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Sibling Relationships of Adults with Intellectual and Developmental Disability

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Sibling Relationships of Adults with Intellectual and Developmental Disability

Submitted by Cecile M. Kudela
May, 2012

MSW Clinical Research Paper

The Clinical Research Project is a graduation requirement for MSW students at St. Catherine University/University of St. Thomas School of Social Work in St. Paul, Minnesota and is conducted within a nine-month time frame to demonstrate facility with basic social research methods. Students must independently conceptualize a research problem, formulate a research design that is approved by a research committee and the university Institutional Review Board, implement the project, and publicly present their findings. This project is neither a Master's thesis nor a dissertation.

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Abstract

This is a small, qualitative study about the lived experiences of adult siblings of individuals with intellectual and/or developmental disabilities (I/DD). Previous research has focused primarily on the caregiving experiences of parents with adult children with I/DD. However, as people are living longer, healthier lives, it is increasingly becoming the role of adult siblings to support their brother or sister with I/DD. The purpose of this study was to explore the lived experience of siblings of adults with I/DD regarding decision-making around quality of life and end-of-life. The goals of this study were to 1) contribute to the literature on the relationships of siblings and adults with I/DD, 2) discover ways to support families of adults with I/DD, 3) add to the conversation on end-of-life care for adults with I/DD and 4) develop ideas for further research in these areas that will support social workers who work with individuals who have I/DD and their families. This study included nine participants who are currently involved in supporting their sibling with I/DD. Findings of this study include that the kind of support siblings provide is guided by, yet different from, the support provided by their parents. Also, that siblings use their relationship and values to guide decisions about quality of life and, ultimately, end-of-life for their sibling with I/DD.

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Sibling Relationships of Adults with Intellectual and Developmental Disability

Introduction

Intellectual and developmental disability

Individuals with an intellectual and developmental disability (I/DD) are living longer, often healthier, lives than ever before. In 2004 it was estimated that there were 641,000 persons over the age of 60 with intellectual and developmental disabilities living in the United States (Heller & Factor, 2004). This number is expected to increase to 1.5 million people by the year 2030 (National Center for Family Support as cited in Hodapp, Urbano, & Burke, 2010). This is a small but significant percentage of the projected 71 million older adults who will be aged 65 and older in 2030 (Administration on Aging, 2010).

Improvements in access to health care, better living conditions, and medical advances have contributed to an increase in average life expectancy (Griswold & Goldstein, 1999; Heller & Factor, 2004; U.S. Department of Health and Human Services, 2007). The average life expectancy for people in the United States increased to 78 years in 2007 (Miniño, Xu, Kochanek, & Tejada-Vera, 2009). For individuals with I/DD, life expectancy ranges from the mid-50s for persons with Down syndrome or other severe disabilities, to the mid-70s for persons with mild/moderate I/DD (Heller & Factor, 2004). These increases have greatly impacted families who now have a longer period of caregiving and providing support to their family member with an intellectual and developmental disability.

Whose role is it, anyway?

In 2010, The Arc conducted a national survey entitled the Family and Individual Needs for Disability Supports (FINDS) that examined issues faced by caregivers of persons with I/DD. The Arc is the organization formerly known as The Association for Retarded Citizens of the United States. The Arc advocates on behalf of individuals with I/DD and their families, promoting the inclusion and participation of individuals with I/DD in the community across the lifespan. The questions in the FINDS survey covered education, employment opportunities, types of services and supports available, as well as the economic impact for families supporting a person with I/DD. The data includes nearly 5,000 respondents who represent all 50 states and the District of Columbia. Findings indicated that 58% of respondents who are the primary caregiver for persons with I/DD are between the ages of 51 and 79 (The ARC, 2011). While this study did not identify the age of the person being supported, other researchers have estimated that 60% of older adults with I/DD are currently living with their parents in their parents' home.

Additionally, 25% of older adults with I/DD live with a parent who is age 60 or older (Heller & Factor, 2004; Hodapp et al., 2010). As the health of the aging parent declines, it is unclear who will accept the role of primary caregiver for the adult child with I/DD who is still living at home. Research suggests that many parents have not made future plans regarding living arrangements for the adult child with I/DD nor made plans for who will provide support (Dillenburger & McKerr, 2011; The Arc, 2011). As aging adults with I/DD outlive their parents, who will provide the primary source of support and care?

The sibling relationship is the longest and most enduring relationship across the lifespan (Cicirelli, 1995 as cited in Doody, Hastings, O'Neill & Grey, 2010; Heller & Kramer, 2009; Myers, 2011; Rimmerman & Raif, 2001; Stewart et. al, 2001). Studies

have shown that it is often a sibling (or siblings) who takes on the support role in the life of a person with I/DD when the parent is no longer able to (Griffiths & Unger, 1994). There is little research on how siblings support their brother or sister with I/DD. Adults with I/DD and their family members who support them have to make decisions about living arrangements, least restrictive environments, access to transportation, opportunities for vocational and/or leisure programs, guardianship or conservatorship, and financial planning, as well as make decisions about medications, treatments, and quality of life (Heller & Caldwell, 2006). In the absence of a parent, it is the role of the sibling to help make these decisions and provide support. But they cannot do it alone. Sixty-five percent of families in The Arc's FINDS study reported that they need more help with future planning for their family member with I/DD.

Social workers are often involved in all stages of this process as both case managers and clinicians. Social workers support individuals with I/DD and their families and work in community-based programs, group homes, care facilities and nursing homes where individuals with I/DD live. Social workers are among the healthcare professionals being asked to facilitate conversations about end-of-life using tools like the new Honoring Choices program in Minnesota, or other advance care planning programs (Baxley, Janicki, McCallion, & Zendell 2006; Botsford, 2000; Honoring Choices Minnesota, 2012; Minnesota Governor's Council on Developmental Disabilities, 2011).

The purpose of this study is to explore the lived experience of siblings of adults with I/DD regarding decision-making around quality of life and end-of-life. Specifically, the researcher is interested in finding out how siblings define quality of life for their brother/sister with I/DD, and how this definition impacts end-of-life decision-making.

The goals of this study are to 1) contribute to the literature on the relationships of siblings and adults with I/DD, 2) discover ways to support families of adults with I/DD, 3) add to the conversation on end-of-life care for adults with I/DD and 4) develop ideas for further research in these areas that will support social workers who work with individuals who have I/DD and their families.

Literature Review

As parents age, siblings often take over the role of caregiver for adults with I/DD. Just as parent roles and sibling roles are different, so too are the kinds of caregiving roles that they fulfill. As the adult with I/DD ages, decisions about quality of life and even end-of-life need to be considered. Studies have shown that while parents express interest in having conversations about future planning with their non-disabled adult children, this conversation rarely happens (Dillenburger & McKerr, 2011; Heller & Kramer, 2009; The Arc, 2011). A review of the literature on family caregiving, sibling relationships and future planning for adults with I/DD will help frame the current study on adult sibling relationships of persons with I/DD.

Parents As Caregivers

One definition of a family caregiver is a spouse, parent, sibling, partner, or friend who has a personal relationship with the older adult who has a chronic or disabling condition and is not paid for his/her caregiving (Heller, Hsieh, & Rowitz, 1997). Sixty percent of adults with I/DD are currently living with their parents in their parent's home (Hodapp et al., 2010). These parents are the primary caregivers for their adult children. As both parents and children age, the parents may become less able to continue to provide support for their adult child with I/DD. Declining health, caregiver stress, and an

increase in the physical demands of providing personal cares like bathing dressing, and feeding all contribute to this inability to provide the level of caregiving needed by the adult child (The Arc, 2011; Dillenburg & McKerr, 2011; Mirfin-Veitch, Bray, & Ross, 2003). The work of a caregiver is not easy. Parents and families reported spending an average of 41 hours a week providing care for a family member with I/DD (The Arc, 2011, Evercare & National Alliance for Caregiving, 2006). In addition, caregiving can have negative effects on both the mental and physical health of the caregiver (Centers for Disease Control and Prevention, 2009; Yamaki, Hsieh, & Heller, 2009). In the FINDS study, over 80% of family caregivers reported suffering from physical fatigue, emotional stress, and emotional upset (The Arc, 2011).

While there is a great deal of research on family caregiver burden (Grant & Ramcharan, 2001), caregivers also feel a sense of satisfaction. In their study comparing the experiences of younger and older caregivers of children with I/DD, Heller, Miller and Factor (1997) concluded that caregiver burden and caregiver satisfaction are different factors and not two ends of the same continuum. They found that parents could identify both the burdens as well as the rewards of caregiving. Parents continue to provide support and caregiving for their adult child with I/DD because they find the role fulfilling. Older mothers and fathers in a study by Heller, Miller and Factor (1997) stated that their son/daughter helped keep them from feeling lonely and shared activities that they enjoyed. Other researchers have identified that there is a reciprocal relationship between older mothers and their son/daughter with I/DD (Greenberg, Seltzer, & Greenley, 1993; Pruchno, 2003). In a study comparing the experiences of older mothers of an adult child with a mental illness to those with I/DD, mothers of I/DD individuals were more likely to

report that they relied on their child to provide them with support (Greenberg et al., 1993). This support can be either functional (help with household chores like laundry, cooking, shopping, and cleaning) or emotional. Pruchno (2003) found that mothers who needed more help with household chores could rely on their son/daughter with I/DD to provide it. The relationship between older parents and their adult children with I/DD can be described as symbiotic with each contributing to the well-being of the other.

Several studies have examined the role of parents as caregivers for their adult child with I/DD (Dillenburger & McKerr, 2011; Gilbert, Lankshear, & Petersen, 2008; Hayden & Heller, 1997; Pruchno, Patrick, & Burant, 1996). Parents make a commitment to provide financial, emotional, and physical support to their child with I/DD across the child's lifespan (Heller, Miller et al., 1997). Studies indicate that 60% of adults with I/DD are currently living with their parents in their parents' home (Hodapp et al., 2010). Many of these parents take on this lifetime caregiving role by choice. For example, a study that included 41 parents with an average age of 60 found that just over 80% believed it was their responsibility to act as primary caregiver to their adult child with I/DD as long as they were able (Griffiths & Unger, 1994). However, studies have also shown that older parents are not always aware of their own declining health. For example, a study by Dillenburger and McKerr (2011) that included caregivers with an average age of 65 years found that 76% described their health as good or fair even though they also reported suffering from significant health problems. Another study found that older caregivers perceived themselves as being healthier than other individuals their age (Yamaki et al., 2009). This disparity between perceived good health and actual poor health may

contribute to older parents' failure to do future planning for their son or daughter with I/DD.

While both parents contribute to the care and support of the child with I/DD, mothers spend more time with the child and feel more of the burden of caregiving (Heller, Hsieh, & Rowitz, 1997). Research indicates that women most often fill the role of primary caregiver in the life of an individual with I/DD (Conway-Giustra, Crowley, & Garin, 2002; Heller, et al., 1997; Mirfin-Veitch et al., 2003; Pruchno, 2003). While fathers contribute to the care and support of the child with I/DD, mothers spend more time with the child and feel more of the burden of caregiving (Essex, Seltzer, & Krauss, 1999; Heller, et al., 1997). One study indicated that mothers continue to experience some level of caregiver burden even after their child has left the family home (Miltiades & Pruchno, 2001). This may be due to several factors including the loss of support from the adult child with I/DD (Heller et al., 1997b).

Family Caregiving

As has already been discussed, parents have a strong influence on the role that adult siblings will take in the lives of their brother/sister with I/DD. Bigby (1998) indicates that sibling roles are associated with parental expectations. Eriksen and Gerstel (2002) found that siblings with at least one living parent were more active in their support of their adult brothers and sisters than those without a living parent. This conclusion is supported in a qualitative study of adult sisters who are the primary caregivers for an adult sibling with I/DD. The women in the study accepted that it was their role to care, just as it had been their mother's role before them (McGraw & Walker, 2007). Those studying the relationship between older mothers and their adult child with I/DD reached a

similar conclusion. They found that it is important to involve siblings of the individual with I/DD as family caregivers early so that they are prepared for the role as adults (Pruchno et al., 1996).

Other studies have looked at the nature of caregiving through the lens of family. Knox and Bigby (2007) looked at families of individuals with I/DD across the lifespan. They found the families in their study to be interdependent, flexible, and open to changing roles and responsibilities, especially as related to care for the individual with I/DD. Decisions around caregiving and decision-making were referred to as “family business” by one family in the study (Knox & Bigby, 2007, p. 287). They defined family business as “an aspect of ordinary family life” (p. 293). Families make hard choices about care for the child/sibling with I/DD. A study from New Zealand focused on families who had made the choice to place a child with I/DD in an out of home placement. This qualitative study includes interviews from several families prior to, during, and following the placement. Families put off placement for as long as they could, with mothers providing care for all of the children, until an event such as the birth of another sibling or an illness in the family disrupted the balance of care. Adult siblings, who recalled events from their childhoods with their I/DD sibling, stated that while they supported their parents’ decision; they continued to struggle with the reality that their sibling had been institutionalized (Mirfin-Veitch et al., 2003). This suggests that siblings bear the burden of family decision-making about caregiving for the individual with I/DD. Dew, Balandin and Llewellyn (2008) sum it up best when they suggest that being a sibling to an individual with I/DD is a family role, not a solitary one.

Adult Sibling Relationships

Siblings share both a common parent and the longest, most enduring relationship. The connection between brothers and sisters has been described in the literature as involuntary, obligatory, or forced (Martin, Anderson, & Rocca, 2005). Yet, there is a bond between brothers and sisters that is maintained and nurtured throughout an individual's life. In a review of the literature on the psychosocial impact of having a sibling with a long-term disability, Dew et al., (2008) conducted a meta-analysis that included 17 studies of children and four of adults with a physically disabled sibling. The researchers concluded that when siblings are asked to report on their relationships, they most often identify the positive impact of having a brother/sister with a disability. This is in contrast to the literature on children that focuses on the negative impact of having a sibling with a disability. For example, a meta-analysis of the research on siblings of individuals with I/DD found a statistically significant negative effect on the functioning of the non-disabled sibling (Rossiter & Sharpe, 2001). One explanation for this difference is that with younger siblings, the parents are reporting on the interaction between their disabled and non-disabled offspring (Flaton, 2006).

