise in the number of community activities siblings participate in together. Second, it would be important to know where resources are housed. If resources are housed mostly in urban areas, community participation in rural areas may be more difficult. Finally, further studies should collect more information about the other factors that might shape participation in activities, such as financial/economic resources, geographic locale, and access to transportation.

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Table 1  
*Demographics of Participant Siblings of Individuals with Disabilities*

Variable	<i>n</i> (%)
Age	
18	19 (12.3)
19	12 (7.7)
20	12 (7.7)
21	18 (11.6)
22	19 (12.3)
23	11 (7.1)
24	16 (10.3)
25	6 (3.9)
26	8 (5.2)
27	2 (1.3)
28	10 (6.5)
29	7 (4.5)
30	15 (9.7)
Sex	
Female	122 (78.7)
Male	33 (21.3)
Race/ethnicity	
African American	10 (6.5)
Hispanic	5 (3.2)
Pacific Islander	1 (.6)
White/Non-Hispanic	137 (88.4)
Other	2 (1.3)
Highest level of education	
Currently in high school	9 (5.8)
High school diploma	44 (28.4)
Associate's degree	13 (8.4)
Bachelor's degree	65 (41.9)
Master's degree	18 (11.6)
Doctoral degree	6 (3.9)
Marital status	
Divorced	4 (2.6)
Living as married	7 (4.5)
Married	26 (16.8)
Single	118 (76.1)
Do they have children?	
No	141 (91.0)
Yes	14 (9.0)
Living arrangement	
Live in the same house as sibling with disability	53 (34.2)
Live within 2 hours of sibling with disability <sup>a</sup>	46 (45.1)

<sup>a</sup>Number and percentage were calculated from the remaining 102 participants who did not live with their sibling with a disability.

Table 2  
*Demographics of Brothers and Sisters with Disabilities*

Variable	<i>n</i> (%)
Age	
1-5 years	2 (1.2)
6-10 years	4 (2.5)
11-15 years	24 (15.5)
16-20 years	51 (33.0)
21-25 years	40 (25.8)
26-30 years	23 (14.8)
31-35 years	9 (5.8)
36+ years	2 (1.2)
Sex	
Female	57 (36.8)
Male	98 (63.2)
Disability category <sup>a</sup>	
Autism	77 (49.7)
Deafblindness	2 (1.3)
Deafness	2 (1.3)
Emotional disturbance	10 (6.5)
Hearing impairment	8 (5.2)
Intellectual disability	97 (62.6)
Multiple disabilities	17 (11.0)
Orthopedic impairment	7 (4.5)
Other health impairment	18 (11.6)
Specific learning disability	27 (17.4)
Speech or language impairment	40 (25.8)
Traumatic brain injury	0 (0.0)
Visual impairment (including blindness)	7 (4.5)
Mobility	
Gets around without assistance	150 (96.8)
Uses a wheelchair independently	1 (1.6)
Uses a wheelchair with assistance	4 (2.6)
Communication style	
Non-verbal	11 (7.1)
Talks	120 (77.4)
Talks, but uses limited words	21 (13.5)
Uses a communication device	3 (1.9)
Occurrence of challenging behaviors	
Never	36 (23.2)
Rarely	43 (27.7)
Sometimes	62 (40.0)
Often	14 (9.0)

<sup>a</sup>Multiple options could be selected but inclusion criteria required the sibling to have autism or intellectual disability; categorization of primary and secondary disability was not requested

Table 3  
*Frequency of Shared Activities Among Siblings With and Without Disabilities*

Activities	% selecting response					
	0 times	1 time	2 times	3 times	4 times	5+ times
Watching television together	5.2	1.9	5.2	5.8	2.6	79.4
Talking on the phone together	18.1	1.9	3.9	3.9	1.3	71.0
Doing hobbies together	28.4	10.3	14.2	9.7	4.5	32.9
Going grocery shopping together	36.1	11.0	14.2	6.5	0.6	31.6
Other activity together (not listed)	37.4	2.6	5.2	11.6	1.9	41.3
Going to the movies together	36.1	21.9	20.6	5.8	5.8	9.7
Going to the mall together	38.7	17.4	14.8	9.7	4.5	14.8
Hanging out with friends together	47.7	5.8	14.8	9.0	3.9	18.7
Attending a faith community activity together	49.7	7.1	5.8	7.1	1.3	29.0
Playing sports together	68.4	7.1	7.7	3.9	0.6	12.3
Other activity together (not listed/different from above)	70.3	2.6	1.9	3.2	1.9	20.0
Going to a community recreation center together	72.9	9.0	5.2	3.9	1.3	7.7
Going to a concert together	76.1	9.7	11.6	1.3	0.6	0.6
Using the public library together	82.6	5.8	7.1	2.6	0.0	1.9
Volunteering together	83.2	5.8	5.2	2.6	0.0	3.2
Taking art, music, or dance lessons together	92.3	3.2	1.3	1.3	0.0	1.9

