

Building Sibling Capacity: A future safeguarding measure for people with intellectual disabilities

Erica Baker-Tinsley, MACD candidate

School of Public Administration

University of Victoria

July 2016

Project Client:

Jane Barken, Board Director

Brockville and District Association for Community Involvement

Supervisor: Thea Vakil, Associate Professor and Associate Director
School of Public Administration, University of Victoria

EXECUTIVE SUMMARY

The sibling relationship is often one of the longest standing relationships held by a person with an intellectual disability. As parents age and are no longer able to provide care, siblings tend to assume supportive roles that enhance and safeguard the life of their vulnerable brother or sister. Aspects of a supportive role may be unique to a family but often encompass a broad range of support and assistance which promotes wellbeing and helps their brother or sister have a good life. However, siblings may not always be prepared to take on these important responsibilities, which is a growing concern of organizations like the Brockville and District Association for Community Involvement (BDACI), the client for this project.

The objective of this project is to provide BDACI with sibling-specific research that will inform and enhance the organization's planning processes, leadership development strategies, membership engagement initiatives, and training efforts by investigating the following research questions:

1. What are effective capacity building strategies to prepare adult siblings of people with intellectual disabilities for future supportive roles?
2. What factors influence the likelihood that siblings will take on such supportive roles?

Background

The life circumstances of people with intellectual disabilities have changed significantly in recent decades. Advances in medical care allow people with disabilities to live much longer lives than in the past and changes in the service system have enabled a transition from institutional to community care. These changes created opportunities for parents to raise their disabled children at home where they could be a part of community life. The first generation of these parents are

now aging and an increasing numbers of siblings will begin to take on supportive roles, assuming the responsibilities previously held by parents. In addition to issues of preparedness research indicates that many factors influence a sibling's willingness and ability to support their brother or sister and that the needs of siblings are often overlooked.

The Brockville and District Association for Community Involvement is a non-profit organization that supports people with intellectual disabilities and their families. As a family support organization, BDACI is committed to enhancing its service practices to meet the changing needs of the people supported. The organization is interested in learning how to support families in a way that builds the capacity of siblings, to enhance the natural role siblings play in each other's lives and to prepare them for the supportive roles they could assume in the future.

Literature Review

The review focused on two key issues related to the common concern held by parents of sons or daughters with intellectual disabilities, namely, "What will happen to my child when I'm gone?" Scholarly literature was sourced for this review, primarily from Canada and the United States, however a few studies from other countries were included to illustrate the universal nature of the issue. The literature spanned the past three decades given the evolving nature of this issue.

The first topic reviewed was future planning, which is a complex issue for many families. The literature highlighted relatively low levels of planning, despite its importance. The review also explored various caregiving options with family-based arrangements reported as the preferred options of parents in many studies. The second topic reviewed issues related to sibling-caregivers. The literature reported that siblings are the most common family member to assume future caregiving roles and that various factors influence this caregiving such as gender, degree

of disability, amount of contact between siblings and involvement in future planning. The literature also highlighted various needs of siblings including training, connections to other siblings, and active involvement in future planning.

Methodology

A qualitative research approach was used as learning from the personal experiences of siblings was essential to this project. Purposeful sampling was utilized to recruit two groups of participants. Group one included nine adult siblings of people with intellectual disabilities who have already assumed supportive roles in the lives of their brother or sister. Group two was composed of eight adult siblings of people with intellectual disabilities who have not already assumed supportive roles in the lives of their brother or sister but intended to do so in the future. This group also included other family members like nieces/nephews and cousins who had similar future intentions. Participants were recruited primarily by the client.

Individual interviews and a focus group were the methods used in data collection. The semi-structured in-depth interviews were conducted using 15 open-ended questions with some follow up questions as needed. On average, interviews lasted slightly over one hour. All interviews were audio recorded and transcribed. The focus group involved a two-hour discussion, facilitated by the researcher, using leading questions in five topic areas. The discussion was audio recorded and the researcher produced a written summary. A thematic analysis was used to identify common themes within the data.

Findings

The findings capture the perspectives of both participant groups. Data was organized in four sections: relationships, influential factors, future planning and building capacity revealing 14 themes.

Data was collected about sibling relationships that revealed participants had close, loving, and deep connections to their brother or sister. Participants also described their relationships as typical, just like other sibling relationships. Siblings reported early and active involvement in their brother or sister's support, which contributed to their close relationship.

Several factors influenced participants' willingness and ability hold supportive roles. Being raised in a family culture that fostered shared responsibility and mutual caring was reported as a major influential factor. Participants also felt that experiences and training had been beneficial as it connected them to people and ideas that shaped their thinking. Siblings reported positive mindsets that helped them view the support to their brother or sister in a positive light, not as a burden. As well, various barriers were discussed that interfered with supportive sibling relationships.

Siblings reported being involved in future planning discussions, many of which had started at an early age. Much of the planning described by siblings had been informal and indirect, with details largely based on assumptions and intentions. Despite the vague nature of this future planning, siblings were quite clear about the responsibilities involved in their supportive roles, describing such things as financial management, decision-making, advocacy, and coordination of services.

The research data revealed specific capacity building opportunities for siblings. Training was seen as essential, with participants recommending values training, a need for information about financial, legal and service matters, and training specific to disability and medical conditions. Siblings expressed a need to connect with others who could be supportive, including other siblings, like-minded people, and paid staff. A slow transition of care between parents and siblings was another identified need. Siblings felt they would be better prepared to support their brother or sister if responsibilities were increased gradually. Having open and honest communication between parents and siblings was seen as essential. Siblings reported a need to be actively involved in future planning discussions at an early age. They also felt planning conversations should be explicit so that the parents' wishes and expectations are clear.

Discussion

An interpretation of the research findings and the literature review provided insight into factors that influence sibling caregiving and the needs of siblings in supportive roles. Key considerations and action implications emerged related to building sibling capacity and enhancing service practices. The need to foster supportive sibling relationships surfaced as an important strategy given the influence close relationships have on a sibling's willingness to assume supportive roles. Promoting typical sibling relationships, shared responsibility, and positive mindsets about caregiving will help to sustain future supportive relationships. Enhancement of future planning was a key consideration given the relatively low rates of planning reported by this study and the literature. Actively involving siblings in the creation and implementation of plans will enhance their ability to perform future responsibilities. To meet the needs of sibling caregivers, organizations should adopt family-centered approaches that are inclusive of siblings. Training was highlighted as a critical resource to siblings, as was practical assistance, like respite services.

Connections to other siblings and disability advocacy organizations was also viewed as enhancing sibling capacity.

Recommendations

Fifteen recommendations have been provided to BDACI within the following three categories:

1. Member engagement and leadership development

Disseminate the results of this project to BDACI's membership to increase awareness of sibling-related issues. Create a Sibling Leadership Network to enhance sibling engagement and promote leadership development and participation in the organization's advocacy efforts. Encourage leadership development by amending bylaws as to increase sibling representation on the board and committees. Increase the number of social events hosted, as these activities are an important means of family engagement.

2. Training and information

Provide training opportunities and resources that will meet the information needs of siblings and address issues of preparedness. Support siblings to attend external training events. Enhance processes for the distribution of training-related materials and improve the organization's webpage by adding information that may be of interest to siblings.

3. Organizational practices

Conduct a board and staff retreat to review the project's findings and discuss action implications. Revise planning processes to optimize sibling involvement. Promote key ideas like the importance of typical sibling relationships and shared responsibility within family support practices.

Conclusion

BDACI's commitment to serving people with disabilities and their families promoted the organization's interest in siblings and the important supportive roles they hold. This project created an opportunity to improve service practices by learning from the perspectives and experiences of siblings. Through interviews and a focus group, data was collected then analyzed to reveal considerations and action implications for the capacity building of siblings. The research led to recommendations in three categories that the organization could implement to improve sibling preparedness and enhance BDACI's support to families.