Studies of adult sibling relationships identify both positive and negative aspects of having a sibling. For example, Bevan and Stetzenbach (2007) looked at the expression of jealousy among siblings in their early adult years. Martin, Anderson and Rocca (2005) were interested in the use of verbal aggressions by siblings and their impact on the quality of the sibling relationship. Both of these studies advance the idea that there are negative aspects of the adult sibling relationship. In contrast, findings from a study of adult siblings across the lifespan indicate that siblings remain a part of each other's social networks well into old age (White, 2001). White and Riedmann (1992) analyzed a sample

of nearly 8,000 respondents from the National Survey of Families and Households conducted in 1987-88. They found that approximately half of the adults surveyed reported talking to or seeing a sibling at least once a month. Another two-thirds stated that they considered one of their siblings to be a close friend. When both the positive and negative aspects of the relationship are considered, it can be concluded that adult sibling relationships are complex and nuanced.

Adult sibling relationships of individuals with I/DD are not very different from typical adult sibling relationships. For example, siblings of adults with and without I/DD did not differ in the areas of conflict, rivalry, and critical expressed emotion (Doody et al., 2010). In addition, siblings of adults with I/DD often benefit from their role as sibling (Hodapp et al., 2010; Stoneman, 2005). A recent study found that participants with a sibling with I/DD had more contact with their sibling than a control group with non-disabled siblings. The researchers also identified that the contact for the control group participants was more likely to be via telephone while contact between adults and their disabled sibling was in person (Doody et al., 2010).

One question that comes up in the research is why siblings maintain their relationships into adulthood. Myers (2011) determined that siblings maintain their relationships for two overarching reasons: circumstance or choice. Circumstance included siblings living near one another and being family. Research on adult sibling relationships of both disabled and non-disabled individuals supports this. For example, White and Riedmann (1992) found that siblings who live within a 300-mile radius are more likely to have contact with one another. Another study concluded that it is easier for adults with a brother or sister with I/DD to maintain their relationship because they tend to live

geographically closer (Doody, et al., 2010; Taylor, Greenberg, Seltzer, & Floyd, 2008). It follows that siblings who live closer have more opportunities to do things together.

In Myers' (2011) study, choice was the other reason identified for adults to maintain sibling relationships. Choice included loving each other, providing support to each other, sharing similar interests or experiences, being friends, and being relationally close (Myers, 2011). This fits with the normative definition of a sibling relationship as egalitarian, mutual, and reciprocal (Seltzer, Greenberg, Orsmond & Lounds, 2005).

White (2001) found that the rate at which adults give and receive support to their siblings dips in middle adulthood and rises again as they age. For example, White found that siblings aged 70 and older who live close to each other are more likely to provide each other with support. Similar results are seen in the literature on adults with a disabled sibling. A study of adult sisters found that they felt closer to their sibling with I/DD as both grew older (Orsmond & Seltzer, 2000). This may be because as siblings get older, their support from individuals outside of the family diminishes. Researchers in Israel concluded that siblings of persons with I/DD feel a commitment to support their brother/sister because they are the only person in his/her support network (Rimmerman & Raif, 2001).

Stewart et al. (2001) concluded that as adults age, their sibling relationships become more positive and siblings feel relationally closer. Siblings classified as supportive had daily or weekly contact with their siblings while those classified as apathetic or competitive had hardly any contact with their siblings. The research on adult sibling relationships for individuals with I/DD suggests that siblings often take on a supportive role. In a study by Hodapp et al. (2010), participants reported that they

enjoyed a close relationship with their brother or sister with disabilities. In addition, these participants stated that they called or visited often and spent time focused on the relationship. The research on adult sibling relationships suggests that adults are able to make choices about who is in their support network and how they choose to engage them.

The voluntary nature of the sibling relationship is important when considering the future caregiving needs of the individual with I/DD. Research suggests that there may be less conflict between siblings as the relationship moves from obligatory to voluntary (Martin et al., 2005). An obligatory relationship is one that has a lot of structural support but not a lot of emotional closeness (Taylor et al., 2008). Some research suggests that emotional closeness is not always achieved between siblings when one member of the sibling pair is an individual with I/DD (Doody et al., 2010; Orsmond & Seltzer, 2000; Taylor et al., 2008). Other studies identify sibling relationships as warm and conclude that siblings do engage in reciprocal relationships (Eriksen & Gerstel, 2002; Hodapp et al., 2010; Stoneman, 2005). Heller and Kramer (2009) hypothesized that pull factors for siblings' future involvement in their disabled sibling's life would include geographic proximity, greater satisfaction with caregiving, and greater current involvement and contact in their sibling's life. They were able to conclude that more contact and support did have an influence on siblings' expectations to provide future caregiving.

Unlike parents, who may feel the burden of caregiving, siblings who caregive for their brother or sister with I/DD may benefit from the relationship. Sisters in the McGraw and Walker (2007) study stated that they were more virtuous, patient and compassionate for having a sibling with I/DD. Furthermore, researchers have found that siblings of adults with I/DD reported themselves as having fewer symptoms of depression than the

general population (Hodapp et al., 2010). Taylor et al. (2008) concluded that siblings of individuals with mild I/DD were not different from the general population on measures of well-being or psychological distress. In addition, caregiver satisfaction in adult siblings is positively correlated with the acceptance of a future caregiving role.

Gender Differences. Just as mothers are most often identified as the primary caregiver for their child with I/DD, the research has shown that sisters provide more help than brothers (Eriksen & Gerstel, 2002; Hodapp et al., 2010; White & Riedmann, 1992). When parents are unable to continue caregiving, they are more likely to identify a daughter to be the caregiver for their adult child with I/DD than a son. (Griffiths & Unger, 1994). Furthermore, parents identified daughters to be legal guardians 48% of the time and sons only 16% of the time. Sisters who provide caregiving for a sibling with I/DD are raised to believe that it is a woman's role to provide care. This belief helps them to have positive feelings about their sibling (McGraw & Walker, 2007).

Sisters are more likely to initiate and maintain contact with their siblings, as well as offer and receive support, than brothers (White & Riedmann, 1992). Research by Eriksen & Gerstel (2002) found that women are more likely to provide their siblings with help cleaning, doing laundry, preparing meals, and providing child care than men. Also, women are more likely than men to address the personal concerns of their siblings. There is more contact and a closer relationship between siblings when the sibling pair includes a non-disabled sister (Hodapp et al., 2010; Orsmond & Seltzer, 2000). This is supported by the research of Heller and Kramer (2009), who concluded that sister-sister sibling pairs tend to have stronger relationships. A study by Orsmond and Seltzer (2000) identified

sisters as engaging in more activities with their brother/sister with a disability than brothers.

Brothers are often less prepared to take on a caregiving role than sisters. This may be due to the gendered nature of the caregiving role (McGraw & Walker, 2007). Male respondents in one study were more likely to be categorized as apathetic. Characteristics of the apathetic relationship include living further away from siblings and maintaining the relationship out of a strong sense of family obligation (Stewart et al., 2001). Several findings from the Orsmond and Seltzer (2000) study suggest that brothers of individuals with a disability have more negative feelings about the sibling relationship than sisters. This effect is greatest when the sibling pair includes a brother and his sister with I/DD. Other research indicates that male siblings are least likely to maintain contact with a brother who has I/DD (White & Riedmann, 1992). Brothers also express more worries about the future for their disabled sibling when their parent is ill or dying (Orsmond & Seltzer, 2000). This may be because male siblings feel less equipped to take on the role of caregiver that was previously held by a parent.

Future Planning

Older parents who feel burdened by the ongoing responsibility of caring for their adult child may also worry about their child's future (Heller, Hsieh et al., 1997; Heller & Kramer, 2009). Consequently, the perceived lack of support, respite care and future planning cause increased levels of stress in older parents (Dillenburger & McKerr, 2011). However, this increased stress and worry seldom leads to action. Research indicates that while the majority of parents would like their adult child with I/DD to continue living with family, very few parents actually make a plan for the future that would include their

wishes (Heller & Caldwell, 2006; Heller & Factor, 1993; Heller & Kramer, 2009).

Gilbert, Lankshear, and Petersen (2008) suggest that parents do not like to think about future planning because it makes them more aware of their own mortality. Thinking about a time when they will be unable to be the primary caregiver may lead to thoughts of their own aging and decline in health and physical ability. Participants in the study also responded that they were afraid that the care provided in a community setting would not be as “responsive and loving” as the care the parents could provide at home (Gilbert et al., 2008, p. 59). Yet, in a study that was interested in what parents would do if they had to place their child immediately, 51% of parents stated that they would place their child in a group home (Griffiths & Unger, 1994). Older parents may feel conflicted by their desire for action and their desire to maintain the status quo.

Barriers to future planning. A question that emerges in the research literature is what barriers keep older parents from asking for help from their families. One explanation is parental guilt. Research shows that parents who already feel burdened by their caregiving role have expressed guilt about asking for support from their non-disabled children (Heller & Kramer, 2009). This fits with Griffiths’ and Unger’s (1994) finding that parents who perceived their caregiving role as physically demanding were less likely to consider placing their son/daughter with I/DD with another family member. Family, in this context, included siblings of the child with I/DD. Only 22% of parents considered placing their adult child with his/her sibling. When parents do not plan for the future, their wishes for their child may go unmet. Parents who believe that their adult child could be placed in a group home (Griffiths & Unger, 1994) may not be aware that finding the right placement for their child takes time. Parents wanting a specific

community residential placement for their child may encounter wait lists for services and supports (Miltiades & Pruchno, 2001). Failure to plan can lead to crises, inappropriate placements, disagreements among family members about the best course of action, and confusion for the individual with I/DD (Heller & Kramer, 2009).

Another barrier to future planning is the fear of talking about end-of-life. Grief and loss are universal experiences. One's culture, family values, and life experiences can affect how one expresses grief. Botsford (2000) notes that the expression of grief is influenced by a person's developmental stage and intellectual level. For individuals with I/DD, expressing feelings of grief and loss can be difficult. For example, individuals with communication deficits may express their grief non-verbally or in socially inappropriate ways such as by acting out physically (Botsford, 2000; Tuffrey-Wijne & McEnhill, 2008). Furthermore, families may try to shield the adult child with I/DD from reality by not sharing what is really going on.

Future plans can include living arrangements, financial security, assignment of a guardian, least restrictive setting, leisure and vocational options, and choices about lifestyle (Heller & Caldwell, 2006). The Arc (2011) estimates that individuals with I/DD and their families can expect to wait an average of five years for some of these services. Planning for the future of an adult family member with I/DD may be made more difficult by lack of information or access to resources. For example, in their study of older caregivers in the United Kingdom, Gilbert et al. (2008) found that 25 out of 28 respondents did not know what housing options were available for their family member whom they identified as needing a high level of care. In addition, respondents in this study had not received or were not aware of government-sponsored literature on housing

options for individuals with I/DD in the United Kingdom. In an Australian study, families reported that the options available to their family member with I/DD failed to meet both the needs of the individual with the disability and the family's needs (Mirfin-Veitch et al., 2003). Similar results can be seen in the literature in the United States. Fifty-nine percent of respondents to the FINDS survey stated that they don't have enough information to make decisions about housing options for the individual with I/DD in their care (The Arc, 2011).

Those families who are able to make a choice about services face government cuts in programs and spending that affect individuals with I/DD, as well as wait lists for community based placements (The Arc, 2011). The Arc (2011) estimates that there are over one million people with I/DD "waiting for services that may never come" (p. 7). Miltiades and Pruchno (2001) concluded that placement on a waiting list for a service does not guarantee the individual with I/DD permanent housing in the community. Mothers in their study noted that their adult child's first placement was not always their last. Adult children with I/DD were removed from group homes and other residential placements because they did not get along with their roommates, the mothers perceived their children as being over-medicated, there were issues of abuse or neglect, or they lost funding for the placement. Heller and Caldwell (2006) identified lack of trust with professionals and emotional struggles with the service system as two barriers to future planning for families in their study.

Predictors of future planning. One of the most important aspects of successful future planning is that it should be an ongoing conversation that happens over time (Bigby, 1998). Siblings who are already involved in supporting their brother/sister with

I/DD are more likely to be involved in future planning. For example, Bigby (1998) identified three areas where adult siblings provide instrumental support to their brother/sister with I/DD. These are financial management, mediation with formal services, and decision-making. She also noted that siblings who had a close relationship with their sibling also shared activities, provided opportunities to be social, and provided companionship. These are all activities associated with both future planning and the maintenance of quality of life for the sibling with I/DD. Furthermore, Heller and Kramer (2009) found correlations between involvement in future planning with both disability-related activities and current support provided by the sibling. For this study, disability related activities included participation in parent-sibling support groups or advocacy groups, attending meetings for their sibling with I/DD, and volunteering at day programs/schools. Support tasks included caregiving, assisting with household tasks, helping the sibling out financially or with advice, and doing fun things with the sibling. Siblings who are involved in the life of their brother/sister with I/DD are more likely to know what his/her future needs are and how best to meet them.

Another predictor of involvement in future planning is age of the family members providing support. A study by Neely-Barnes, Graff, Marcenko, Weber and Warfield (2008) studied the relationship between demographic factors of families of individuals with I/DD and access to and satisfaction with services and supports. Family included a parent or adult sibling of an adult with I/DD living at home. The researchers identified that individuals with I/DD in families categorized as highly involved were younger than those in the other categories and received more services. In addition, these families identified themselves as having more caregiver satisfaction and were more likely to view

providers as competent. Families who were primarily financially supportive had the highest average earned income while families in the planning group gave more informal support to the individual with I/DD. Families in the uninvolved group were older than those in the other three groups. These families did not make decisions about planning, provide financial support, or make decisions on types of services received. This finding supports earlier research by Hayden and Heller (1997) that older families use fewer services and have fewer expectations about services. It also supports the research showing that older family caregivers are less likely to be involved with planning for the future of their family member with I/DD.