Table 4  
*Participants in Shared Activities Among Siblings With and Without Disabilities*

Activities	% participated at least once	% selecting response <sup>a</sup>			
		Only the siblings	Also with family	Also with friends	Also with others
Talking on the phone together	81.9	85.8	33.9	2.4	0.8
Taking art, music, or dance lessons together	7.7	66.7	33.3	25.0	0.0
Other activity together (not listed)	62.6	55.7	78.4	33.0	13.4
Watching television together	94.8	54.4	86.4	27.2	4.8
Doing hobbies together	71.6	53.2	70.3	24.3	9.0
Going grocery shopping together	63.9	49.5	74.7	4.0	3.0
Playing sports together	31.6	38.8	71.4	26.5	10.2
Using the public library together	17.4	37.0	55.6	7.4	3.7
Going to a community recreation center together	27.1	35.7	66.7	19.0	4.8
Other activity together (not listed/different from above)	29.7	37.0	78.3	21.7	10.9
Going to the mall together	61.3	35.8	84.2	17.9	2.1
Going to the movies together	63.9	32.3	82.8	28.3	1.0
Going to a concert together	23.9	16.2	70.3	40.5	0.0
Hanging out with friends together	52.3	13.6	65.4	75.3	6.2
Volunteering together	16.8	11.5	65.4	38.5	30.8
Attending a faith community activity together	50.3	6.4	96.2	33.3	16.7

<sup>a</sup>Multiple options could be selected

*Note.* Percentages are based on the number of participants who participated at least once for each activity item.



Table 5  
*Sibling Views on the Quality of their Relationships*

Items	% selecting each response						<i>M (SD)</i>
	Not at all (1)	Not much (2)	Somewhat (3)	Pretty much (4)	Very much (5)	Extremely (6)	
How much do you RESPECT your brother/sister?	0.0	3.9	8.5	10.5	30.1	47.1	5.08 (1.13)
How much AFFECTION do you have toward your brother/sister?	0.0	5.3	7.2	14.5	26.3	46.7	5.02 (1.18)
How FAIR do you feel you are toward your brother/sister?	1.3	2.6	11.8	26.1	35.9	22.2	4.59 (1.12)
How much do you UNDERSTAND your brother/sister?	0.0	3.9	17.6	17.0	38.6	22.9	4.59 (1.14)
How much do you TRUST your brother/sister?	2.6	7.8	9.8	19.6	31.4	28.8	4.56 (1.35)
Taking everything into consideration, how CLOSE do you feel in your relationship between you and your brother/sister?	0.7	8.5	11.8	20.3	26.1	32.7	4.61 (1.31)
In general, to what extent do you think that your relationship with your brother/sister with disabilities has been mostly POSITIVE?	0.7	4.6	7.8	18.3	26.8	41.8	4.92 (1.20)

*Note.* Percentages are based on the number of participants who completed each item.

Table 6  
*Expectations for Sibling with a Disability*

Items	% selecting each response				<i>M (SD)</i>	Currently is
	Definitely yes (1)	Probably yes (2)	Probably no (3)	Definitely no (4)		
<b>Employment expectations</b>						
I expect my sibling to have a paid job in the community.	16.1	40.0	19.4	9.7	2.27 (0.90)	14.8
I expect my sibling to have a volunteer job in the community.	8.4	42.6	32.3	9.0	2.45 (0.79)	7.7
I expect my sibling to go have a job at a sheltered workshop.	1.9	20.0	49.7	24.5	3.01 (0.74)	3.9
<b>Residential expectations</b>						
I expect my sibling to live with family members.	16.1	16.1	12.3	5.8	2.15 (1.01)	49.7
I expect my sibling to live independently.	2.6	18.1	46.5	28.4	3.05 (0.77)	4.5
I expect my sibling to live in a group home.	2.6	23.2	34.8	36.1	3.08 (0.85)	3.2
<b>Other expectations</b>						
I expect my sibling to go to college.	11.0	11.0	32.3	41.9	3.09 (1.00)	3.9
I expect my sibling to get married.	5.8	18.1	32.9	40.6	3.11 (0.91)	2.6

*Note.* Percentages for the four response items “Definitely yes”, “Probably yes”, “Probably no”, and “Definitely no” were calculated after excluding participants who selected “currently is”