Table of Contents

EXECUTIVE SUMMARY	ii
Background.....	ii
Literature Review	iii
Methodology	iv
Findings	v
Discussion	vi
Recommendations.....	vii
Conclusion	viii
INTRODUCTION.....	1
BACKGROUND	5
Client.....	6
LITERATURE REVIEW	8
Future Planning	10
Caregiver options	12
Parental preferences	15
Sibling Caregivers.....	16
Factors that influence sibling caregiving	18
Needs of sibling caregivers	20
Summary	22
METHODOLOGY.....	23
Sample	23
Recruitment	24
Instruments.....	24
Interviews	25
Focus Group	25
Analysis.....	26
Limitations.....	26
FINDINGS	28
Relationships.....	28
I love him deeply	28
One of the gang.....	29
Included me from the beginning	30
Influential Factors	32
It's more about family than disability	32
Powerful ideas and amazing people.....	33
It's not a burden, it should be a privilege.....	34
The biggest barriers.....	35
Future Planning	37

I have always been part of the conversation	37
Underlying assumptions.....	37
Holding ‘the ball’	39
Building Capacity	40
Purposeful coming together	41
Can’t do it alone.....	42
Gradual release.....	43
Open and honest communication.....	44
Summary	45
DISCUSSION.....	47
Fostering Supportive Sibling Relationships.....	47
Enhancing Future Planning.....	49
Meeting the Needs of Siblings in Supportive Roles.....	52
Summary	55
RECOMMENDATIONS	56
Member Engagement and Leadership Development.....	56
Training and Information.....	58
Organizational Practices.....	59
Summary	60
CONCLUSION	61
REFERENCES	63
Appendix A: Interview Questions.....	71
Appendix B: Focus Group Topics.....	72

INTRODUCTION

The relationship between siblings tends to be one of the longest standing relationships in a person's life. For people with intellectual disabilities, this dynamic has added significance since siblings regularly hold supportive roles that enhance and safeguard the life of their brother/sister. An intellectual disability, also referred to as a developmental disability, affects a person's ability to learn and use information, often resulting in the need for assistance with various aspects of daily life (Community Living Ontario, 2015, What is an Intellectual Disability?, para. 1).

Typically, parents are the primary provider of such assistance, however siblings often assume this supportive role as parents age or after their death. For the purpose of this research project, the term supportive role encompasses the broad range of support and assistance a sibling may provide to their brother/sister in areas of decision-making, advocating for supports and services, ensuring health and well-being, and future planning. Despite the likelihood that siblings will assume supportive roles, research indicates that they are not always prepared to take on these crucial responsibilities (Heller & Factor, 2008, p. 134). This project seeks to address this problem of preparedness by investigating how to build the capacity of siblings so they are better able to support their brother/sister with an intellectual disability.

The client for this project is the Brockville and District Association for Community Involvement (BDACI), a non-profit charitable organization that provides services for people with intellectual disabilities and their families. BDACI has a long history of supporting families and believes that family is essential to individual and social wellbeing (BDACI, 2013, Service Purpose and Principles Policy). Given its family focus, the organization has a keen interest in learning about the needs of siblings and assisting them in their future supportive roles.

The research questions for this project are as follows:

1. What are effective capacity building strategies to prepare adult siblings of people with intellectual disabilities for future supportive roles?
2. What factors influence the likelihood that siblings will take on such supportive roles?

The project objective is to provide BDACI with sibling-specific research that will inform and enhance the organization's planning processes, leadership development strategies, membership engagement initiatives, and training efforts. In addition to this report, the client will be provided with a short document highlighting key themes that emerged from the research. This document will be distributed to BDACI's membership and posted on its website. The researcher will also present an overview of the project at the organization's annual general meeting.

Siblings have been chosen as the specific research focus given the longevity of the sibling relationship and because adult siblings tend to be extensively involved in the life of their brother/sister with a disability (Heller & Schindler, 2009, p. 322). However, an extended family member, like a cousin, or even a close friend could also fill supportive roles. The project's findings and recommendations may therefore be equally applicable to these other parties.

Following this introduction chapter, the report is organized into the following seven chapters.

Background: This chapter is divided into three parts. First, an overview of the issue is provided, highlighting the importance of siblings in the lives of people with intellectual disabilities, the likelihood of siblings filling supportive roles, the concern over preparedness, and the lack of related research. Second, the client organization is described, including organizational structure and mandate. Third, the client's rationale for its interest in this topic and the project specifically is explained.

Literature review: The review examines issues that have a bearing on the common concern held by parents of sons/daughters with intellectual disabilities, namely, “What will happen to my child when I’m gone?” The review has been divided into two sections, the first relates to future planning and the second focuses on literature about sibling-caregivers. The literature reviewed is primarily from scholarly sources, spanning the past three decades. The research discussed is mostly Canadian and American, however some work from Australia, England, Ireland, and China has also been included.

Methodology: The qualitative approaches used in this project are explained in this chapter. The sampling and recruitment processes are discussed, and a detailed description of the two research methods used: individual interviews and a focus group. A thematic analysis was conducted, producing themes that are explained in the discussion sections. The project limitations are also noted in this section.

Findings: The findings chapter reports on experiences siblings shared during individual interviews and the focus group discussion. The chapter is organized into four sections, namely relationships, influential factors, future planning, and building capacity. Each section provides a description of the related themes.

Discussion: This chapter integrates and interprets the findings and literature review, in relation to the research questions and project objective. Key considerations and action implications for building sibling capacity will be explored in key areas including fostering supportive sibling relationships, enhancing future planning concerns, and meeting the needs of siblings in supportive roles.

Recommendation: This section provides recommendations that are relevant to the capacity building of siblings and the improvement of service practices of the Brockville and District Association for Community Involvement. Fifteen recommendations have been offered within three categories: membership engagement and leadership development, training and information, and organizational practices. Short and long-term implementation goals have been indicated.

Conclusion: The final chapter provides an overview of how key project elements came together to answer the research questions and meet the project objective.

BACKGROUND

The notion of siblings assuming supportive roles in the lives of adults with intellectual disabilities is relatively new. Today's siblings assume such roles more often than previous generations because the life circumstances of people with intellectual disabilities have changed in a couple of major areas in recent decades. First, medical advances allow people with disabilities to live longer, likely outliving their parents, which creates a need for new caregivers. Second, with changes in support approaches in the developmental services sector, more people with disabilities are living in their community, instead of large government-operated institutions (Heller, Kaiser, Meyer, Fish, Kramer & Dufresne, 2008, p. 20). Siblings are also more likely to fill a supportive role because people with intellectual disabilities tend to lack the typical sources of support that people count on as they age, namely a spouse and children (Bigby, 1997, p. 333).

As is the case for most people, having a supportive relationship with a sibling can have a positive influence in the life of a person with an intellectual disability. Family is considered one of the universal good things of life (Wolfensberger, Thomas & Caruso, 1996), but for a person with intellectual disabilities the importance of family has more significance given the safeguarding role family members typically fill. One typically thinks of parents as the primary safeguard, but siblings can also be a protective factor throughout the person's life. When parents are no longer able, siblings often transition into primary safeguarding roles. Even though siblings are the most likely to assume supportive roles when parents are gone, siblings are not always prepared to do so. In Rawson's study (2009), siblings acknowledged feeling unprepared to take on additional responsibilities, questioning their own capabilities and knowledge. Many factors can influence a sibling's willingness and ability to support their brother/sister in the future including few

opportunities for capacity building, parental attitudes, and exclusion from future planning discussions (Heller & Kramer, 2009, p. 1).

The topic of how to better prepare siblings for their potential future role has not been heavily researched. Rawson (2009) noted that even though several studies have acknowledged siblings' concern for the future, very few offer any practical suggestions or strategies for addressing these concerns. This is echoed by Heller and Arnold (2010, p. 24), who stated that no studies specific to interventions exist and emphasized that such work could improve the ability of siblings to support their brother/sister with a disability.

Client

The Brockville and District Association for Community Involvement has been a family-driven organization since its founding in 1956, when family members created the organization to ensure their children would receive the services they needed in their community. The organization is governed by a volunteer Board of Directors, and consists of two organizational components. The first component is a membership-based association that is responsible for member engagement, family-specific training, social activities, and systemic advocacy efforts (Osburn, 2011). The Executive Director, board directors and association members carry out the work of the association. The second organizational component is the service program, operated by paid employees, that provides direct services to people with intellectual disabilities and their families. Within this component there are three service programs, the largest being a family support program that provides case coordination, assistance with accessing funding and services, recruitment, hiring and supervision of support workers, and future planning (BDACI, 2015, Family Support Coordination Program, para. 1).

Assisting families to plan is central to the work of both BDACI's Association and its service programs. Two recent assessments have identified the need for BDACI to review and enhance its current planning processes to better address a major concern of many families, namely who will care for their son/daughter when they are gone (Osburn, 2011, p. 65). Engagement of brothers and sisters in future planning is specifically identified as an effective way of addressing this concern (Osburn, 2011, p. 73). Even with BDACI's family focus, the organization has not intentionally concentrated on engaging and supporting siblings. This appears to be a common issue as many family-friendly agencies have overlooked brothers and sisters (Conway & Meyer, 2008, p. 113). As part of its effort to improve supports to families, BDACI would like to learn how to support families in a way that builds the capacity of siblings as to enhance the natural role siblings play in each other's lives and to prepare them for the supportive roles they could assume in the future.