Heller and Caldwell (2006) explored the efficacy of providing a structured learning environment based on peer support for parents and siblings of individuals with I/DD to learn about future planning. Their approach was based on research that has shown that families often lack the information needed to do future planning (Heller & Factor, 2004; Gilbert et al., 2008; Miltiades & Pruchno, 2001; Mirfin-Veitch et al., 2003). The researchers found that families who participated in the intervention completed a letter of intent, took action on a residential plan for their family member with I/DD and developed a special needs trust. This research is supported in a later study Heller and Kramer (2009) conducted. Siblings with more involvement in their siblings' lives were more likely to participate in future caregiving roles.

End-of-Life Planning

End-of-life planning is an area of future planning that is often neglected by both parents and adults with I/DD. End-of-life decision-making can be defined as a series of choices that an individual makes throughout his/her life that is based on life experiences,

support systems, and specific health issues (King, Janicki, Kissinger, & Lash, 2005).

According to the National Association of Social Workers (2004), “End-of-life decisions encompass a broad range of medical and psychosocial determinations that each individual may make before the end of his or her life” (p. 9). Like future planning, decisions about end-of-life are meant to be an ongoing dialogue between the individual and his/her family.

End-of-life planning includes two key components: medical management and care planning (Reilly, 2005). Medical management refers to the ongoing treatments that maintain mental and physical health as well as decisions about any life-sustaining treatments the individual chooses to receive. These decisions are often made with the help of family or friends as well as the individual’s primary care provider. Medical decisions for persons nearing end-of-life in Minnesota include the Provider Order for Life-Sustaining Treatment (POLST) form. The form formalizes the kinds of medical care the individual wants to maintain in his/her life. These include the use of antibiotics, ventilation, and cardiopulmonary resuscitation (CPR). The POLST form is completed with an individual’s primary care doctor and is archived into his/her medical record (Minnesota Medical Association, 2010).

The other component of end-of-life decision-making is care planning. Care planning is the specific choices that the individual or family makes about end-of-life. One goal of care planning is to provide the best quality of life for a person nearing death. Care planning can include choices about treatment options, choices about the kinds of services the individual/family wants to receive, and the choice of where to die (King et al., 2005). Reilly (2005) suggests that there is no right or wrong way to develop a care plan. Rather,

the goal of a care plan should be to improve the life of the individual as s/he faces end-of-life.

Advance care plans. Advance plans are a framework of written instructions that can be used to express values, beliefs, and concerns regarding end-of-life (Stein, 2007). Sometimes called an Advance Directive or a living will, these plans can be used to designate another person who will make health care decisions when the individual is incapacitated or unable to make decisions for him/herself (Friedmann, 1998).

For both families and individuals with I/DD, an advance care plan can be an extension of future planning. Friedmann (1998) concludes that persons with I/DD who have cognitive deficits may still be able to comprehend and contribute to conversations about end-of-life wishes. Honoring Choices Minnesota has developed one guide or framework for making end-of-life decisions that has the support of several major metropolitan hospitals and the Minnesota Governor's Council on Developmental Disabilities. Honoring Choices helps individuals think about what quality of life means, how values may influence end-of-life decisions, and who will make decisions if s/he were unable to make decisions for him/herself. The creation of advance care plans can involve family, friends, medical professionals, and social service staff. Individuals with I/DD might choose to invite their inter-disciplinary team into the conversation.

Advance care plans and individuals with I/DD. The literature supports the inclusion of the adult with I/DD in making decisions and developing plans about his/her own future (King et al., 2005). Both older parents and their adult child with I/DD can benefit from advance care plans. For parents, it is a way to express wishes for future care for the adult child. Planning could include writing a letter of intent, making provisions for

the adult child with I/DD's financial well-being, or establishing a guardian or conservator (Heller & Caldwell, 2006). Parents who may be reluctant to ask their non-disabled children to take on a support role might opt to appoint a private guardian or conservator (Griffiths & Unger, 1994; The Arc, 2011). Knox and Bigby (2007) concluded that future planning is "an issue for the whole family, to be handled when the time is right" (p. 300). However, finding this right time can be difficult. Kingsbury (2009) suggests that Americans with and without disabilities often wait until there is a crisis before making important end-of-life plans. If the crisis point is the sudden inability for the parent to provide caregiving, family members can feel pressure to make the best decision in the moment (Mirfin-Veitch et al., 2003; The Arc, 2011). End-of-life plans often include components to help families cope with grief and loss. The individual with I/DD may be grieving the loss of not only his/her parent and primary support, but also the loss of his/her home, community, relationships and identity (Botsford, 2000).

Person-centered planning. Kingsbury (2009) advocates for the use of a planning tool already in place for most adults with I/DD: person-centered planning. This planning tool puts the individual with I/DD in the center of all decision-making and future planning. It includes dreams, goals, fears, and things that the individual finds important to maintain in his/her life. It is a planning tool that recognizes the rights of the individual with I/DD to make choices for him/herself while ensuring that s/he will have the supports needed to live safely and healthily. Person-centered planning, according to Kingsbury, is about helping individuals with I/DD communicate their wishes. She argues that this is also the goal of advance care planning. Because the person with I/DD is at the center of the planning process, his/her interdisciplinary team works together with him/her to make

the best possible choices that enhance quality of life. Kingsbury concludes that self-determination should be part of an individual's whole life and that advance-care planning should be included in the individual's person-centered planning process. This conclusion is supported by King et al. (2005) who stated that end-of-life planning should be an ongoing conversation that begins before an individual with I/DD receives a life-ending diagnosis. For individuals with I/DD, conversations about future planning and advance-care planning can be included in the annual person-centered plan.

Conceptual Framework

In this section, the researcher will explain the conceptual framework that guides the understanding of the problem. Social workers are trained to look at the Person in the Environment (PIE), develop an awareness of life cycles, and help others focus on the identification of strengths, rather than deficits. PIE is an approach that synthesizes the biological, psychological, and spiritual person with aspects of the environment (including family, culture, and social institutions). The PIE perspective recognizes that changes in all these areas occur over time (Hutchinson, 2008). The family life cycle perspective is another frame that this researcher uses to understand adult siblings of individuals with I/DD. This perspective focuses on the relationships within the family as they change over time. The final perspective that this researcher utilizes is strengths perspective. Strengths perspective underpins both PIE and family life cycle perspective. Social workers are taught to identify strengths first, then, apply other theoretical frameworks to understand the problem. Hutchison (2008) defines the strengths perspective as a way to identify how families have overcome difficulties in the past. The families use the strengths identified to make changes in the future. Social workers are trained to apply strengths perspective to

every theoretical framework they use. Both strengths perspective and PIE are defining pedagogies for social work.

PIE

One application of PIE in the literature on adults with I/DD is person-centered planning. Person-centered planning has been used extensively in the field of I/DD to help individuals achieve self-determination. In person-centered planning, the wishes, dreams, and goals of the individual are balanced with the supports needed to maintain health and safety (Kingsbury, 2009; Tomasa, 2010). Person-centered planning can be a useful tool for bringing the individual, the family, and the team together to make decisions about both quality of life and end-of-life for the individual with I/DD.

In considering adult sibling relationships, PIE is one frame through which the researcher views the sibling dyad. For example, research demonstrates that adults grow closer to their siblings as they age (Stewart et al., 2001; Orsmond & Seltzer, 2000; White, 2001). This reflects both the physical environment (family) and the psychological well-being of the adult and sibling with I/DD as it changes over time. Through the framework of PIE, the researcher gains an understanding of the physical changes and challenges that adults with I/DD and their siblings face when considering quality of life. Persons with I/DD often navigate the world differently than their non-disabled sibling. A person with I/DD may need support with Activities of Daily Living (ADLs) like bathing, dressing, grooming, and eating. S/he might use an assistive communication device or may not speak at all. S/he might use a wheelchair or have a physical disability that alters his/her access to the environment. A task that may seem simple to complete for the non-disabled sibling may be complicated for his/her sibling with I/DD. One of the factors that non-

disabled siblings of adults with I/DD have to consider when helping to make decisions is accessibility. Access to services can influence the location of community residential placements, day programs, and work options (Tomasa, 2010).

PIE must also be considered in making decisions about end-of-life. Choices for end-of-life care are complicated by funding streams, professional ethics, policies, and procedures (Botsford, 2000). For example, Botsford and King (2005) noted that physicians are less likely to prescribe medications for pain management for individuals with I/DD who are not able to adequately express their level of pain or comfort. These findings are opposite to the goal of palliative care, which is to provide comfort at end-of-life. Family members may need to advocate for the care of the individual with I/DD at end-of-life (King et al., 2005). Quality and access to end-of-life care are issues that inform practices for individuals with I/DD. This is reflected in the research of Tuffrey-Wijne and McEnhill (2008) who present strategies that can be used to augment communication with the individual with I/DD. These strategies include using pictures, gestures, and objects of reference. Again, understanding how the individual with I/DD interacts with his/her environment is important. Another concern discussed in the literature is that some aspects of end-of-life care and decision-making are part of the normal cares that a person with I/DD receives. For example, some individuals with I/DD use a ventilator to help them breathe. Yet, one of the questions on the POLST is whether the individual would want to be put on a ventilator if it would prolong life (Minnesota Medical Association, 2010). PIE needs to be considered when making choices about end-of-life specific to the individual and his/her disability.

Family Life Cycle Perspective

Family life cycle perspective is another way for the researcher to frame an understanding of the changes experienced by family caregivers of adults with I/DD. According to this theory, change is inevitable as families age and roles change across the course of the lifespan (Whiteman, McHale & Soli, 2011). However, these changes also give family members opportunities to adapt. This perspective is most clearly seen in the literature on family caregiving (Bigby, 1998; Knox & Bigby, 2007; Pruchno et al., 1996), but can also be seen in sibling studies (Seltzer et al., 2005). Family life cycle perspective can be used to explain why siblings of individuals with I/DD have an expectation of future caregiving (Damiani, 1999). As families age and responsibility for caregiving shifts from parents to siblings, family roles change. Both the disabled and non-disabled adult children become caregivers for aging parents (Greenberg et al., 1993; Pruchno, 2003), siblings rely more on each other for support (Hodapp et al., 2010; Riggio, 2000), and adult siblings of individuals with I/DD become more involved in the lives of their brother/sister (Bigby, 1998).

Strengths Perspective

In social work, a strengths perspective underlies all other theoretical concepts. Strengths perspective looks at what is going well, identifies how families are coping with their problems, and gives hope for the future. The focus is on what is going right, rather than on what is going wrong. By helping families identify strengths, the social worker can work with the family to build a ladder that leads to a solution. When we apply strengths perspective to adult siblings of individuals with I/DD, we start by looking at the strengths of the sibling relationship. Research on adult sibling relationships in both the general and I/DD populations has shown that the sibling bond lasts into adulthood

(Bigby, 1998; Eriksen & Gerstel, 2002; Hodapp et al., 2010; McGraw & Walker, 2007; Mirfin-Veitch et al., 2003; Stoneman, 2005; White, 2001).

An example of the application of a strengths perspective can be seen in the research of Orsmond and Seltzer (2000). In a study looking at adult sibling relationships for individuals with I/DD and Autism Spectrum Disorder, the authors concluded that a sibling's use of coping strategies had a positive impact on his/her relationship.

Furthermore, Riggio (2000) concludes that sibling relationships provide social support and influence psychological well-being for adults. Another example of a strengths perspective in the literature can be found in the research on the implementation of education and support groups (Heller & Caldwell, 2006). Building on family members' skills and knowledge supports better future planning for the individual with I/DD.

PIE, family life cycle perspective, and strengths perspective are three frameworks that explain the researcher's approach to adult sibling relationships of individuals with I/DD. Utilizing these three conceptual frameworks, the researcher will identify how adult siblings guide decisions about quality of life and end-of-life for their brother or sister with I/DD. In the next section, the researcher will describe the methods of the study.

Methodology

Research Design

In this section, the researcher will describe the methods used for this qualitative study of adult siblings of individuals with I/DD. Qualitative interviews allowed the researcher to explore the lived experience of siblings of adults with I/DD regarding decision-making around issues of quality of life and end-of-life. For this study, the researcher conducted nine interviews with the adult siblings of individuals with I/DD.

Through the use of semi-structured interview questions (Appendix A); the researcher began to explore the dynamics of the sibling relationship. The open-ended questions were structured around the themes of decision-making, advocacy and planning found in the literature. The questions began with some basic demographic information such as the age of the participant and the age of his/her sibling. The questions funnel down to more sensitive topics with questions specific to quality of life and end-of-life planning at the end of the interview. The interviews were expected to last one hour and included time to review the informed consent and answer any questions that participants may have. Actual interview times ranged from thirty-five minutes to two hours. Following the formal interview questions, the researcher gave participants some time to debrief, as needed. Interviews occurred at a time and semi-private location convenient to the participants.

Sample

Participants in this study were adults between the ages of 25 and 65 who have a sibling with I/DD. Participants were recruited using both convenience sampling and snowball sampling techniques. The convenience sample included adult siblings of persons with I/DD known to the researcher in both the Minneapolis metropolitan area and Mankato, Minnesota. The convenience sample participants were recruited through an e-mail invitation (Appendix B) from the researcher, inviting them to be included in the study. Initial potential participants were recruited from a convenience sample of persons the researcher knows. An information sheet (Appendix C) describing the purpose of the study and the participant's right to withdraw from the interview at any time was sent with the invitation. The snowball sampling was accomplished by asking previously identified participants to share the e-mail invitation (Appendix B) and information sheet (Appendix

C) with one or more other adults who have a sibling with I/DD. These additional participants had the opportunity to contact the researcher if they were interested in contributing to the study. All participants were asked to contact the researcher directly via e-mail or phone to discuss the interview process and determine a time and place for the interview. The researcher ensured that the interviews were conducted in a semi-private public space like a library conference room or neighborhood center. Anonymity of participants was assured and informed consent was provided to all participants at the time of the interview.

Subjects interested in participating in the study received an information sheet (Appendix C) about the study prior to setting up an interview time. In the information sheet the researcher explained that a study was being conducted to explore the experiences of adult siblings of individuals with intellectual or developmental disabilities. The researcher described her interest in interviewing adult siblings of individuals with I/DD who have had experience supporting their brother or sister. In the information sheet, the researcher explained that her interest was in learning how siblings help make decisions about quality of life and end-of-life. It was hoped that this study would help social workers and service providers understand the experiences of siblings and develop better ways to support individuals with I/DD and their families.

Protection of Human Subjects

The information sheet (see Appendix C) explains the procedures for interviewing, tape recording, and storing of tapes as well as how the information may be used for publication. The tapes from the interview were stored in a locked filing cabinet in the researcher's office at the St. Thomas Interprofessional Center. Only the researcher and

her adviser had access to these tapes. The interview tapes were destroyed after they had been transcribed. The data will be kept until August 2012, at which time all notes and reports will be shredded.

Participants were asked to complete a consent form before the interview was conducted. Information about confidentiality was explained to participants at this time. At the start of the interview, participants were asked to choose a color by which they would be known on the interview tape and in data collection. This color is not associated with the informed consent form. The researcher explained to the participants that this was to maintain their confidentiality. Participants were asked to state their color on the tape before the interview began. In addition, the researcher did not ask any identifying information regarding the sibling with I/DD. All names given in interviews were changed to protect the identity of the participants and their siblings. The information sheet included information on risks and benefits of the study as well as where participants could get help should they need assistance.

Interviews were conducted at a time and semi-private public place convenient to the participant. When possible, the interviews occurred in a quiet room to facilitate the interview recording process and provide privacy. Demographic questions as well as questions related specifically to the research topic were asked (see Appendix A). Examples of interview question themes include the participants' understanding of quality of life, his/her experience as an advocate for his/her sibling, and his/her experience with end-of-life planning. The researcher was aware that some of these questions could provoke a strong emotional response from participants. Participants were reminded at the start of the interview that this study is voluntary and that they could choose to stop

participating at any time. The participant could also choose not to answer any question and, if s/he became upset during the interview, could terminate the interview and the researcher would stop taping.

At the end of the interview, the researcher provided a list of counseling resources that the participant could access as well as provided a list of places to get more information on the specific topics addressed in the interview (Appendix D). Participants were given a \$10 gift card as compensation for their participation.

Data Collection

All interviews were tape recorded and transcribed following the interview. In addition, immediately following the interviews, the researcher wrote down notes and impressions from the interviews that were kept in a research journal. This research journal was also utilized during the data analysis process described below. The researcher had a research assistant available to help with the transcription of the recorded interviews. Once the tapes were transcribed, they were destroyed. The tapes and the transcriptions were kept in a locked office at the St. Thomas Interprofessional Center when not in use by the researcher or her assistant.

Data Analysis

Data analysis was conducted by hand using grounded theory and content analysis. It was hoped that a deeper meaning and richness would emerge from the data when analyzed by hand as opposed to utilizing a qualitative program to analyze the data. This allowed for more flexibility and helped to maintain the tension between the data and the theoretical framework. Monette, Sullivan, and DeJong (2008) write that it is important to maintain theoretical sensitivity during data analysis. This means that as data collection

and data analysis overlap, the researcher is able to make changes to her theoretical stance. The interaction between data collection and analysis inform theory which in turn may inform data collection and analysis (p. 421). Berg (2009) suggests that it is useful to keep a “record of where in each document similar comments, concepts or categories seem to convey the same elements that originally triggered the theory” (p. 355). This gives the researcher flexibility to try out different explanations for the kinds of meaning that are emerging from the data.

Data analysis required both deductive and inductive approaches. The interview questions were structured to tease out themes related to family life cycle perspectives, strengths perspective, and PIE. However, the researcher could not know ahead of time what kinds of meaning, perspective, or relationships would emerge from an analysis of the data. The responses to the interview questions have guided the researcher to move from concrete observations to abstract theories that explain the observations. The researcher began by looking for common themes among participant responses. In this way, the data guided the application of theory and meaning unfolded as themes emerged from the interviews.

Strengths and Limitations

A strength of this study is that it will add to the literature on adult siblings of individuals with I/DD. One of the topics this study explored is end-of-life planning for adults with I/DD. This is a new area of concern that is impacted by the lack of historical precedence regarding opportunities for individuals with I/DD to participate in decision-making. The literature in this area is just starting to emerge and has been focused on helping families and providers begin conversations about future planning. Limitations

include the small sample size of nine siblings. With such a small sample size, it will be difficult to generalize findings to the larger population. Also, there was not a great deal of diversity in a sample of nine participants from the Midwest. Another limitation of this study is that the researcher was not able to interview individuals with I/DD. Due to IRB limitations; it was not possible to interview self-advocates on decision-making, future planning or their wishes for end-of-life care. Not being able to include adults with I/DD in the study does limit what the researcher will learn about adult sibling relationships, future planning, and end-of-life planning for individuals with I/DD.

Findings

Subjects

For this study, the researcher interviewed nine adult siblings of a person with an intellectual or developmental disability. The majority of the participants interviewed currently live in large suburban cities in the Midwest. One participant lives in a more rural area of the state. Seven of the participants were women and two were men. The participants ranged in age from 25 to 65. Household income for participants ranged from \$40,000 per year to more than \$130,000. All participants in the study identified their race as Caucasian. Four of the participants support a younger brother with a disability, two support an older brother, and three support a younger sister (See Table 1). In the interview with one participant, the partner contributed to the conversation regarding end-of-life decision-making.

Table 1

Summary of participant demographic information

| Sex | Age | Race | Annual Household Income | Number of Siblings | Sex of Sibling with I/DD | Age of Sibling with I/DD |
|--------|-----|-----------|-------------------------|--------------------|--------------------------|--------------------------|
| Female | 25 | Caucasian | \$85 - 100,000 | 3 | Male | 32 |
| Female | 27 | Caucasian | \$25 - 40,000 | 1 | Female | 25 |
| Female | 36 | Caucasian | \$40-55, 000 | 2 | Female | 31 |
| Male | 40 | Caucasian | \$130,000 + | 3 | Male | 33 |
| Female | 54 | Caucasian | \$100 - 130, 000 | 3 | Male | 60 |
| Female | 57 | Caucasian | \$115 - 130,000 | 2 | Male | 51 |
| Female | 61 | Caucasian | \$55 - 70,000 | 10 | Male | 46 |
| Male | 63 | Caucasian | \$130,000 + | 7 | Male | 62 |
| Female | 65 | Caucasian | \$40 - 55,000 | 2 | Female | 59 |

The Role of Parents

Parents and other primary caregivers are our first models for how we should be in the world. They set the rules, establish the boundaries, and teach us how to live to our potential. For the nine siblings interviewed, it became clear that their parents had laid the foundation for the relationships within the family.

Generational differences. It is important to note that for the participants with a sibling with I/DD aged 45 and older, the first consideration for the parents was whether their child would live at home. This is exemplified in the following excerpts from three different participants with brothers with I/DD.

A participant with a 62-year-old brother reported:

Mom never wanted him to go to any institution, anything like that, so he stayed at home. He stayed with her prob'ly four years after my dad died...it was the three of them in the same house for 42 years.

The sister of a 60-year-old brother described it this way:

Dad was in medical school when (brother) was born and he diagnosed his disability before the doctors did! The doctors all said that he would be better off in an institution but my mom would not hear of it. She fought it!

This same theme emerged in an interview with a sister of a 46-year-old brother:

And in the late 60s, the feeling at that time among the white coat establishment was that it would have been better to put them in a, a home of some sort. My mother and father had nothing to do with that.

Participants with siblings in their twenties and thirties did not talk about their parents having to make a decision about institutionalization. Our society's views on disabled children had changed and out of home placements were no longer considered to be in the child's or family's best interest.

Parents also shaped the sibling relationship in more directive ways. For example, several participants described being given the role of supporting a brother or sister with I/DD by their parents. The following passage is from the oldest sister in a family of eleven children. She reported on the experience of welcoming her brother back into the home:

Once he arrived back home, we were all given jobs. We were all given jobs and the expectation was there. We celebrated every word he said, every movement he made...because he had lots of surgeries, Harrington rods and so forth. My

brothers were tasked with introducing him to everything on the outside so he was either in a wheelchair or he was on a sling, in a sling on their back or whatever. The entire neighborhood all grew up knowing that, that the brother was part of their world. Myself, and some of my sisters, we were tasked with language. I was Sesame Street three times a day, y'know. Needless to say, my mother was involved in what was then called MARC, Minnesota Association of Retarded Children. My mother and father approached it from the point of view that as far as he was concerned, he being my brother, there wasn't anything wrong with him. We were not allowed to do any baby talk, no nothing. You talk to him as if he understands, period.

Another participant describes what it was like to help care for a younger brother who also had a lot of medical needs. The participant was seven years old when his brother became part of the family. Their dad worked a lot but Mom stayed at home with the three children. The participant reported that when he was really young, "I was changing diapers, feeding him, doing whatever needed to be done." He explained that at 8 months, his brother:

...had a cleft palate and so like eating was a slow, slow tedious process because three quarters of food that went in his mouth came out his nose. So just a regular really soft diet of baby food, baby cereal, so it took about 2 hours to get enough in him.

Another participant told the interviewer, "It was never, ever, ever, 'oh shoot I have to take care of (brother) today. We all had our jobs, all had our days.'" From these quotes,

we can see how some parents were able to set early expectations for the non-disabled siblings to help provide support to their brother/sister with I/DD.

My sibling, my gift. Yet another way in which parents helped their children understand disability can be heard in the language of the interviews. One phrase that reoccurred in several interviews and became a theme in others was that the sibling with I/DD is a gift. One sister stated that her brother “had taught us all to be humble. He accepts us with all our imperfections.” Another sister said, “My mom always considered him the gift. He’s the gift; he’s gonna be letting all of you guys know how things are gonna go.” A third participant simply stated, “*He* is the gift to *us*.”

The language of gifting can also be heard in how the participants describe their sibling. For example, “he’s always happy, it gives a positive response from everyone and it’s like a big circle. He’s a super happy kid!” Another participant had this to say about her sister, “we’re the best of friends!” While another said that his brother “has a really great relationship with my kids.” The gift of presence that the siblings describe in their own lives is also reflected in the lives of their sibling in the community-at-large. One sister explained that her brother “was just a part of” the life of his siblings, his neighborhood, and community. To this day, he is still “the gathering point.” Another sibling describes her sister as “the unofficial mayor of our town, she knows everyone.” While a third sibling proudly shared her sister’s successes as a Special Olympics athlete and speaker. “She does a whole bunch of speeches for different organizations. Now she is getting ready to speak at the regional Down’s syndrome conference.” This participant also talked about how her parents “encouraged us to become friends quickly. I never

noticed a disability with her” and gave examples of how her parents continue to support both daughters in living their dreams today.

Growing Up Together

One participant described growing up in an “Ozzie and Harriet home except probably with the stress of a disabled brother.” Another participant said that growing up, she and her brother “mostly we still fought, y’know, we still snuck around doing naughty stuff, we stayed up watching movies...y’know, it was just a little different.” Another brother reported that he and his sibling were a year apart and “slept in the same bed!” This contributed to their continued close relationship as adults.

Early advocacy. This theme is captured really well in the following quote from an interview with a 27-year-old participant who reported that:

I started going to ARC’s sib shops, have you ever heard of that? It was really important to me. I was a teenager for all that and got to talk to other sibs about their experiences and things and I always felt it was my job to make sure that (sister) got the best that she needed and to just follow along with my parents on that. And I always felt it wasn’t fair just because she was born like that she wasn’t able to get all the things out of life that everybody else was. So that was always part of my goal to make her fit in everywhere.

Participants also gave examples of advocacy that was less formal and more organic in nature as in this example:

And the friends, the friends that would come over or come into the house or whatever. They...everybody knew! Everybody knew that if you came over for Joe and it happened to be Tuesday and you guys were going to the park to skate, the

first thing you gotta do is to figure out how to get (brother) down there, 'cuz that's just how it went. I can tell you a thousand stories about trying to push a wheelchair down the middle of the street when there's ten inches of snow...

My role as the oldest. Not all siblings interviewed shared the same experiences growing up. For two participants, there is a fairly large age difference between themselves and their sibling with I/DD. For each of these siblings, the age gap has had an impact on their sibling relationship. One sister reported:

I was the eldest and (brother) was the youngest. I was part of the first five years of his life, well, maybe actually a little more than that...for the first maybe seven years maybe off and on.

She goes on to explain that when she and her siblings were growing up, there wasn't always positive regard for the brother with a disability:

A lot of years I spent in resentment...maybe not resentment but questioning...questioning like, well, now, I gotta have a normal life, too! Those are all normal things when one person is the focus. So, in those early years, you didn't necessarily understand what the mission was...but you did it because it was what Mom and Dad said and that became part of your norm.

For another participant, trying to balance her own life with caring for her sister and other family members has been a challenge. Growing up, she describes her mom as disabled, "I was her feet." She states that her dad lacked education, and had to drop out of school when he was in second grade. "So my job was to protect the kids...and take care of 'em." Her sister, who is five years younger, grew-up "emotionally dependent on me." While

both sisters have been in support roles as eldest siblings their whole lives, how these roles have played out has been very different.