LITERATURE REVIEW

This literature review examines topics that have a bearing on the common concern held by parents of sons/daughters with intellectual disabilities, namely, “What will happen to my child when I’m gone?” The first section will review issues related to future planning of parents, including caregiving options and parental preference. The second section reviews literature specifically related to sibling-caregivers, since they are the most common party to assume future caregiving roles.

The review focuses primarily on scholarly literature spanning the past three decades in an effort to be reflective of the evolving research in this area. Literature was incorporated from various geographic locations, given the universal nature of this issue. The majority of literature included in this review comes from Canada and the United States, however Australia, England, Ireland, and China are also represented.

In Braddock, Emerson, Felce, and Stancliffe’s (2001, p. 116) historical review of the living circumstances of people with intellectual disabilities, it is noted that living in their family home is a relatively new concept since specialized institutions had been the dominant service model in North America since the mid-19th century. Since intellectual disabilities were seen as a sickness requiring treatment, physicians and other professionals routinely advised families to place their babies and young children in large government-run institutions (Meyer & Holl, 2014, p. 95). The prevailing mindset of the time was that people with intellectual disabilities needed to be congregated in institutions on a short-term basis, where they could be educated by experts, then returned to their own community once they gained adaptive skills (Wolfensberger, 1975, p. 24).

Wolfensberger (1975, p. 60) noted that institutions became asylums where people were subjected to physical and mental abuse, neglect and inadequate care, and restriction of basic rights.

In North America, the human rights movement and innovative ideas like the Principle of Normalization initiated a move away from institutional care in the mid-1900s (Pedlar, Hutchison, Arai, & Dunn, 2000, p. 331). Starting in the 1950s, parents played a part in the transition to community-based care by forming local associations, spear-heading what is known as the community living movement (Canadian Association for Community Living, 2016, History, para. 4). The 1970s and 1980s brought federal and provincial/state level legislative changes in areas of social service provision and education that opened the door to more community-based services (Dang, 2010; Pedlar et al., 2000). Many of the family-founded associations took advantage of new funding generated by these changes, creating programs that allowed their children to live at home and to be supported in their own communities (Brockville and District Association for Community Involvement, 2006, p. 2). Braddock et al., (2001) noted that England and Australia experienced a transition in services similar to Canada and the United States.

Parents are often the primary caregivers of their sons/daughters with intellectual disabilities, often co-residing. In Canada, approximately 50-60 % of people with intellectual disabilities live with a family member (Weeks, Nilsson, Bryanton, & Kozma, 2009, p. 181). In a United States study, 72% of the individuals with intellectual disabilities were reported to live with a family caregiver (Braddock, 2013). According to Chadwick et al. (2013), families remain the main providers of support for people with intellectual disabilities in Ireland, as is the case in Australia and England (Braddock et al., 2001).

Future Planning

The topic of future planning has been well researched. Heller and Factor (1991), one of the first studies about future planning, interviewed 100 family caregivers of people with intellectual disabilities. Less than one third of the caregivers had made any future living arrangements for their relative, however two thirds had made some financial plans (Heller & Factor 1991, p. 163). Similarly, Bigby's (1996, para. 16) study looked at plans made by the parents of 62 adults with intellectual disabilities and found that residential plans had been made by 30% of parents and 50% had made financial plans. In Freedman, Krauss, and Seltzer's (1997, p. 177) study that interviewed 340 mothers who still lived with their disabled son or daughter, 45% had made residential plans. Heller and Kramer's (2009) findings are consistent with studies from the previous decade. Their study surveyed 139 siblings about future planning and reported that 32% of families had made residential plans, 44% financial plans and 39% had addressed the issue of guardianship. Even though Egan and Walsh's (2001) research reported on planning done by sibling caregivers, the numbers are consistent with parental planning. Only one-third of siblings had made any future plans, which the authors noted was reflective of planning by Irish mothers (Egan & Walsh, 2001, p. 35). A study in England yielded similar results, with 42% of families making clear future plans (Davys, Mitchell, & Haigh, 2010, p. 172). In Taggart, Truesdale-Kennedy, Ryan, and McConkey's (2012, p. 226) study of caregivers, 10 of the 19 caregivers interviewed reported having made definitive future plans addressing living arrangements, as well as legal and financial matters. Hole, Stainton, and Wilson's (2013, p. 577) study, the most recent one reviewed, interviewed 11 family members and despite speaking about the importance of future planning, three reported having engaged in any planning.

Griffiths and Unger's (1994, p. 221) study involving parents and siblings noted the difficult nature of future planning, describing it as an emotional issue that involves feelings of guilt, relief, anxiety, and uncertainty. Taggart et al., (2012, p.226) stated that when future planning is raised within research interviews, parents can be uncomfortable, distressed and emotionally upset. Similarly, engaging in the planning of future living arrangements for their son/daughter appears to be anxiety-provoking since it reminds parents of their own mortality (Heller, 2000, p. 61). Hole et al. (2013, p. 578) reported that some family members in their study stated that they felt too burnt out to engage in future planning, that they believed a family member would step up when needed and that barriers within the service system influenced their lack of planning. In the study by Taggart et al. (2012, p. 227), the nine caregivers who had not explored any future options identified a lack of support for planning as an obstacle, stating they did not know which professionals and organizations to turn to for information and practical assistance with planning. Heller's (2000, p. 70) review of various planning approaches also identified issues with the effectiveness of planning processes since many of the approaches reviewed had limited success in actually helping families to make future plans.

Freedman et al. (1997, p. 114) found that a lack of planning creates significant difficulties in times of crisis, as when a parent dies. Without adequate planning, adults with intellectual disabilities face the possibility of emergency placements in inappropriate settings and disruptive transitions (Heller. 2000, p. 60). Additionally, Hole et al. (2013, p. 586) stated that when planning had not occurred within the family, crisis management was needed, which strains the family, aging adults, and the service system.

Caregiver options

Heller and Factor (1991, p. 164) characterized the two basic options available to families as recruitment of another family member to continue family-based care or the arrangement of out-of-family placement. These basic options were echoed by Krauss, Seltzer, Gordon, and Friedman (1996, p. 84), who noted that when parents can no longer provide care, adults with intellectual disabilities either move in with a sibling or live in a non-family setting, like a group home. Relatedly, studies about future planning commonly investigate living and decision-making arrangements made by caregivers (Heller, 2000; Krauss et al., 1996).

Braddock et al. (2001, p. 116) described the common out-of-home placement options for people with intellectual disabilities in Canada as institutions, residential group settings, supported apartments, foster family care/house parents, and boarding homes. However, more recent research conducted by the Canadian Mortgage and Housing Corporation (2006) identified independent living models, cooperative housing communities, seniors' complexes, and the L'Arche group home arrangement as favoured housing models. Options in the United States are similar, including public and private institutions, supported residential group settings with up to 15 occupants, supported apartment living, and foster/host family homes (Braddock, 2013).

Meyer and Holl (2014, p. 124) also noted arrangements where a college student lives, rent free, with a person with a disability who requires some assistance. In England and Australia, living arrangements include hospitals, staffed residential homes, nursing homes, hostels, and supported independent living (Braddock et al., 2001, p. 118). Finally, Golstein and Godement (2003, p. 254) report that high numbers of people with intellectual disabilities in Geel, Belgium are served within a foster family model.

Davys et al. (2010) and Krauss et al. (1996) noted that the major waitlists that people with disabilities face when seeking out-of-home placements is reported as a common concern in studies of residential services. The Taggart et al. (2012, p. 226) study also highlighted service quality as a concern, noting that despite having made residential care plans for their children, parents expressed concern over the quality of care they would receive in these facilities. Service quality was also identified as a concern in a study by Krauss, Seltzer, and Jacobson (2005, p. 119) on the positive and negative aspects of the residential status of adults with autism. Similarly, Wolfensberger (2003, p. 10) identified concern with the quality of formal residential arrangements and the harmful discontinuities associated with such service models as a historical worry of parents of sons/daughters with intellectual disabilities. Krauss et al. (2005, p. 119) also found that deficiencies in staff training, a lack of programming and activities, and high staff turnover had a negative effect in residential settings. O'Rourke, Grey, Fuller, and McClean (2004, p. 19) found that people with disabilities also reported difficulties with staff, staff shortages, and strictness of staff as problems. In a study conducted in Northern Ireland, adults with intellectual disabilities reported that large-scale residential care homes, housing approximately 20 people, were restrictive, citing issues with freedom and privacy (McConkey, Sowney, Milligan, & Barr, 2004, p. 120).