Sibling conflicts. Several of the participants were very honest and said that it was not always easy to grow up with a sibling with I/DD. A participant with a younger sister with I/DD reported:

Being candid, there was a point at time at which...just let me be a kid, just let me be a teenager, just let me be...I'm tired of this having, always looking after... You know even though (sister) is the greatest person on earth, I'm over it. Why do other's relationships have to deal with ... you know always go back to her. How she's treated, you know, meeting boyfriends, and what not, and why does that have to dictate what I do or don't do? So there definitely have been some great moments but some points of contention.

A second participant had this to say about her older brother:

At first when I was young and I went to grocery stores, he would be talking really loud and everyone was looking at us and I was walking very fast to get away from him because I didn't want any of my friends to catch me with him. And you didn't have friends that could play with you either and hang out because (brother) was special needs and they didn't understand. So you went through that. So it was tough.

A third participant had this to say about her sister:

She's very anxious and depressed and she kind of thinks the world revolves around her y'know, it doesn't make any difference what anyone else has to do, if she needs something (clap!) you better be there!

These participants were very honest in reporting that it wasn't always easy to grow up with a sibling with I/DD. However, all of the participants interviewed are now actively involved in the life of their sibling. As one participant stated, "I outgrew that. And now it doesn't bother me."

The role of other siblings. The siblings who participated in this study are all currently involved in the lives of their brother/sister with I/DD. Eight out of nine participants interviewed have other non-disabled siblings in their family. Some of the participants stated that one or more of their siblings have either chosen not to be involved in or are not able to be involved the life of their sibling with I/DD. Several participants talked about siblings who had poor physical or mental health that disrupted their ability to provide support, others talked about distance as a factor. One participant stated that her brother always felt embarrassed by his older brother with I/DD. Furthermore, one participant reported that her brother never had to be involved because she was the oldest and the one charged with taking care of everyone else. A participant from a large family had this to report, "There are maybe some of the siblings who didn't get as much attention as they should have. And it becomes, almost, survival of the fittest." Another participant summed it up this way, "the others aren't involved. You know they don't hate him. It is what it is."

Brothers and sisters don't always share the same interests or have experiences that connect them while growing up. This theme is echoed by a participant who reported on the experiences of her brother, who is the middle child:

(Brother) had nothing to do with (sister) so I was always taking care of (sister).

(He) could always do what he wanted. I was always her guardian and protector.

He was never really accepting of her...disability. He could never really communicate.

One of the women interviewed noted that in her experience with supporting her brother who lives in a group home, “it seems that in that house it’s all of the sisters who take care as the guardians.”

Sibling Alliances. Participants in this study not only identified sibling conflicts; they also identified sibling alliances. One older sister said that her brother was always treated as “one of the boys.” She went on to tell this story about growing up:

The friends that would come over and everyone knew that you had to take (brother) with you. Going to the corner to shoot baskets, going bowling in a wheelchair, he just went. Boys had him in slings, because he always had surgeries and casts so one of the boys would have him in a sling, everybody laughing.

Connectedness can also be seen in this quote from a middle sibling in a family of four:

And it was my older sister and I and my mom who all pitched in and we all had responsibilities around the house and helping and taking care of him and it was different from all my friends, but it was good.

In some families, there was an expectation that everyone would share in the burden of care. For example, a participant who comes from a large family stated, “There are all these personalities in our family. Each one represents a different approach, a different conversation...and pretty much everybody knows what their role is.”

How Long Have You Supported Your Sibling?

My whole life. Another theme that emerges from the interviews is the length of time participants have been providing support for their sibling. Almost all of the participants interviewed felt that they had been supporting their disabled brother or sister since they were children. Two participants answered, “Since he was born,” while another stated “Ever since I can remember. It’s always been.” Another said simply, “my whole life.” One participant described it this way, “I was a part of the bringing of him home, of my parents saying, okay guys, this is your brother and this is who he’s going to be and this is what he’s going to be.”

This finding was true for both older and younger participants. One participant who is the guardian of her older brother reported:

I was always in the caregiver role. Little things like when I was five and I would put his toothpaste on his toothbrush; on the bus I always made sure he got on the bus and sat where he needed to, even without anyone telling me to. It was kind of natural.

For some siblings, providing support has also meant taking on an official role as a guardian or conservator of their sibling with I/DD.

When my parents were no longer able to. Three of the nine participants identified that their “official” support role started when their parents began to age and were less able to care for their adult child with a disability. These three participants are all currently guardians or conservators of their sibling. “Well, I guess we’ve been here for him for, ten years here now? Yeah, since my mother died” was one participant’s response. The participant of an older brother with I/DD identified that she and her husband have been guardians “since Dad had his stroke” about 20 years earlier. Another

stated that as her parents age, “I’m starting to do more but gradually.” One of the participants interviewed took on the role of co-guardian for her brother when she was 18. She explained, “Our mom had breast cancer and I was scared if something happened to her, my brother wouldn’t have a person to stand up for him.”

However, it does not always take age or illness for parents to decide that they no longer have the energy or resources needed to support a son or daughter with I/DD. One participant reported:

I moved out of the house when I was 18 and he lived with my parents. They sort of took care of everything. And as he got older, my parents, you know, they knew he needed assistance and things, but I don’t think they were really willing to admit that he had a developmental disability and they always felt... kept waiting for him to catch up and it would take longer to get to where my other brother was. And I started working with people with disabilities so it really took me in his adulthood to help my parents understand that probably he couldn’t grow more, but there would always be limits that he would never be able to surpass and he would always need some assistance in his life.

By virtue of growing up together, siblings have a different understanding of each other and a different way of supporting each other than parents.

What Does Your Support Look Like Today?

Participants in this study fill a variety of roles in the life of their brother or sister with I/DD. They provide both instrumental support and social support. Instrumental support includes the giving of time, money or advice; while social support may include

helping the sibling make connections or stay connected in their community. In the nine interviews, there was often a blending of these two kinds of support.

Instrumental support. Participants in guardian or conservatorship roles, tended to identify the support they provide their brother or sister as primarily instrumental. They reported helping their sibling with accessing services like county programs, health insurance, and social security. For example, one participant reported that he “started the process of getting medical assistance and social security and getting him a waiver and those things.” Participants also attend annual meetings for day programs or residential placements, help their sibling identify annual goals, and help navigate the complexities of the various systems in place to support individuals and families with I/DD. A few participants spoke directly about the amount of paperwork that is needed to keep supports in place. For example, one participant who has been supporting her sister for over 40 years had this to report:

I was doing everything myself and I, with a *masters* degree in administration, it was difficult for me to navigate the services that are available to her. Which, what happens to normal families, that only went to school to eighth grade or high school...It’s just...when we get a form to fill out, I mean, you have to read all this stuff to figure out, what are they asking for here and are they going to ask for it down here and then you misunderstood this question up here. So I asked her (sister) not to sign any documents unless I look at them first.

Instrumental support also includes giving of one’s time and talent in the service of a sibling. This can be exemplified in this quote from a participant whose parents continue to be involved in the life of their son with I/DD:

My support is when I go over there. Mom and Dad don't do anything to help keep the apartment clean that he is in. So I'm the one who, when I go over, I do some organizing. I notice the carpet needs cleaning, so I've got a carpet cleaner and when I go over, I'll probably clean the carpet in the next couple of weeks. Just sometimes watching for clothes to go on sale to buy him some things. Something my mom might do once a month.

Participants also reported that they help with accessing services and maintaining health and wellness. One participant stated that he accompanies his brother to “doctors, dentist, glasses, physicals...camp, when he goes to camp, whatever.” Another participant, when asked about the kinds of support she provides, identified it this way:

Financially, and of course, you know, she's on assistance so...she can't have any money in her account, you know so I, I have a separate account. Then I haul her to all her doctor's appointments and go in with her and even when she goes in to surgery, I'm right there until she falls asleep. So yeah, (laughs) it's a full-time job, actually!

Social support. The other major role that participants identified is to provide social support by connecting siblings to the life of the community and the life of their family. For example, one participant reported that her sibling enjoys “movies, shopping, she loves to go to Trader Joe's. We go figure skating.” Another participant reported, “I still go home a couple times a month—you know some bonding sibling time, but to give the parents a break.” Yet another stated, “We get him for holidays or his birthdays or pick him up for birthdays and spend time with him at our house.”

Blending supports. The following quotes from two different participants exemplify the blending of instrumental and social support. In the first example, a participant discussed the kind of support he and his family give his brother with I/DD:

Money management is something he struggles with, social he definitely struggles with and we try to help him with that area, appointments, medical and hygiene are issues...responsibilities around the house, picking up after himself, keeping things tidy in his living area he struggles with. If things are messy or cluttered and people aren't picking them up we are talking to them (the kids), he says well I did mine already or I've got my stuff picked up, and he sort of puts himself in that group. That's interesting. And I tell him well, you're an adult, you're not my kid. I'm not here to tell you what to do or boss you around.

In the second example, a participant reported of a time when her brother with a disability called for some help problem solving a family relationship.

So he calls me up, and he's going "Okay, (sister), what do I do...I don't want to be impatient..." and I said, well you know who you're dealing with, y'know how he is...so what do you want to do and he says "Well...I don't want to get him *mad* but, I sure wish he'd answer his phone," and I said, here's the bottom line: you have to make a choice...you know that youngest brother is gonna call, it's just going to be on *his* time. "Yeah. Thanks, for being there," to take the call.

It is interesting to note that in both of these examples, the participants identified that their brother with I/DD is capable of making his own choices. The participants use what is sometimes called a teachable moment to reinforce this and provide support for the sibling

to make his own choice. They treat their brother or sister as a peer. This theme will reoccur during the discussion on quality of life.

Defining Quality of Life.

The following interview question was asked among participants: “Is your definition of quality of life different for you than it is for your sibling?” This question got a mixed response that does not seem to be correlated to the age of the participant or sex of the sibling with I/DD.

We define it the same...I think. Several participants felt that there was no difference, “I think it’s really similar,” or “I would think that that it’s we both share very similar beliefs, we are raised the same.” The participant with a 25-year-old sibling had this to say:

I think it should be the same. I really do. She has the right to marry if she wants to she...maybe could have a child if she wants to. She deserves all that. She deserves to have a boyfriend who loves her. She deserves to have sex. I think she deserves every right that we have. And I hope we can help her achieve all that.

While the participant with a 62-year-old brother gave this answer:

Well, I kind of define prob’ly as a balance. Y’know I think I have a pretty good *balance* in y’know in physical, mental and social, whatever...work, work and play, work and family. And (brother) has it the same. He loves to work. I like to go to work, I like my job. He likes his job. And, we probably have somewhat similar attitudes. Y’know what I mean, we’re not too disgruntled. He’s a pretty happy guy. Life’s good I think, and I think he thinks that too, it’s hard to tell.

This theme is also reflected in this response from a participant whose sister is 31:

I think so, we're really a lot alike - warm comfy bed, roof over her head, can we go to a movie, can we go shopping? She's a lot like you or I in this way. And do we have cable?

We define it differently. Two of the participants interviewed reported that their sense of what was included in quality of life was different for them and their sibling.

The participant with a 51-year-old brother responded this way:

Well, y'know, yes and no. His... My quality of life probably is focused on things that are more, definitely more high level. Where (brother's) world, what gives him quality of life is a much smaller world, what he is capable of doing. It has to be modified. But in his mind he would like to have a full-time job and he would like to feel more productive and that is something that gives *me* quality of life. I can't judge his quality of life compared to my quality of life, because if I do that, it's too painful. He has a different value system.

While a participant with a 59-year-old sister responded:

Only in one aspect and that is that I can't afford to take her on every vacation that I go on and she would like to go, but I need time away from her. And because she's depressed and anxious, I don't think she has a very good quality of life because I'm very positive and upbeat and I think I can do anything and I'll try to do it, and she doesn't think she can do anything, y'know, she doesn't. So she has a completely different – I mean, you would never know we were siblings. She cries all the time and she's anxious and I, I rarely cry.

What Contributes to Your Sibling's Quality of Life?

My life, my choice. The one big theme that emerged when participants were given the opportunity to describe what they felt were important measures in the quality of life of their sibling with I/DD was that the sibling felt in charge of his/her own life. One participant stated that she uses the language “in charge of” with her brother because “that’s what he knows, somebody’s out there to help me make decisions.” This same participant went on to report:

As far as who’s in charge, he’s in charge. Now he’s 46, he’s had supportive people who help him along. He knows what he wants to do, he knows it’s his choice...whatever you do you will have to live with. So a choice can be listening to everyone else too...gather a little information...you can feel comfortable with what you have to live with.

Another example of this comes from a 40-year-old participant who described his younger brother as follows:

He’s definitely a guy who wants to be independent. And in many areas he is really, really independent. He doesn’t need any support at all and the areas that he does require some assistance in, we find that the best way for him to be successful in those areas and support him are still by allowing him to be independent in the way he makes choices and whether he is going to do, he needs to do, or not. So I think the thing that will always be important to him is that he has the sense that he’s the one making decisions, and he is, and he should be.

Furthermore, another participant reported that the following things are important to her 25-year-old sister:

She would want to live on her own. She talks about being married; she talks about being an aunt. She talks about all that kind of stuff. She loves people. She really loves people. So being around people is probably one of the highest things on the list so being out in the community, being involved with people, being seen being heard.

For the 62-year-old brother of a third participant, being able to keep a routine is important:

And he's real on the clock with everything. Goes to bed at 8 o'clock, y'know he gets up at 6 o'clock. His meals are basically the same...so...we can come home at 2 a.m. in the morning and he'll want to take a shower, cause he always takes a shower before he goes to bed. Real hard to talk him out, that you don't need to take a shower, just go to bed. Oh, no, gotta take a shower (laughter) so he's pretty y'know, uh, on the clock with what he does.