Krauss et al. (2005, p. 118) identified the following to be positive aspects of residential placements: improvement of the person's skills, increased independence, a better social life, and access to program-based services. In a study by McConkey et al. (2004, p. 122), participants favoured supported living models as they offered freedom and privacy. In O'Rourke et al. (2004, p. 21), caregiver interviews revealed staff members as a positive feature of residential programs, as well as accessibility and availability of activities. In Schwartz's (2005, p. 150) study,

questionnaires completed by parents of 71 adults living in residential care indicated that they believed residential placement improved the person's quality of life and promoted independence. People with intellectual disabilities involved in the study by O'Rourke et al. (2004, p. 19) stated that they valued the staff within their residential placement and listed availability of activities and aspects of the physical setting, like good meals, as strengths.

In family-based options, the person with the disability lives with a family member, such as a sibling, aunt, or cousin. The Krauss et al. study (2005, p. 117) noted that family-based arrangements offer such benefits as good quality care, security and an enhanced quality of life for the family unit. In McConkey et al. (2004, p. 118) people with disabilities who live with a family member identified the following positive themes of their living arrangements: having contact with family members, being able to participate in household activities, accessing local facilities, and having their own room. Weber and Fritsch (1999, as cited in O'Rourke et al, 2004) noted continuity and constancy of caregiving as benefits of living with a family member. Some professionals have similar views, describing family-based living arrangements as loving, stable, and familiar environments (Krauss et al., 1996, p. 91).

In Hole et al. (2013, p. 581) some participants saw family-based arrangements as placing a burden on siblings. Meyer and Holl (2014) devoted a chapter of their book "The Sibling Survival Guide" to strategies that family members can use to reduce stress and promote self-care. In addition to caregiver burden, Weber and Fritsch (1999, as cited in O'Rourke et al., 2004) described loneliness, a lack of activities, and a lack of competence in rehabilitative techniques as disadvantages to family-based arrangements. A lack of activities was also mentioned in O'Rourke et al. (2004, p. 23) as an area of dissatisfaction among people with disabilities living

with a family member. Professionals have raised concerns over independence stating that the person's autonomy is restricted when living with family members (Krauss et al., 1996, p. 91).

Issues of decision-making are commonly addressed through the appointment of a legal guardian, which studies indicate is often the sibling of the person with the disability (Griffiths & Unger, 1994; Krauss et al. 1996). In a review of historical decision-making approaches, Wolfensberger (2003, p. 42) identified guardianship as being a reliable protection for vulnerable people. In Flynn's (2010, p. 31) analysis of various legal advocacy models it was noted that despite being extremely influential advocates, family guardians potentially have a conflict of interest and may be tempted to prioritize the best interests of the family unit over those of the person with the disability. However, Carney and Keyzer's (2007, p. 272) analysis of legal planning options acknowledged the limitation of non-family guardians, noting the impersonal nature of such arrangements and that these guardians are not able to maintain close personalized management of the person's needs. The Canadian Association for Community Living (2010, p. 2) noted that substitute decision-making processes, like guardianship, removes the legal capacity of people with intellectual disabilities against their will, denying their personhood and making them more vulnerable. According to Gordon (2000, p. 64), supported decision-making is seen as a more desirable option since the person with the disability retains his/her legal status. In Bigby's (1997, p. 338) study of the informal networks of 62 people with intellectual disabilities, 76% of parents had identified key decision-makers through informal means and these arrangements were accepted by service-providers despite the lack of legal standing.

Parental preferences

In relation to future living arrangements, Heller and Factor (1991, p. 163) noted that 53% of families preferred future placement within a family member's home over residential placement,

noting a sibling as the preferred caregiver. Of the families who had already made financial plans, 48% had willed money or property to another family member who would use it to care for the person with the disability (Heller & Factor, 1991, p. 167). Bigby (1996, para. 18) reported that where a key future caregiver had been named, the majority were close relatives, with siblings accounting for 88% of those named. Siblings were also the preferred family member option noted in the study by Freedman, et al. (1997, p. 11). In Krauss and Seltzer's (1993, p. 55) study involving 387 aging parents of people with intellectual disabilities, 51% anticipated continued family-based care, 23% anticipated a mix of family-based and residential care and 9% anticipated full residential care. In Taggart et al. (2012, p. 224) the most acceptable options were for the person to remain in his/her own home and receive support from family members, or to move in with a sibling. Similarly, in Weeks et al. (2009, p. 182), when interviewed about their desires for the future, most parents hoped other family members would provide care, some having already made such plans. In Griffith and Unger (1994, p. 224) only 22% of parents reported a preference for a family member to be the future caregiver and 51% preferred placement within group homes or state-operated facilities. An Israel-based study reported that 90% of the 71 parent participants perceived residential placement as the preferable option (Schwartz, 2005, p. 150).

Sibling Caregivers

Siblings are the most likely family member to assume caregiving roles when parents are no longer able (Heller & Arnold, 2010; Heller & Kramer, 2009; Krauss & Seltzer, 1993). In Griffiths and Unger's (1994, p. 224) study, 44% of the 41 sibling participants were willing to be the primary future caregiver. Bigby (1997, p. 388) found that 77% of future caregivers identified within the study were siblings. Other studies note significantly higher numbers, like Greenberg,

Seltzer, Orsmond, and Krauss' (1999, p. 1218) study, which reported over 60% of the 119 sibling participants expected to be future caregivers. The lowest numbers were reported in the most recent studies reviewed namely, 36% of siblings in Heller and Kramer (2006, para. 5) and 38% by the same authors in 2009 (p. 215).

Griffiths and Unger (1994 p. 224) found that one role siblings are likely to assume is that of legal guardian. Bigby's (1997, p. 337) study indicated that when siblings are the primary caregiver they are responsible for oversight of the person's wellbeing, management of service provision, and advocacy. Sibling advocates in China were the focus of Li and Ping's (2006, p. 176) study, which noted that siblings commonly press for better service provision and improved service quality for their brother/sister. In addition to service oversight and advocacy, Heller and Factor (2008, p. 133) stated that sibling responsibilities can also include primary care. Burke, Taylor, Urbano, and Hodapp's (2012, p. 38) study, which researched levels of sibling responsibilities within five common areas, living arrangements, legal guardianship, interaction with services, provision of companionship and emotional support, siblings reported holding responsibilities in one or more areas, however 30% expected to be the primary caregiver in all five.

A conclusion made by the Family Support and Intergenerational Caregiving working group was that although siblings are taking on larger roles in the care of their brother or sister with an intellectual disability, they are often unprepared for this responsibility (Heller & Factor, 2008, p. 134). Siblings reported a similar concern in Rawson (2009, p. 226), disclosing fears about their own capabilities and knowledge, with 12 of the 13 siblings feeling unprepared to take on future responsibilities (Rawson, 2009, p. 228). Some authors have noted that a lack of involvement in future planning is a major contributor to issues of preparedness (Freedman et al., 1997; Heller & Caldwell, 2006; Heller & Kramer, 2009).

Factors that influence sibling caregiving

The literature discusses the following factors as influencing a sibling's willingness to take on caregiver roles and/or the likelihood that siblings will assume such roles.

Seltzer, Begun, Seltzer, & Krauss (1991, p. 313) used interviews and questionnaires with 411 families and reported sisters as being the more involved family member (64% compared to 35% brothers). Krauss et al., (1996, p. 87) found that 68% of the siblings who expected to live with their brother/sister with a disability were sisters. In the Greenberg et al. (1999, p. 1218) study, sisters were reported to provide more emotional support and when compared to brothers, sisters expected to be the future caregiver. Orsmond and Seltzer (2000, p. 502) surveyed 329 adult siblings and found that sisters provided more care and support than brothers. Burke et al. (2012, p. 39) reported similar findings, with sisters expecting to assume greater levels of caregiving.

Krauss et al. (1996, p. 87) found that siblings were less willing to co-reside with their brother/sister if he/she had significant behaviour problems. Griffiths and Unger (1994, p. 224) noted that the more stressed siblings were about the demands of the person's disability, the less likely they were to be a caregiver. In their study of sibling caregivers, Egan and Walsh (2001, p. 35) found higher stress levels among siblings caring for a brother/sister who was less independent in daily activities. However, Heller and Kramer (2009, p. 215) found that the level of disability did not have a significant impact on the sibling's expectation of future caregiving. Similar results were found by Greenberg et al. (1999, p. 1219) and Burke et al. (2012, p. 39) noting that the brother/sister's behaviour problems and levels of function were weak indicators of future caregiving.