Natural consequences. Participants were also able to identify times when their sibling with I/DD was allowed to make their own choice and experience the consequences of that choice. For example, one participant described a time when her brother decided to quit his job:

He worked at the animal hospital for ten years...there was a family there and they were so good to him. One day he just took a piece of paper...and he wrote I (name) am giving my two-week notice. And we didn't know how this came about, if it was because his job coach left or he wanted another opportunity. So we sat down and tried to explain, y'know this is an awesome job, but he just kept saying that *he* didn't want to be there. Then he realized, oh I don't have any

money. I can't buy my movies. This is really hard! And then he realized that a job is really important and they got him a new job but this was about six months later. But yeah, six months ago, a job wasn't necessarily important to him, but now a job is important but his motives are his movies, his books.

Another example of natural consequences can be seen in this quote from a participant who is actively involved in the life of his sibling with I/DD:

He's lived in his own place without any supports and he failed miserably. That was in our hometown just a block from my parents' house. He ended up losing his job through that process and he didn't clean his apartment, and that was a nightmare. That's really part of the process in which my parents started to come to terms with this...seeing him fail made them understand that maybe he couldn't live on his own and so he moved back home. My parents helped him get that job back - they knew the employer, and he had some periods of success at home with my parents helping him get things done. Then he lost that job, and he and my mom had a hard time; didn't get along. He resented my mom being bossy, telling him what to do and him not recognizing that on his own he wasn't taking care of hygiene, showering, brushing his teeth. Going to work was a huge issue, so he ended up losing his job and he and my mom just had a really hard time being together and so I started the process of getting him moved up (here).

Natural consequences do not always affect positive changes in the life of the individual with I/DD. One participant addressed the down side of having a sister with I/DD who makes many of her own decisions about the kinds of services and supports she wants:

She won't even have tests that might save her life, like she won't have a colonoscopy, and, she's incontinent she won't let them check her bladder or any of that kind of stuff y'know, she's very, very private...she'd probably have a better quality of life if they could...well, she's sick every day...if they could figure out what's causing her illness, but they can't because, she won't let them do the tests.

While the previous two participants reported of a time when their siblings learned from the consequences of their choices, for this participant, the sibling's ability to make her own choices has negatively affected her quality of life. However, even when the consequences are not optimal, several participants identified the importance of giving their sibling the right to make choices about his/her life.

Respecting Choices. Several of the participants identified that part of enhancing quality of life for their sibling with I/DD means both respecting their sibling's right to make choices and respecting the choices that s/he makes. A good example of respecting choices comes from a participant who had this to report about his brother:

He was pretty miserable in his apartment and I'd see him every day, talk to him, but just for short periods. Staff would come and help him out, and then he'd be alone and sort of sad. He just wanted to move back home to my house. So that's where he is now. We finished the basement and he has his own space and he lives with our family and is very much part of the family.

Another way to respect choices is "to think about what *you* would want and do it." This is exemplified by the following from a participant who is the guardian of her 30-year-old brother:

Then we have to look at kind of the bigger picture of exactly what quality of life is for (brother). So what is important to him? So he didn't shave that day, but if he's happy, whatever. Y'know it's hard too because some days, I don't want to take a shower either! Y'know I don't want to do laundry. You can't force someone to do all that stuff when we don't want to do that. It's about finding that balance and having him have those choices.

Another participant described decision-making with his brother this way:

Maybe something as simple as sitting down and saying ok this is one option for looking at the situation and here's another. Option A has these kinds of consequences likely and Option B has these. What do you think is the best for you? He's really receptive to that but really resistant to really pick A or B. As long as he feels he makes the decisions or is allowed to make decisions, he'll be good.

Not only is it important to give the individual with I/DD the opportunity to make choices, it is also important to respect the choice that you have asked him/her to make. One participant gave an example of a time when her brother was not heard. Their parents were retired and moving back to the small town they grew up in. The participant explained:

...initially mom was going to bring (brother) with, but he got vocal "I don't want to go there." They introduced him to a few other families and he spoke up and said, "I don't want to go. I don't like how those people do things." Not so much about he did want to leave all of us, but "what is there for me up there?"

According to the participant, her parents were able to come up with a compromise. Her brother asked, "Can you just let me try it?" with the understanding that, if it didn't work out, he could come back.

Supported choices. Participants recognized that there are places where their sibling needs more support to guide his/her decision-making. One participant stated that her brother "...knows he's not the same as everybody and sometimes he'll make a comment, 'You know, I don't know how to do that.'" Participants also noted that there are places that their sibling needs support to make choices that maintain their health and safety. For example, one participant reported on some changes that were made at her brother's group home regarding his support plan:

He smokes and that's one subject that gets him crabby if you talk to him about quitting smoking. We used to have a limit of six a day, but we found when he was winning the lottery and buying his own cigarettes he was much happier, because it was unlimited, so we decided to take that little rule away and let him buy when he wants to and we've given him an allowance. He's pretty good with money. Now he's into lottery tickets. We just had a situation where he bought himself quite a few lottery tickets. He got himself scratch offs and he was winning and he had over \$600, and that's how he was buying cigarettes. Then we decided on a weekly allowance, but no cigarettes rationing. He has a budget. If he spends more than budget that's too bad. It's weekly. If he gets more money than the allotted \$35 a week, then they wouldn't give him any more.

This participant identified that her brother would be at risk in the community of being taken advantage of or mugged if he was carrying around large sums of money. Another participant stated that without support from the family, her sister:

...would sit in front of the TV and play with the computer all day long and eat pizza and pop. And she'd get overweight. But she just needs that get out, push out the door, type of thing.

Furthermore, many individuals with I/DD have limited choices. One participant had this to share about her brother:

I think the life I have is completely based on my choices and the outcome is based on choices. In his case, being in the system, they don't have as many choices. Part of my role is to have him take ownership of where he works and where he lives...your place where you live has to be your refuge. They don't have that choice they don't get to pick where they live.

When you do not have the opportunity to make your own choices or the choices you make might be detrimental to you, it is important to have someone on your side who can see the big picture.

Future Planning

Parents and future planning. Most of the participants responded "none" to the question, "What kind of future plans have your parents made for your sibling?" However, as participants thought about the question, two additional answers came up.

Financial Security. A few participants were able to say that their parents had made financial arrangements for their sibling. The participant of a 31-year-old sister reported, "They have a special needs trust for her. Everything is really spelled out. They

have a directive. Ultimately she is wherever I'm at." While the participant of a 61-year-old brother stated, "she (Mom) just wanted him to stay with us and they provided some monetary things to, I mean we all got inheritance." Another participant said that her 25-year-old sister "has a trust. And...my parents have been taking money from her paycheck and putting that into her trust too."

Who Will Be in Charge of Me? Several participants noted that the only plan their parents had made was to identify who would be the decision-maker. The oldest sibling in one family had this to report, "(I) will be taking care of her. That's the plan." Another participant, when asked if she would be the one caring for her brother after her parents are no longer able to, responded "I don't know if we actually had a formal conversation, quite frankly. But I just know that's it." A third said, "It's sort of my deal to figure out. Honestly." One participant, who shares legal guardianship with a younger brother, reported:

My father was lost without mother...I remember we were in a van at my mother's funeral, and (brother with I/DD) said " I just wonder who is going to be in charge of me now?" I said, "Well you know Dad's still here." And he said, "That's not happening." He understood it. I shared it with Dad and he waited for opportunity and he said to (brother)." I think I am going to put (oldest sister and youngest brother) in charge of you. And he said, ok.

A similar conversation occurred in another participant's family. The participant stated that before his parents died:

...my older brother who's ten years older, my mother, dad, saying we need to think about (brother) and I'm the one who is close by and it's the least disruptive

for *him*. He's been involved with (day program)...and working around this area and my other brothers are outstate. Well no one's really in (the hometown) any more...

After the death of his father, this participant was prepared to take on the role of guardian for his brother, knowing that the family had identified him as being the next logical choice.

Respecting *my* choices. Another theme that emerged around future planning is respect for the diversity of choices that parents and siblings make for their family member with I/DD. Participants were asked to consider what their sibling's life might look like when their parents are no longer able to provide guidance. One participant contrasted the support her parents currently give her brother with the support she would be able to provide. "They take him to church; they take him out to eat every Saturday morning for breakfast. They just took him to Hawaii for two weeks for a trip." Later in the interview she reflects, "Do I see myself doing all they do? Realistically, probably not, because I have three kids and my family. And for my parents, a lot of their world has revolved around him forever." Another participant stated:

My mom and dad right now are on the cusp of it. What are you going to do when we are gone? (Sister's) still here...an ongoing continuous dialogue. What if I have my own family, or what if I have my own life going? It's been pretty real conversations. At the end of the day, I'm going to make the decision and you aren't going to control it, and you're going to have to trust me. I will use my best judgment and I'll do the right thing. So part of it is a dynamic power struggle between my parents and I. I'll always have her best interest in mind, but I also

have another life here, which is mine. I know my brother won't be there and he won't help out; I'll be her guardian or conservator.

A third participant had this to say, "Truth be told, I have a different plan going on" with regards to decisions she makes for her brother.

Who will continue to be a support? Participants were also asked to reflect on whether *they* had made any future plans for their sibling. The following interview question was asked among participants: "What kinds of plans have you put in place to ensure that your brother or sister will continue to have someone to advocate for him when or if you are no longer able to?" Several participants reported that they had not made plans yet. For example, the participant with a 33-year-old brother reported:

I'm not sure who would step in. I have a couple of people that I think would be good, but it's really hard to take yourself out of the equation and think that person is going to do a good enough job, and so it's a struggle. Something we talk about all the time and it's the same conversation we have when thinking about our will and our own children if something happened to us because no one is going to be good enough. So who's the best choice? It's something we talk about a lot, a lot.

When asked this question, one participant and her husband had this conversation:

Participant, "It has been a conversation, but we haven't done anything about it."

Husband, "We assume that our three kids would step up to the plate. I honestly do. Don't you think so?"

Participant, "Oh yeah. I think it will be a challenge for them though."

Another participant, whose 62-year-old brother has been living with the participant and his wife for almost ten years, responded:

Future plans? Well, he's going to be living with us until he can't live there any longer or we can't take care of him...so, we haven't really done much any other *planning* other than, this is what it's going to be.

Family or friends will help. Other participants were able to identify family members who are already in place to provide support. A participant with an older brother had this to report:

...we do have a solution, a backup plan...(brother's) aunt. And she can see the bigger picture too and what's important to (him). So we have her, if anything happens to my mom she'll just come in. She's going to look at it like this is my nephew, I see what (he) wants and what's best.

While a participant currently supporting a younger brother answered the question this way:

My husband or our three sons would absolutely step up. Have I ever asked them? No. But it's true. I probably would want to think about that. I would want to think of some kind of a back up. I think obligations of the family would continue that within the family.

Two other participants identified close family friends. One participant reported, "We have a really good neighbor who has a daughter with Down's syndrome and her daughter is a social worker...I have a feeling that that would come into play for sure and they're like family to us." While the other stated:

I have a best girlfriend that I have known for about ten years now. She absolutely adores (my sister)...we have openly talked about it with her that if I need some

help would you be there to help me, and she said yes and if I pass away, would you be there to help me and she said yes.

Professional helpers. One participant brought up this point, “Sometimes with family I think you get tied into all these emotions and other stuff. As where you need a clear view to see just what’s important for the individual with I/DD.” This participant suggested that it is also important to have a good relationship with her brother’s county social worker. “It’s the same with her, she can see the bigger picture, too, what’s important for (my brother). That’s all she cares about.” This theme is echoed in the response of a 65-year-old participant who has made the following plans for her younger sister:

I have a trust set up for her so there will be somebody who handles the financial part of it and...that person may or may not take care of her but, then y’know, she is connected to the county and she has a social worker and, umm, financial worker. And her housing is...subsidized. So, umm, I’m pretty sure the social worker would help her fill out forms and stuff like that and when she can no longer be in her own home I’m sure that they will facilitate moving her into like, a group home or that type of thing. So I’m not real concerned about it,

It will depend on my sibling’s need. A 62-year-old participant also thought that there would come a point where professional helpers may be needed to support his sibling with I/DD. He stated:

What’s going to happen, is he going to be, get to where *we* can’t take care because of his situation or is it going to be *our* situation, where we can’t take care of him because of our situation. If it’s because of *his* situation, then he’ll have to go

someplace or be someplace where people can *do* it, if we can't do it. But, more than likely, our plan is our *family*. We prob'ly don't believe too much in nursing homes and that type of thing and y'know, I think we have the wherewithal to chip in and take care of...it depends on what it is, I suppose. How bad *is* it?

Experiences with End-of-life Planning

Participants have had very different experiences with end-of-life planning. Some participants have been part of their parents' planning; others have begun to do some of their own planning. A 20-something participant noted that she has "never had anyone close to me die." Another participant explained, "I think it's maybe one of those things that no one wants to think about it. It's so easy to not think about it." While another stated, "Y'know you think you're going to be able to plan your death but it doesn't always work that way either."

Planning for my end-of-life. Several participants stated that they have begun to make plans for end-of-life for themselves. A 40-year-old participant reported:

My wife and I we have definitely shared what we would want, or the thing we have not done is made it official or legal. It is sort of silly not to do, yeah; we've had those conversations. And I think we know what each other would want.

This is echoed by a 63-year-old participant who stated:

So, we talk about it but we really haven't set down and said okay. We have a will, y'know...and do you like that song? Would you like that at your funeral? But we haven't really said, well, here it is kids.

Then there are the participants whose own life experiences have normalized the process of talking about end-of-life. For example, one of the participants, a breast cancer survivor, advised:

Something should be written down. I have something written down for my children. They say, “Mom for God sake!” and I’m comfortable with the fact, even though no one wants to talk about it. When the day comes they will say, “Thank God she was so repetitive.”

Another participant who has had a personal experience with death and dying stated:

I’m really matter of fact about death because I had a near death experience. And I think, being a teacher, I’ve always talked about most things that no one else would ever address in a classroom. So, I’m comfortable about just bringing things up that are going to happen to you in your life and people need to talk to you about.

Planning With My Parents. Two participants stated that they had thought about what might be important for their parents. One stated, “I know their wishes really well...I think my parents’ (wishes) would be the same as mine. Life without quality of life is not life.” The other participant said that she had some conversations with her parents about hospice. She concluded:

I really like non-traditional, not a person to shove them in a nursing home; a directive that I couldn’t physically carry out. Or not, you know, not keeping them on life support. If you can’t stay alive on your own bodily function then it’s time to go.

Have you had a conversation about end-of-life with your sibling?

No, we have not discussed it. For most participants, talking about death and dying is not easy. Even participants who were able to begin making plans for their own end-of-life stated that they had not had discussed plans openly with their sibling with I/DD. A 27-year-old participant reported on her reluctance to make plans:

I've thought about it only because I've worked with somebody with Down's syndrome and who had Alzheimer's and died that way. And it really put it quite a reality check for me. I saw my sister in her and thought about it a lot. And we haven't discussed much of end-of-life planning at all. Scares me to death to think about it...it's the Alzheimer's thing too. I can't imagine. So there hasn't been really any end-of-life, which there should be. You never know.

Another participant reported:

We haven't officially sat down and had that conversation. And I never, I have an idea, but seriously I have never really asked the question or really never thought about it...the importance of doing that with him...I could be way off base and not know it so it's sort of foolish and silly, not to explore that and to have that conversation.

A third participant reported the following:

I think with (brother) any end-of-life planning would most likely be done by - assuming my parents would have died by then - I think it would really be me directing my value system. Would it be: Intubated? Tube fed? Not interacting with people? That would not be quality of life. Quality of life for (brother) would be interaction with people, animals. From that perspective...would that simplify

it? Yes and no. I think I would have a pretty good idea of making decisions that would be loving.

Barriers to the conversation. A common barrier to talking about end-of-life is the desire to protect the sibling from emotional anguish. “When we start to talk about what might happen at the end of his life, he’ll really get agitated,” was one participant’s response. Another participant reported that having a conversation about death with her sister, “will upset her. It will turn her world upside down...you have to introduce it and then it takes a while to process through. But who likes change really?” There is also the concern that the sibling with I/DD will lack the coping skills needed to process the idea of end-of-life. Another participant reported:

It’s just that...I don’t know how he would take that; I think he would worry about it. I don’t think he has enough cognitive skills to, to comprehend it. I mean, he would think that he has never had anyone close to him pass away. Like I said, he worked at an animal hospital, so there were some sick animals all the time and he literally would cry for an hour when a rabbit died. And it was hard, and now that I look back, it was hard for him. I mean, I guess no one really realized it. I guess that’s why we just never told him. If I were to sit down and have a conversation, I don’t know how it would go. I don’t know. I can’t imagine he would ever even think about it.

Another barrier is the sibling’s ability to conceptualize death. One participant stated that her sister, “really doesn’t understand death at all. As far as she’s concerned she’s going to live forever. So talking about it with her right now, we wouldn’t really get anywhere.”

A similar conclusion is drawn by the participant who reports that her sister’s:

...concept of death is very interesting—we've had a couple of grandfathers and a number of pets, and the Pope, She always says that the Pope is in heaven.

Hanging out with and all the animals, our bunny or grandma and grandpa...she likes watching the Catholic channel and we're not even raised Catholic. She doesn't like the new Pope. She watched Pope John Paul II when he was buried and she was crying so she has a concept of death and dying and afterlife. So it's interesting to see how she will process it. When it happens.

The language participants use to talk about death and end-of-life planning can also be a barrier. One participant reported:

Right now I am setting up his prepaid burial thing. He sees it as retirement plan. That's another piece of support - you have to figure out a way to come in the back door. There is no way I can say, “(Brother) I am preparing your funeral.” He has no place to put that. Funeral is Mom left, Dad left, brother left that's the end you don't see them again. Now retirement is your legs hurt, you have to retire sometime and you need money put aside.

Yes, we have talked about it. Not all participants have shied away from making end-of-life plans with their sibling. A participant with an older brother described her experience this way:

When (brother) got some money we got him his casket right next to Mom and the vault, we talked about it, you know, dying, but not if something happened to him. He knows he will be buried by Mom. So we have thought about it but not in detail.

Her husband, who shares guardianship, added, "I brought him over there and he picked out his casket and everything. Wow, he didn't pick out the expensive one or the cheapest...he picked the next one above that." Another participant shared this experience of end-of-life planning with her younger sister:

We actually have a, the document, and I have the power of attorney for her end-of-life stuff and she does NOT wish to be resuscitated...or any...uh, heroic measures taken. And that's how my parents were too, they didn't want a feeding tube any of that kind of stuff and that's how *mine* is too. My end-of-life is...if you think I'm going to be mentally disabled, don't bring me back (laughs). And also, we even have...we went down to the funeral home and signed documents that she's going to be cremated, and I am. And then, she and I are going to share the same plot because you can have two cremains in one cemetery plot. So we already have, all that, in place. And, uh, y'know, my dad was down here when he died...and we were dealing with the funeral home anyway, and then I said, as long as we're here do you think we should take care of this anyway? And she said, "Oh I think we should 'cuz I want to be with you." So that part's all taken care of.

For one participant, her sibling with I/DD found the right moment to make his wishes known. The family had gathered for the funeral of one of the other brothers when the family had this conversation:

(Brother) asked, "When it's my turn, are we going to have this kind of lunch kind of thing?" I said, yeah and people want to share stories. And he said, "I hope people laugh." And I said, of course, we know you're happy because it's your

turn, you're with Mom and Dad and (brother). We'll be happy. He went "Ok, ok." Besides, nobody's sad for long. We'll start saying goofy stories. And he said, "Ok you got that figured out, (sister)" and that was it. He wanted to know what would happen. I consider that some kind of advance directive. He asked the question for a reason. Because of the innocence, we all have this ridiculous, the taboo subject. In their innocence, he sits and says, "You know sis, is it going to be this way for me?" When it is going through their mind, they have already thought about it, and maybe he asked himself a question, and then he got to this point and he asks. And he knows I am going to give a straight answer. I never ever say I don't want to talk about it...what he needs to know is what he internalized, "I want what (brother) had." Beer in the corner for toasting and he thought it was nice. "Count it out so everyone gets *one*." He laughed and laughed.

It takes a good partner

One unexpected theme that emerged from the interviews was the importance of having a good life partner, someone who could understand the struggles and share the joys of active involvement in the life of a sibling with I/DD. This came up in multiple places in the interviews. One participant, reflecting on making decisions with his brother had this to report:

...my wife, (is) his legal guardian, I didn't want to do that. I chose that, I didn't want to be his guardian; I just want to be his brother. And so, we will be the ones who will have to help to make those decisions, if we're ever in the situation where we have to make those decisions. In many ways we really work together. He's never forced to do what he doesn't want to do.

For another participant, this theme came up as she answered questions about end-of-life planning. She introduced the subject by stating that “it helps to have a third party” to help with the conversation. Then went on to add that her husband’s “been a godsend, but having someone in your life who has that understanding, because if you don’t have that, you’re in big trouble.” A 25-year-old participant made a similar comment when identifying who she could turn to for support “my boyfriend. We’re going to get married some day. And he adores (sister) and we’ve already talked about taking care of her together.”

Discussion

One of the overarching themes that came out of this study is that siblings support their brother or sister with I/DD differently than parents do. While it is possible to compare and contrast the research on parental caregiving roles (Hayden & Heller, 1997; Hodapp et al., 2010) with those of siblings, this study also shows how parents influence how siblings fulfill their roles as caregiver. For example, parents influence the definition of sibling roles, the types of support provided to the brother or sister with I/DD and even the definition of what quality of life looks like for the participant and his/her sibling with I/DD. This study has also shown that adult siblings of individuals with I/DD share many of the experiences of other siblings (Dew et al., 2008; Eriksen & Gerstel, 2002; Hodapp et al., 2010; Martin et al., 2005; Stoneman, 2005; White, 2001; White and Riedmann, 1992).

The Role of Parents

One theme that emerged in this study is that parents stay involved in their son or daughter with I/DD’s life for as long as they are able. This finding supports the work of

Griffiths and Unger (1994). In the interviews, participants talked about the length of their parents' involvement and how it has impacted on the support they have been able to provide to their sibling with I/DD. In three cases, the participants were asked to take on the role of guardian when one parent passed away. For those participants whose parents are currently involved, the plan is for the participant to take on more responsibility as their parents age. One sibling identified that right now she is providing more instrumental support by helping her brother maintain his apartment, but she anticipated a change as her parents age. Another finding in this area is that participants see their support role differently. The siblings in this study recognize that their role will be different from that of their parents because the relationship is different. Several participants alluded to their sibling with I/DD being the center of their parents' world. That's a responsibility that parents can take on, but not one that siblings felt drawn into. One participant summed it up this way, "Do I see myself doing all they do? Realistically, probably not."

A study by Bigby (1998) concluded that sibling roles are shaped by parental expectations. One of the first themes to emerge in this study was that participants identified that their parents helped them to see their sibling with I/DD as a gift to the family. Participant stories included supporting a sibling with I/DD's early learning or helping with physical cares like assisting with feeding or changing diapers. One participant was quoted as saying, "We all had our jobs, we all had our days." This concurs with a study by Knox and Bigby (2007) in which families were seen as being interdependent and working together for the common good. This also concurs with research done by Dew, Balandin, and Llewellyn (2008) who noted that being a sibling to an individual with I/DD is a family role. In all of the stories in this study, one can hear

echoes of the parents' expectations of what it means to be a family, what it means to support each other, and what it means to be a sibling.

What It Means To Be A Sibling

In a study of adult sibling relationships, Myers (2011) found that siblings maintain their relationship for two reasons: choice or circumstance. Participants for this qualitative study are all actively involved in the life of their sibling. Elements of circumstance that emerged in this study include being the sibling who lived the closest or who had the resources to provide the level of support the sibling with I/DD needs. One example of this is the instrumental support provided by participants who have made themselves available to accompany their siblings to doctors' appointments. Elements of choice include social supports, involving the sibling in the life of their sibling's families, and making time for what one participant called "sibling bonding." In the interviews with the nine participants, it was clear that they all genuinely enjoy their time with their adult sibling. Three of the participants in this study are in the role of guardian or conservator for their brother or sister while the others provide both instrumental and social support. In addition, many of the participants traced their current involvement in the life of their brother or sister with I/DD to the moment their sibling became part of their life. This supports the work of Pruchno et al. (1996) who concluded that parents who model family caregiving help prepare siblings for a continued support role as adults.

Previous studies have identified both the positive and negative impacts of having a sibling with I/DD (Dew et al., 2008; Bevan & Stetzenbach, 2007). The participants in this study also reflected on positive and negative aspects. Positive themes were seen in how participants described their sibling. For example, "He's a happy kind of guy" or

“She’s the unofficial mayor of our city.” Positive impacts can also be seen in the theme of sibling alliances and connections. Examples of this include early advocacy for the sibling with I/DD and including the sibling in the everyday life of the family. Participants also explored the negative impacts of having a sibling with I/DD. This was seen in participants’ reports of both their own experiences as well as their reports on the experiences of other siblings in the family. One participant stated that her sister is “emotionally dependent on me” while another reported that their brother never really learned to communicate with his sibling with I/DD. Previous studies have identified caregiver stress as it relates to families of individuals with I/DD (Essex et al., 1999; Heller et al., 1997a; Yamaki et al., 2009). In this study several participants alluded to the “stress” of growing up with a sibling with I/DD and how that impacted their relationships both within the family and without the family.

Future Planning

This study supports studies that have shown that parents are reluctant to make future plans for their adult child with I/DD (Heller & Caldwell, 2006; Heller & Factor, 1993; Heller & Kramer, 2009). A majority of the nine participants stated that their parent did *not* express future plans for their adult child with I/DD. For those whose parents had talked about it, the plans are vague. For example, my parent “just wanted him to stay with us” or I’ll “be taking care of her. That’s the plan.” It is interesting to note that just as parents did not make plans for their adult children with I/DD, the adult siblings in this study who are next in line to provide support have not made future plans either.

Previous studies have also identified that parents of adult children with I/DD have concerns about housing and financial stability (Gilbert et al., 2008; Griffiths & Unger,

1994; Heller & Caldwell, 2006). These concerns have often led parents to believe that the best place for their adult child is in the parents' home (Gilbert et al., 2008). This may help explain why four of the participants in this study either have a sibling with I/DD living in their home or have included this idea in their own future planning. Unlike parents in the Gilbert, Lankshear, and Petersen study (2008) who had not really thought through their decision to move their child into a community based setting like a supported apartment or group home, the participants in this study have given the decision a lot of thought. It takes commitment to find the right placement and it takes compassion to understand that, as one participant stated, "Your place where you live has to be your refuge."

While some participants in this study reported that their parents had set-up a trust or left an inheritance for the sibling with I/DD; others reported on their struggles to get their sibling on waiver programs or complete paperwork for financial assistance. Support around money management and concern with finances was important to participants in how they support their brother or sister with I/DD. For example, participants referred to the way their brother or sister manages money. "Money management is something he struggles with," or "Now he's into lottery tickets." Another participant stated that she has been saving money for her sister her whole life because her parents were not able to provide much financial support.

End-of-life Planning

The life experiences of both the participant and their sibling have had an influence on conversations about end-of-life in families. For example, one participant expressed her reluctance to talk about it with her brother because he has not experienced the death of anyone close to him. She also worried that, based on his experiences at his job with

sick animals, that he might get overwhelmed and not have the skills needed to cope. In contrast, a participant who has had her own near-death experience has been able to be very open with her sister in discussing what is important at end-of-life. Participants talked about finding opportune moments to begin the conversation. For one participant, this was the death of a sibling that prompted a conversation about what her brother with I/DD felt was important. For another participant, it was planning her father's funeral that helped her normalize the experience for her sibling with I/DD.