In Seltzer et al. (1991, p. 313), siblings who were the most involved lived within a one-hour drive. Over half, 58%, of the sibling participants in the Krauss et al. (1996, p. 88) study lived within a 30-minute drive of their brother/sister. Heller and Kramer's (2009, p. 213) study showed similar findings, reporting that a shorter distance between siblings was a predictor of a sibling becoming the future primary caregiver. Burke et al. (2012, p. 39) also found that siblings who lived closer provided greater levels of future caregiving.

Multiple studies show that sustaining regular weekly contact with their brother/sister, either in person or by telephone was an indicator of future caregiving (Davys et al., 2010; Seltzer, et al., 1991). Greenberg et al. (1999, p. 1218) found that feeling emotionally close to their disabled sibling was a significant predictor of future emotional support. In their findings they highlighted the importance of positive family bonds and note that such relationships encouraging siblings' sustained involvement in the lives of their disabled brother/sister (Greenberg et al., 1999, p. 1218). In Heller and Kramer (2009, p. 216), sibling participants were more likely to expect to be future caregivers if they had more contact with their family member. Siblings who described having close relationships with their brother/sister, also indicated an expectation of future caregiving (Burke et al. 2012, p. 39).

With respect to family expectations, communication, and involvement in planning, Griffiths and Unger (1994) concluded that when siblings are involved in planning, they are more willing to take on future responsibilities. In their study, over half of the parents and siblings reported that discussions about the future had taken place (p. 225). Davys et al., (2010, p. 173) reported that 12 of the 21 sibling respondents in their study stated they had full discussions about the future with their parents. In Bibgy's (1996, para. 19) study, the people nominated as the future caregiver stated they were strongly aware of the parents' expectations. Coyle, Kramer, and

Mutchler (2014, p. 307) researched transitions in care from parents to siblings and found that when parents communicated their expectation to the siblings and engaged them in future planning, siblings were better prepared to become future caregivers.

In a 1996 study Krauss et al. found that 75% of the 140 siblings involved in the study had children (p. 87). However, Greenberg et al. (1999, p. 1217) noted that siblings with minor children were significantly less likely to provide support to their brother/sister with a disability. Burke et al. (2012, p. 39) also found that siblings with children reported less intended future caregiving than siblings who did not have children. In the Coyle et al. (2014, p. 304) study of siblings who already providing primary care, 40% had children of their own. Meyer and Holl (2014, p. 37) noted that some siblings struggle with the idea of having their own children since it can impact their future commitment to caring for their brother/sister.

Needs of sibling caregivers

Arnold, Keller, and Kramer's study (2012, p. 378) surveyed 139 siblings and found that siblings wanted educational opportunities, like conferences and workshops, to learn about important topics such as advocacy, caregiving and navigating the service system. Coyle et al. (2014, p. 310) found that siblings need training about available services and how to access them. Li and Ping (2006, p. 177) interviewed six sibling advocates who identified a need for advocacy skill training. The most prevalent information need stated by siblings related to legal and financial matters (Rawson, 2009, p. 228). To meet this need, Rawson proposed the use of information packages for siblings that included useful websites and hotlines (p. 230).

In Li and Ping (2006, p. 178), siblings reported interest in support groups or sibling networks. Heller and Kramer (2009, p. 214) reported that 70% of sibling participants thought support

groups would help them care for their brother/sister. Arnold et al. (2012, p. 377) recommended an increase in sibling support groups and Burke et al. (2012, p. 45) suggested that siblings should participate in these support groups as a means of preparing them for future caregiving roles.

Seltzer et al. (1991, p. 316) recommended that siblings be an active part of the creation and implementation of future care plans. In a description of a comprehensive planning process, Heller (2000, p. 71) also described this need for increased involvement of siblings. Davys et al. (2010, p. 176) called for a proactive planning process that would involve siblings. Burke et al. (2012, p. 46) supported siblings' involvement in the development of future plans, stating they should receive the support they need to do so.

Financial support for sibling caregivers was identified as a need by Heller and Kramer (2009, p. 217). Siblings in Arnold et al. (2012, p. 378) indicated a need for funding sources, financial support and access to respite services. Meyer and Holl (2014, p.87) stated that siblings need to take care of themselves and that one means is to access community respite services. Coyle et al. (2014, p. 309) commented that accessing such formal support can be helpful to sibling caregivers, but they may need assistance to do so since the system can be very difficult to navigate.

Arnold et al. (2012, p. 377) reported that siblings wanted to be part of the services offered to families, stating that such services should be about the whole family, not just parents. The Sibling Leadership Network recommends changes at the policy level that ensures the term family includes siblings (Heller et al., 2008, p. 12). Conway and Meyer (2008, p. 113) suggest that siblings need to be actively included in agencies' definition of family before true family-centered care will be provided. Tozer, Atkin, and Wenham (2013, p. 486) stated that 'whole family'

approaches require the routine inclusion of siblings in care. With increasing numbers of siblings providing primary care, there is growing interest in expanding the definition of family so that agencies can adequately support siblings in their caregiving role (Meyer & Holl, 2014, p. 195).

Summary

The literature reviewed in this report highlights the complexities faced by parents who are concerned about the future of their son or daughter with an intellectual disability. With changes to the service system, increasing numbers of people with disabilities are living with their natural families, which means parents are struggling with questions of who will be the future caregivers of their adult children. The planning research illustrates that discussions of the future are quite difficult for parents and despite the overwhelming need to plan, many parents are not engaging in that process. The future options available to parents involve both advantages and disadvantages, and parents have a strong preference for family-based options. Siblings were noted as the desired future caregiver for the person with the disability. The literature reflects these expectations and depicts various factors that influence siblings in caregiver roles. The needs of siblings are also discussed within some studies, rendering some consistent recommendations. This review reinforces that the concern for the future is a very real problem faced by parents and that supporting the next generation of caregivers will help ensure people with intellectual disabilities continue to receive quality care.

METHODOLOGY

This project used a qualitative research approach, utilizing interviews and a focus group as the primary means of data collection. Qualitative approaches explore social phenomena as experienced by the individuals themselves and are an excellent means of eliciting people's stories (Grossoehme, 2014, p. 109). Learning from the personal experiences of siblings is central to this project, making qualitative methods an appropriate and effective choice.

The individual interviews explored the life experiences of siblings already holding supportive roles in the life of their brother/sister with a disability. The focus group provided an opportunity to learn about the thoughts and experiences of future sibling caregivers. Such qualitative methods allow the researcher to arrive at an understanding of the particular phenomenon from the perspective of those experiencing it (Vaismoradi, Turunen, & Bondas, 2013, p. 398). As the project objective is to influence service practices of the client, and specifically those related to siblings, understanding the issue of supportive roles from a sibling perspective is critical.

Sample

The researcher used purposive sampling, which involved the establishment criteria for potential participants from the onset of the project (Grossoehme, 2014, p. 112). The primary characteristic used for recruitment of participants was their current or future involvement in supportive roles for their brother/sister with an intellectual disability. Participants were separated into the following two groups:

Group one: Adult siblings of people with intellectual disabilities who have already assumed supportive roles in the lives of their brother/sister.

Group two: Adult siblings of people with intellectual disabilities who have not already assumed supportive roles in the lives of their brother/sister, however intended to in the future. This group also included other family members, like nieces/nephews and cousins, who had similar future intentions.

Recruitment

Brockville and District Association for Community Involvement (BDACI), the project client, was the primary recruiter for participants in both groups. The Executive Director selected possible participants from within the organization and through her professional contacts. The researcher provided the names of two potential participants, who were not known to BDACI, but had expressed interest in the project. Invitations to participate that explained the key project details were emailed to all potential participants. People who were interested contacted the researcher directly either by telephone or email, at which time they were provided with additional information. The original goal was to recruit eight participants for group one, but nine were selected due to participant interest. The desired number for group two was eight to ten and eight individuals participated in the research.

Instruments

The project utilized interviews and a focus group. Semi-structured in-depth interviews were conducted using 15 open-ended questions (See Appendix A). Follow up questions were used to pursue relevant topics that emerged during the interview (Grossoehme, 2014, p. 110). This method was selected because in-depth interviews are an effective means of eliciting detailed narratives and stories (DiCicco-Bloom & Crabtree, 2006, p. 317).

The focus group involved a discussion, facilitated by the researcher, around five topic areas (See Appendix B). Leading questions were used in each topic area to generate conversation among group members. Focus groups provide an excellent means of generating a range of responses on a particular topic (Grossoehme, 2014, p. 110). A group discussion would also provide a more of a casual environment, which seemed suitable for this group of young adults.

Interviews

Interview participants were provided with the interview guide one week in advance. Ten interviews were conducted from August 28th to November 12th, 2015. Nine interviewees were members of group one, and one was from group two. Data collected from the group two participant was included with the focus group analysis. Interview dates and times were selected based on participant preference. Five interviews took place in person at a location convenient for the interviewee. Four interviews were conducted by telephone and one through a video call to accommodate for geographic distance or interviewee convenience. In one interview, a question was missed so the interviewee provided a response by email at a later date. All interviews were recorded, with participant consent, and transcribed. Some additional notes were taken by the researcher during the interviews. Interview length ranged from 42 minutes to 115 minutes, with an average length of interviews being approximately 67 minutes.

Focus Group

The focus group was conducted on September 5, 2015 and lasted approximately two hours. Seven people participated in the focus group. Participants were provided with the discussion topics and sample questions a week before the focus group was conducted. The timing and location of the focus group was selected based on participant preferences. The discussion was divided into five topic areas, with the researcher posing questions to initiate the conversation.

The focus group discussion was recorded with the participants' permission, and the researcher took detailed notes. A written summary of the focus group discussion was compiled by the researcher.

Analysis

A thematic analysis was used to identify common themes within four sections. These sections were based on the structure of the interview questions and focus group topics. Thematic analysis was suitable for this project because it employs low levels of interpretation and is a useful and flexible tool for providing a detailed account of data (Vaismoradi et al., 2013, p. 400). Analysis involved the review of audio recordings, the focus group summary, and transcripts. The researcher coded participant responses by section, then highlighted commonalities and differences among personal experiences, answers that illustrated similar and contrasting viewpoints, particularly powerful or insightful perspectives, and any specific suggestions or recommendations made by participants. Common threads that emerged within each section were organized into logical groupings, leading to the identification of themes. The name of each theme was derived from actual words or phrases used by individual participants. These themes are reviewed at length in the findings section.

Limitations

The focus group composition was a limitation as participants had similar family backgrounds and experiences, were from the same small geographic area. Their families had all been served by the same organization and most had attended similar disability-related events and trainings. This limitation was mitigated in two ways. First, to ensure a different perspective was explored, an interview was conducted with a participant who met the group two criteria, however came from a different background and had different experiences. Second, during data analysis, the

researcher discussed how such commonalities likely influenced specific perspectives and noted the impacts of any variation in participant background. The narrow recruitment method is another limitation, since the pool of potential candidates was mostly limited to people served by the client organization or contacts of the Executive Director. To mitigate this issue, the researcher recruited two additional interviewees who did not have a connection to the client.

FINDINGS

This chapter reports on the experiences siblings shared during individual interviews and the focus group discussion. The findings capture the perspectives of two groups of participants. The first group included interviews with nine siblings already filling supporting roles for their brother/sister with an intellectual disability. The second group involved eight close family members of people with intellectual disabilities, mostly siblings, who are not currently holding supportive roles but intend to in the future. Seven members of group two participated in the focus group and one was interviewed. For the purpose of the findings, the responses from the one interviewee in group two are included in focus group data. Data was organized into four sections based on the structure of the interview questions and focus group topics: relationships, influential factors, future planning and building capacity. The themes that emerged within each section will be described and each theme is titled using the words of research participants.

Relationships

Participants were asked questions about their relationship with their sibling. They described elements of these relationships growing up and now as adults. The following three themes emerged.

I love him deeply

Close relationships emerged as a common theme, with all 17 participants reporting having strong relationships with their family member since childhood. Common descriptors of these relationships were strong, deep, very close, and excellent. Six of the siblings currently in supportive roles grew up together, mostly living in the same home throughout their childhood. Two siblings reported some periods of living apart when their brothers were institutionalized or living in some other type of residential program. One sibling only lived with her brother while he

was quite young, before he was admitted to an institution. Even during these periods of separation, the three siblings spoke of regular visits, from weekly to six times per year depending on the geographic distance. Despite the separation, these siblings described having close relationships with their brothers. Siblings who were planning to fill supportive roles in the future had lived with their brother/sister. In addition to describing their relationship as close, focus group participants highlighted the strong bonds they had with their family member.

Participants spoke of regular contact with their sibling. Three of the siblings currently holding supporting roles have daily contact since they live with their brother/sister on a full or part time basis. The other seven siblings reported at least weekly contact, living in the same town or within one-hour drive.

Future caregiving siblings described regular contact despite their current living arrangement. The majority live with their brother/sister, in the same town or a neighbouring city. The siblings who lived farther away still reported regular contact. Even the siblings whose brothers had been institutionalized, described their time together during visits as typical, recounting stories of holiday dinners and playing together as children.

One of the gang

Having typical sibling relationships was a common theme among both interviewees and focus group participants. All referred to their experience growing up with their sibling as typical and/or normal. Interviewees told stories of holiday dinners, birthday parties, playing games with their brother/sister, watching movies, going on family vacations, going to community events, spending time with neighbourhood friends, and even fighting and teasing each other. One interviewee described his brother as just part of the family. A sister said, “we spent a lot of time

together, the way that siblings do”. Focus group participants spoke similarly about their relationships and said that fostering typical involvement would encourage quality relationships among siblings. They felt they spent time with their brother/sister just like in any other sibling relationship. When asked about what may have influenced these typical interactions, only one interviewee felt it resulted from intentional actions on the part of a parent. She described her mother as being a driving force behind it, encouraging her children to spend time together.

Included me from the beginning

Another relationship theme that surfaced was early involvement in disability-related discussions within the family. All interviewees noted that since they were children, their parents had included them to some degree in conversations about their siblings’ disabilities and/or care. The focus group discussion also indicated the importance of early communication, recommending that families create an environment where they can openly talk about disability. One interviewee described her parents as being very matter-of-fact about her brother’s disability, even including the interviewee in doctor’s appointments. Five interviewees recounted direct conversations with parents about why particular things had happened in their siblings’ life, or why something was the way it was, like their sibling attending a different school. Six interviewees reported having clear knowledge of their parent’s advocacy efforts to access schooling or other services for their sibling. Awareness of advocacy efforts was common among focus group members as well.

Eight interviewees reported having some type of active role helping with their brother/sister’s support when they were young. This was common among focus group members as well. Some of the common activities described by the research participants were keeping an eye on their brother/sister when their parents went out, helping them learn skills or academics, participating in their siblings’ speech or behaviour therapies, providing transportation as teenagers and helping

their brother/sister interact or communicate with others. One sister described herself as being “part of the teaching team”, helping her brother to learn ways to communicate. Another sibling reported early memories of organizing play dates for her sister so that she would have strong friend connections. One sibling described having an active role supporting her sister right from the beginning, including helping care for her when she was ill, waiting with her every day to catch her school bus, volunteering with a church group so she could attend and addressing school issues when they arose.

Participants spoke of a keen awareness that their brother/sister with the disability was vulnerable and that part of their role was providing protection (past and future). Six interviewees made explicit comments about the vulnerability of their siblings and three described themselves as protectors. One sister said, “I always saw him as a little bit vulnerable and I was kind of his protector”. Another sister felt it was important that siblings understand the nature of their responsibility and that they are going to be an advocate and defender. Focus group members described their desire to look out for their family member and reported concerns with the person being taken advantage of. Three interviewees talked about their siblings’ experiences with abuse, ridicule, and bullying and their desire to prevent such things in the future. When asked about their future roles and responsibilities, focus group participants identified themselves as advocates, specifically noting the need to look out for their family member. A specific worry among the future caregivers was the trustworthiness of workers. They were concerned about siblings receiving adequate care and support.

Influential Factors

Several questions elicited discussion of the factors that influence a siblings' willingness and ability to hold supportive roles in the lives of their brother/sister. The following four themes surfaced in participant responses.