When the questions about end-of-life planning were asked, several participants responded with statements like "We really haven't thought about that yet." This researcher thinks that this is a normal response to end-of-life planning. No one wants to think about death. As one participant stated, "Y'know you think you're going to be able to plan your death but it doesn't always work that way either." However, for participants who have had more life experiences with death and dying, end-of-life planning was something that they felt they could comfortably talk about with their sibling with I/DD.

Two of the participants over the age of sixty agreed that the state or county would make provisions for their sibling if they were unable to continue to provide support. However, the other seven participants all identified that it would be other family members who would continue the continuity of care. This reinforces findings in the Knox and Bigby (2007) study, the authors conclude that caregiving is a "family business."

Findings of this study include that the kind of support siblings provide is guided by, yet different from, the support provided by their parents. Also, that siblings use their relationship and values to guide decisions about quality of life and, ultimately, end-of-life

for their sibling with I/DD. In the next section, the researcher will discuss the strengths and limitations of this study.

Strengths

A strength of this study is that it will add to the literature on adult siblings of individuals with I/DD. One important finding in this study is the topic of end-of-life planning for adults with I/DD. This is a new area of concern that is impacted by the lack of historical precedence regarding opportunities for individuals with I/DD to participate in decision-making. The literature in this area is just starting to emerge and has been focused on helping families and providers begin conversations about future planning.

Another strength of this study is the finding that both male and female participants provide supports to their sibling with I/DD. The researcher had anticipated that there would be gender role differences in the kind of support that adult siblings provide. Previous research has shown that it is often the sister who takes on the caregiving role when parents are no longer able to (Eriksen & Gerstel, 2002; Griffiths & Unger, 1994; Hodapp et al., 2010; White & Riedmann, 1992). As expected, in the current study, female participants were the larger sample than male participants (i.e., seven women compared to two men). One female participant even noted that it has been her experience that more sisters are involved in role of guardian for their siblings with I/DD. This supports the idea of caregiving as a gendered role (McGraw & Walker, 2007). However, one of the male participants reported on helping with the care of his brother from a very early age. This care included what may traditionally be considered female caregiver roles such as helping to change diapers and assisting with feeding at meals. In addition, both male participants have invited their brother into their homes and their lives

despite the fact that they both have female siblings who could take on that role. This may indicate a changing trend in the gendered nature of caregiving or it may reflect on the family making the most practical choice for the sibling with I/DD. Either explanation would represent a new finding that adds to the conversation on family caregiving and the roles of siblings.

Limitations

Limitations of this study include the researchers own lived experience of working with adults with I/DD and their families. My twenty years of experience working in the field may give me a biased opinion of how families and services work together to support individuals with I/DD. The framework of my personal experiences may also have skewed both the design of the study and my analysis of the data. This was a small, exploratory study of nine adult siblings of individuals with I/DD. All participants in this study are Caucasian and live in the Midwest. In addition, several of the participants interviewed are people whom the researcher knows personally. This may have had a significant impact on the depth of the information provided. Another limitation is the small sample size of nine siblings. With such a small sample size, it is difficult to generalize findings to the larger population. Furthermore, the researcher was not able to interview all of the siblings in the family or include individuals with I/DD. Due to Institutional Review Board (IRB) limitations, it was not possible to interview self-advocates on decision-making, future planning or their wishes for end-of-life care. Not being able to include adults with I/DD in the study does limit what the researcher was able to learn about adult sibling relationships, future planning, and end-of-life planning for individuals with I/DD.

Implications for Social Work

This study has implications for social work practice at the micro, mezzo and macro levels. At the micro level, the researcher will reflect on individual practice and consider the work that social workers do with individuals with I/DD and their families. At the mezzo level, the researcher will look at social work policy and programs that can be implemented to support individuals and families. At the macro level, the researcher will look at implications for further research.

Practice. An important goal of this study was to identify ways for social workers to better support individuals with I/DD and their families. Self-determination was one area that participants identified as being important to their sibling. Being able to make their own decisions about work, free time, housing and what contributes to quality of life were common themes. Participants reported on the importance of giving their sibling choices, learning from natural consequences, and recognizing where their sibling would need support. One participant reported that what works best for his brother is to offer two choices, explaining the consequences of each. It is important for social workers who are supporting individuals with I/DD and their families to recognize the value of offering choices.

Another finding from this study that will benefit social workers is learning to use the language of the individual and his/her family. One participant stated that she “comes in from the back door” with her brother while another said that she is very direct with her sister. Understanding how families have framed conversations and using that same language can be powerful. For example, one participant described talking with her brother about his “retirement plan” while another participant was able to talk with her

brother about “being next to Mom in the vault” and invited him to participate in his own funeral plans.

As the researcher asked questions about the quality of life and what this meant for end-of-life planning, she realized how the two concepts are interrelated. Participants were able to see that their brother or sister with I/DD values many of the same things they value. For example, one participant stated that both he and his brother with I/DD value work and family while another concluded that her sister is “a lot like you or I.” The connection between quality of life and end-of-life became very clear in the conversation one participant had with her brother about funeral planning. He was able to say that he felt it was important for people to have good food, toast with a beer, and tell stories. This conversation was really not that different from the participant who said that he and his wife had started to think about the music they might like at their funeral. End-of-life planning really comes down to those things that give each of our lives meaning. This finding is useful for social work practice because it focuses on what the individual and family value. The health professions focus on the mechanics of end-of-life – do you want antibiotics, do you want your heart restarted if it should stop, do you want to be on a ventilator or have a feeding tube? Social work practice takes a both/and approach. Social workers are trained to view both the person in the environment *and* family *and* cultural values. We ask questions like what gives your life meaning? What kinds of experiences do you value? What are your beliefs about end-of-life?

Policy. This study also reflects changes that can be made at the policy level.

Person-centered planning. This theme manifested in the language of choice that permeated the interview responses. Participants stated the importance of decision-making

abilities and choices among their sibling with I/DD, the consequences of some of those choices, and how to support making choices that are beneficial to the life, health and safety of the sibling with I/DD. The participants in this study are very skilled at putting their sibling with I/DD at the center of planning and decision-making. As social workers, we are also trained to think of the person in the environment and to look for the strengths already inherent in the individual. All of us in the helping professions can learn from the families who are involved in helping individuals with I/DD make their own choices, who support them when they make mistakes, and are skilled in framing choices in a way that allows the person with I/DD to feel in charge of his or her own life.

Participants in this study worried about grief and loss issues with their sibling. Some of the unanswered questions included, does my sibling have the skills to process losses? And does s/he understand death? Clearly, building in supports to help families talk about death and to help individuals with I/DD process losses is needed. One way to implement this would be to offer grief and loss curriculum in schools, day programs, and other agencies that support individuals with I/DD and their families.

Research. As end-of-life planning becomes more normalized in our culture, it will be important to continue research on best practices for teaching people how to make end-of-life decisions. It will also be important to continue to identify the needs of families of persons with I/DD and change the current way services are provided to include flexibility of choice. In addition, it would be interesting to talk with families who have experienced palliative care and hospice care with their sibling with I/DD. What kinds of things did you find to be the most important? How were services delivered to

you and your sibling? What did you find most beneficial? Where could the service have been better?

Future research might also include the opinions and experiences of adults with I/DD. In addition, studies that look at the role of *all* the siblings involved in the life of the person with I/DD are needed. An understanding of siblings who are less involved or non-involved among participants in this study would contribute to the body of knowledge on adult sibling relationships. Research that includes the opinions of self-advocates and/or all of the siblings in a family would give a more nuanced and deeper understanding of the struggles and joys of growing up with a sibling with I/DD. Additionally, a larger study may show that there are generational differences among siblings or that gender roles are becoming less important as both brothers and sisters take on support roles. In this study, seven of nine participants support a younger sibling with I/DD. Another question that future research could address is the role of birth order.

Conclusion

I have spent most of my adult life working in group homes, day programs, and residential facilities that serve the I/DD population. Over the years, I have seen firsthand that as parents age, siblings are relied on to provide additional support to their brother or sister with I/DD. When I began to think about a research project, I knew that I wanted to do work that would give back to the people I have had the honor to work with for so long. I hope that what I have learned from the nine participants in this qualitative study will add to the research that explores the lived experience of adult siblings of persons with I/DD.

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APPENDIX A
INTERVIEW GUIDE

Demographic Questions

How old are you?

How do you define your race?

What is your economic status? (give a range)

Interview Questions

How old is your sibling with I/DD? Is your sibling a brother or a sister?

How many other siblings do you have?

Did your sibling grow-up in the same home as you?

How long have you been involved in supporting your brother/sister with I/DD?

What does that support look like – what kinds of things do you do?

Did you always plan to be involved in the life of your sibling? If not, what changed?

Can you tell me what kinds of future plans your parents made for your brother/sister?

For example, did they make specific plans for financial support or tell you what their expectations were?

Is your definition of quality of life different for you than it is for your sibling?

When you think about quality of life for your brother/sister, what kinds of things do you think are important to him/her?

Tell me about your experiences with end-of-life planning – For example, some people have used a living will, an advance directive, or five wishes. Others have had conversations about what they may want or need at end-of-life.

Have you and your sibling had a conversation about end-of-life?

If yes, how has that gone for you? If no, why not?

What kinds of plans have you put in place to ensure that your brother/sister will continue to have someone to advocate for them when/if you are no longer able to?

APPENDIX B

FLYER



Recruiting adult siblings of individuals with intellectual/developmental disabilities for a research study!

Looking for adult siblings to interview on topics related to planning, advocacy and quality of life.

Study purpose: To learn more about the lived experience of siblings who support a brother or sister with I/DD.

Criteria for participation:

- 25 years or older
- Sibling of an adult with I/DD
- Willingness to share your experiences

Commitment: 1 1/2 hours for an interview

Participants will receive a \$10 gift card for their time and participation

Please call Cecile Kudela at XXX to arrange an interview at a time and location convenient for you.

Research is being conducted under the supervision of
Dr. Catherine Marrs Fuchsel, Assistant Professor of Social Work
St. Catherine University/University of St. Thomas.

If you have any questions about your rights as a subject/participant in this research, or if you feel you have been placed at risk, you can contact the Chair of the Human Subjects Institutional Review Board, through St. Catherine University at (651) 690-7739

APPENDIX C
INFORMATION SHEET FOR THE STUDY

My name is Cecile Kudela and I am a masters of social work student under the direction of Professor Catherine Marrs Fuchsel, PhD, LICSW in the School of Social Work, St. Catherine University and University of St. Thomas. I am conducting a research study to explore the experiences of adult siblings of individuals with intellectual or developmental disabilities. I am interested in learning how siblings help make decisions about quality of life and end-of-life. I hope that what I learn from this study will help social workers and service providers understand the experiences of siblings and develop better ways to support individuals with I/DD and their families. I would like to interview adult siblings of individuals with I/DD who have had experience supporting their brother or sister. An example of support can include attending annual meetings and advocating for the sibling.

I am inviting the participation of adult women and men who have a sibling with I/DD. I will be conducting the interview at a location of the participant's choice. I will set up the time and day for the interview depending on what is best for you. If you agree to participate, I will ask you on tape if you understand the information letter, if you have any questions, and if you agree to take part in the interview. This study is voluntary and you may choose to stop participating at any time. You may also choose not to answer any question.

In the interview, I will ask you about your experiences as a sibling who is involved in supporting and advocating for your brother/sister. I will ask you what family life was like and how your parents prepared you to support your brother/sister. I will ask you to tell me how you define quality of life and how this impacts on the advocacy you do on behalf of your sibling. I will ask you about end-of-life and if you have thought about the choices that are important to you when planning for the future of your sibling with I/DD.

If you become upset during the interview or if you decide after the interview that you would like to process with someone, I will provide you with a list of community resources. For example, I will have telephone numbers of counseling centers that you can contact.

There is one benefit directly to you for being in this study. You will receive a \$10 gift card for your time and commitment. This study may help other people understand the role that siblings have in the lives of individuals with I/DD. The information from this study will be published in my thesis and may be published in social science journals. Your name will not be used to identify you and information will be recorded anonymously. I will ask you to select a different name that will be used in the reports and in the data collection.

The interviews will be tape-recorded and they will not be recorded without your permission. You will have the right to ask for the recording to be stopped. The audiotapes will be locked in a filing cabinet at the St. Thomas University Interprofessional Center. Only Dr. Catherine Marrs Fuchsel and I will have access to the confidential information.

The data will be kept until August, 2012 and all reports and notes will be shredded. The tapes will be destroyed and discarded immediately after the tapes have been transcribed.

Contact information:

Cecile Kudela

Cell phone: XXX

E-mail: XXX

If you have any questions about your rights as a subject/participant in this research, or if you feel you have been placed at risk, you can contact the Chair of the Human Subjects Institutional Review Board, through St. Catherine University at (651) 690-7739

APPENDIX D

List of Resources**Twin Cities- Metro Area**

| | |
|---|--------------|
| Crisis Connection Phone Hotline (24 hours) | 612-379-6363 |
| St.Thomas Interprofessional Center for Counseling | 651-962-4820 |
| Walk-in Counseling (Minneapolis) | 612-870-0565 |
| United Way | 211 |

Mankato Area

| | |
|--|----------------|
| Blue Earth County Mental Health Center | 507-304-4319 |
| Mankato Psychology Clinic | 507-387-3195 |
| RiverView Clinic | 507-625-4060 |
| Minnesota Crisis Connection | 1-866-379-6363 |

Honoring Choices Minnesota

<http://www.honoringchoices.org>

Health Care Directive Forms

<http://www.metrodoctors.com>