It's more about family than disability

Interviewees overwhelmingly indicated that their family culture was the most influential factor in their support to their sibling. Similarly, when discussing what helps siblings in supportive roles, focus group members recommended that families create a culture where supporting each other is the norm. Even though the explanations varied, all participants described their support as being less about the disability and more about being raised in an environment where family members helped each other. One brother said, "I think it's just our family value system, it's just underlying and assumed...it's just who we are". Eight interviewees said that taking care of each other was about family membership. Six interviewees and focus group participants identified a family mindset of shared responsibility that fostered a commitment to helping all family members. Three of those siblings recounted growing up in multigenerational homes, caring for grandparents. Five siblings spoke about their family values as an influential force, making references to such things as strong values systems, Christian values and principles, moral responsibility, faith, and the value of family. One sibling described thinking in terms of the family unit, another one spoke of a whole family mindset. One sibling did not speak directly about family culture, but commented on her commitment to family and that the idea of caring for her brother had been instilled in her since she was young.

Powerful ideas and amazing people

Both groups of siblings identified having been influenced by ideas and people they encountered through various types of training over the years. Eight siblings in supportive roles reported specific training activities that either influenced their mindset or provided useful information that assisted them in their supportive roles. Seven interviewees and two focus group members described being influenced by the work of Dr. Wolfensberger ¹ including training in Normalization, Social Role Valorization, and PASSING. Two interviewees were influenced by John O'Brien ² and two by Jean Vanier ³. One sister said that Jean Vanier's writing had altered her thoughts about disability. Other training/concepts that were mentioned included MAPS ⁴, Circle of Friends ⁵, and the Meaningful Life workshops ⁶. Four interviewees indicated they had received training in legal and financial matters or navigation of the service system, which they

¹ Dr. Wolf Wolfensberger is a world-renowned scholar, author and expert in the field of developmental disabilities. He is best known for bringing the Principle of Normalization to North America and creating Citizen Advocacy, Social Role Valorization and PASSING.

² John O'Brien is a leading thinker and author in the field of disability. He is the pioneer of Person Centred Planning.

³ Jean Vanier is a Canadian humanist, philosopher and theologian. He is the founder of L'Arche, an international organization of faith-based communities where people with intellectual disabilities live with supporters. He has authored many books about religion and tolerance.

⁴ MAPS is a facilitated planning process developed by Jack Pearpoint and Marsha Forest in the mid 1980s.

⁵ The Circle of Friends is a concept created by Judith Snow and Marsha Forest in the 1980s. It is designed to bring people together who know and care about a person with a disability to support them in planning and decision-making.

⁶ "Supporting People with Severe/Multiple Disabilities to have a Meaningful Life During the Day" is a two-day workshop, developed by Darcy Elks, to help anyone supporting people with severe/multiple disabilities to have a full and meaningful life.

found helpful. All focus group members reported being involved in some form of influential training, information session or guest speaker event.

Another common element among research participants was a connection to the disability movement or disability advocacy organizations like Community Living Associations and People First. Some participants had significant and direct involvement, however others talked of subtle, indirect connections. Only one of the 17 participants had no involvement with the disability movement or advocacy organizations. Five interviewees were exposed through the heavy involvement of their parents, who often held leadership roles. This connection started at an early age for four interviewees who were actively engaged through their parent's participation. One sister said, "I grew up in the culture...I'm a child of this movement". Now as adults, six interviewees are actively involved in such activities themselves. One interviewee reported being influenced by the values of a disability organization with which her parents had an indirect connection. All focus group participants had family members connected to the disability movement or advocacy organizations, with four having relatives in leadership roles.

It's not a burden, it should be a privilege

There was an overwhelming message among participants that supporting their family member with a disability was not a burden and that burden mindsets should not be fostered. Of the nine siblings already in supportive roles, eight explicitly spoke to the topic of burden. Seven interviewees stated that they never saw their siblings as a burden. One focus group member said he did not think of supporting his brother as a burden and that he wanted to be there for him. Six interviewees warned of the problems created when parents have a burden mindset or reinforce burden messages. One sibling knew that his mother was worried about his brother being a burden to him, but he said, "I don't see him as a burden, he can teach us lots of things". Focus group

participants also discouraged families from sending a message that supporting their brother/sister was a burden. One interview gave the following advice to parents, “tell them not to worry, tell them it’s ok and that it’s good for their daughter”.

The biggest barriers

Participants identified many factors that could discourage siblings from holding supportive roles as they make providing support more difficult or cause interference. The most common barriers reported by interviewees and focus group participants are presented by category.

Other people: One potential issue was a lack of support from other family members and friends. Some siblings reported a lack of emotional or practical help from their siblings. Others commented on the problems created when the spouse of the caregiving sibling is not supportive.

Lack of knowledge: Lacking sufficient knowledge about their sibling’s needs, the service system, legal issues and financial matters could all create problems.

Mindsets and values: When a family does not support typical relationships, does not engage siblings early, or lacks values that foster shared responsibility, siblings may be less likely to commit to holding supporting roles. Participants also reported that mindsets that foster messages of burden or resentment among siblings are problematic. The issue of resentment emerged among focus group members who were concerned that their sibling with the disability may be resentful of them in the future when they take on supportive roles. When asked, none of the nine siblings currently holding supportive roles felt their brothers/sisters were resentful of their assistance.

Level of support need: Some siblings identified concerns with being able to provide certain levels of physical care. One sister commented on how providing personal care to a sibling can

have an impact on the relationship as this is not characteristic of a typical sibling relationship. Another sibling described her brother's level of independence as being helpful and that some siblings may have more difficulty when their brother/sister requires significant care. Their sibling's ability to communicate their wants and needs was a reported concern.

Issues with services: Another common barrier was a lack of services available to siblings. Some siblings may need respite care or other paid services that are not available or not adequate. Some siblings also stated that support staff could interfere in their relationship with their brother/sister, preventing or discouraging active involvement.

Separation: Siblings described separation between siblings as a barrier since it impacts the quality of the relationship. For example, this could occur when children are not raised together, such as when a person has been institutionalized or when siblings attend separate schools. The siblings who experienced the institutionalization of their brothers spoke about how difficult this separation was for them. Siblings living a great distance apart as adults can also be an issue.

Money: A common concern was a lack of money, specifically when parents had not engaged in financial planning that would create some level of security for the person with the disability and would assist the sibling in their supportive role.

Balance of responsibilities: Issues of time and the ability to support their sibling while juggling their own family and work responsibility was consistently identified as a worry. Some siblings also commented about the additional responsibility of providing care for their parents.

Unclear expectations, plans: When parents do not plan and/or explicitly state their expectations, some siblings may be less prepared to take on future roles. This can also complicate the

transition between parent and sibling support. Relatedly, siblings commented on the problems created when there is disagreement between the parents and sibling around support or decisions.

Age/gender/birth order: Large age gaps can be a barrier, as can expectations associated with birth order and gender, namely more expectations placed on older siblings and sisters.

Future Planning

Interviewees and focus group participants answered questions about future planning within their family. They were asked to describe the future plans that were made by their parents, the planning processes used and their involvement in planning discussions. While future planning elicited the most variation among participate responses, three common themes emerged.

I have always been part of the conversation

Interviewees said they were involved in some type of family conversation about the future. The degree of involvement varied, but all siblings reported being a part of the conversation and being aware of what was happening even when they were not part of the decision-making process. Four siblings had memories of involvement in direct planning conversations even when they were young. One sister remembers being part of planning sessions as a teenager. Similar circumstances were reported within the focus group discussion. All participants felt they had been involved to some degree in conversations about the future.

Underlying assumptions

To help distinguish between types of planning, participants were asked if their family future discussions were indirect or direct and if informal or formal planning processes were used. Three siblings reported parents who either did not or would not engage in any kind of formalized planning. Two had actively tried to engage parents in such conversations, with little success. The

majority of planning was reported to be indirect and informal among both participant groups. Focus group members and eight of the interviewees described their family conversations about the future as mostly indirect and informal. One sister said, “our planning has been very informal, we’ve had conversations, general ones”. Siblings did not characterize those informal discussions as official planning sessions. Only four interviewees reported being a part of formalized processes, including participating in their siblings’ support circle or in a facilitated planning session by an independent planner or agency staff person. Three focus group members reported participating in a support circle, only one of which was active. Five interviewees said they had been involved in direct conversations about specific plans, most of which related to financial planning.

Participants had varying amounts of specific details about future plans. Among the future sibling caregivers, only three could point to any concrete future planning on the part of their families. Two participants knew of a future living arrangement and another had information about formal financial planning. When asked about information they did not know, focus group members stated they did not have details about timelines, support plans, or finances.

There was no significant difference among siblings who were already providing support. The four interviewees with the most specific detail had already assumed the primary support role. In each case, the specific future plans had not been fully laid out by the parents before the siblings assumed the role. Interviewees reported having some awareness of their parent’s intentions or expectations, even when specifics had not been explicitly stated. One sister said, “they knew that I will assume that responsibility, they never consciously placed that on me”. Another sister described it as an “unsaid agreement”. Whether through implicit or explicit means, the siblings were able to describe certain elements of a plan. Financial plans were the most apparent, with

nine siblings having some degree of awareness about financial planning on the part of their parents. In all cases this was through the creation of wills or trusts, but only three referred to having knowledge of specific details about those financial plans. Seven siblings had a concrete living arrangement plan. One family had made a formal plan for decision-making, which was the sibling assuming the role of legal guardian.

In terms of future planning on the part of the supporting siblings, one sister had named an executor to manage her brother's finances when she was no longer able to provide. Three siblings believed their children would play an important role in future support to their aunt/uncle with the disability.

Holding 'the ball'

Siblings who were currently holding supportive roles described seven categories of responsibilities within that role (See Table 1). Four siblings were already performing all or most of the responsibilities described. Seven believed they would be the primary person responsible for most categories. Two siblings described how responsibilities were currently or would be shared among siblings in the future. For example, one brother explained that he was responsible for financial and legal matters, a sister handled medical issues, and another sister managed the support services. Four siblings found it helpful to slowly take on additional responsibilities, transitioning into the role. One sister said, "I have to go in stages, I'm not just all of a sudden jumping in...we have slowly started to release the reins from my mother".

Siblings who intended to assume supportive roles in the future described the following responsibilities as ones they expected to hold:

- Maintaining a relationship and being involved
- Overseeing paid support
- Helping with practical tasks, like shopping
- Making sure things stay the same, as when parents were around
- Decision-making, medical and financial
- Advocacy

Table 1: *Responsibilities reported by siblings currently in supportive roles*

Responsibility	Already held	Not yet, but will in the future	Will be the responsibility of another sibling or a shared responsibility
Managing finances	4	4	1
Overseeing medical care	4	4	1
Decision-making	3	5	1
Advocacy	4	4	1
Coordination/management of services	3	6	0
Providing direct personal care*	4	1	0
Emotional support	9		0

*Four siblings reported personal care is/will be the responsibility of the residential service

Building Capacity

This section describes what participants perceived as being helpful to siblings filling supportive roles. Siblings already in the role were asked to reflect on their experiences and describe things that had been helpful to them and also what might have been helpful that they did not have. The siblings who intend to fill supportive roles were asked to describe what they felt they needed to prepare them for and assist in their future role. There was great deal of commonality between the two groups' responses, yielding the following four themes.

Purposeful coming together

All participants felt that at least some of the training they had received was helpful. The types of training varied, but the idea of training for siblings was a consistent recommendation. The training suggestions seem to fall into three training types. The first type incorporated an understanding of how disability is perceived in our culture and the resulting negative impact. Another aspect of this type was helping siblings think about what a good life would be for their brother/sister and how to implement that vision. Two siblings spoke about training that would promote the idea of family members caring for each other and discouraged dependency on paid human services. Three participants described this first type of training as values training. The second type related to knowledge of financial, legal, and service matters. Of this type, four interviewees and the focus group recommended training to help siblings navigate the service system and how to advocate within that system to ensure their brother/sister's needs are met. The third type involved knowledge of specific disabilities or medical conditions, support strategies, and other practical elements that would help a sibling provide the best possible care for their family member. One sibling mentioned a need for information about loss and grief so that the person with the disability could be better supported to cope with the loss of parents.

Relatedly, four interviewees and the focus group suggested that service organizations should broaden their definitions of family to include siblings. It was felt that organizations provide a lot of training for parents but few intentional efforts are made to involve siblings in those events. One interviewee also encouraged organizations to help pay for siblings to attend workshops. She said the financial support she received from her local association made a big difference.

Can't do it alone

Both groups of participants felt it was important to have the support of others. Siblings highlighted the need for support from other family members, like-minded people, and paid staff. Support from other family members, especially other siblings, was seen as critical. Sharing responsibilities among siblings was strongly encouraged. Five of the nine interviewees had at least one other sibling in addition to the brother/sister with the disability. Two reported active involvement by another sibling which was described as helpful. Two noted minor involvement of another sibling, but not in a way that was overly helpful. One sister noted that she wished her other siblings would be more helpful, in the sense of being more emotionally supportive. Four interviewees did not have other siblings, but spoke of receiving support and assistance from extended family members or close friends.

When reflecting on their own connection to other siblings of people with disabilities, five could pinpoint some minor interactions with other siblings, three of which involved participation on a sibling panel at a conference. Four interviewees reported no connection to other siblings at all. All interviewees felt that a connection may be helpful to some people, even though five indicated that would not have been helpful to them. One sister wanted to hear from other people in the same position and how their families made it work. Focus group participants highlighted a connection to other siblings as something they would find helpful. They envisioned connections where siblings could share experiences and learn from each other. The group felt a mentoring-type relationship between siblings would be helpful. Another recommendation involved organizations hosting social events where all family members could come together, especially when children are young. They felt such events would give siblings a chance to meet other

siblings, be involved with other people with disabilities, and make an early connection to the organization.

Participants from both groups discouraged sibling support groups where members focus on negative elements of having a brother/sister with a disability or their relationships. One interviewee participated in a sibling group as a child and described it as awful, saying it sent the wrong message. Another sibling recalled attending a similar group, stating it was not helpful.

The term “like-minded” was used frequently to describe the type of people siblings wanted involved. This term was used in various ways. Sometimes it was in reference to other siblings in similar circumstances or parents of people with disabilities. It was also used to describe knowledgeable people who could offer needed information or support. People involved in the disability movement were also included in this description.

Paid supports were also included in the list of helpful people. Focus group members talked about the importance of counting on people who had supported their brother/sister and knew them really well. Three interviewees described paid supporters as helpful and a way to ensure siblings received needed breaks. One sibling spoke about the importance of consistent workers and another believed the service system will need to evolve to support siblings, who may have different needs than parents.

Gradual release

Participants spoke passionately though less frequently about the topic of transition in care. Four siblings already in supportive roles spoke about the importance of a slow transition of responsibilities, from parents to siblings. This was reported to be helpful for all parties, including the parents, the siblings, and the person with the disability. One brother felt siblings

needed to be involved in support long before a crisis situation occurred. This thought was shared by siblings in the focus group who did not want to wait until a crisis to assume a supportive role. One sister felt it was important to prepare the person with the disability for the transition well in advance. In her family, her future role was openly discussed with her brother. She felt that he had been prepared for the transition, which made it much easier. Her mother had taken care of financial and legal matters ahead of time, which she felt prevented problems when she assumed care. The belief among participants was that if they could work into the role slowly, it would be easier for them to manage and allow them the time needed to learn the expectations. Taking on responsibilities all at once, or in a time of crisis was described as overwhelming.

Open and honest communication

Common among both groups of participants was the need for clear, open communication between parents and siblings. Siblings wanted direct conversations with parents about their expectations, wishes, and intentions. One sibling felt that parents may be fearful of making specific requests, however believed parents should ask explicit questions instead of relying on assumptions. They also reported a need for specific details about what plans had already been made. When described the information needed, focus group members included specifics about living arrangements, finance and service/funding arrangements. They also reported wanting a clear understanding of the big picture and their parents' goals for their brother/sister. One interviewee spoke about the importance of knowing the vision for the future.

Participants reported that their early involvement in conversations was helpful, even when there was not a lot of specifics. They suggested that families should start these conversations early so that it could become a regular part of family dynamics. The focus group felt this could start in

childhood and there was no need to wait for siblings to be adults. Early involvement was reported by both participant groups as an effective way to prepare siblings for their future roles.

Involving siblings in formal planning processes was another common recommendation. It was felt that formal planning processes typically involved parents, but siblings really needed to be actively involved. The focus group felt that in addition to helping with preparedness, sibling inclusion in the planning process was important since siblings likely bring different perspectives. Four interviewees felt service organizations could play a role in fostering sibling involvement. Organizations that already help parents with future planning could actively engage siblings in the process, but also help parents understand the importance of involving siblings.

Summary

The analysis of the data reveals much commonality among the perspectives of participants in both groups within the relationship, influential factors, and building capacity sections. Minor differences were noted in future planning. All participants reported having close, loving relationships with their family member with the disability, which resembled typical sibling relationship. They also felt they were included in the care and support of their sibling right from the beginning. Siblings already holding supportive roles were influenced by similar factors as siblings who were committed to taking on such roles in the future. Participants reported being raised in family cultures that fostered a sense of shared responsibility and care for all family members. Siblings believed they had been exposed to influential ideas and people who contributed greatly to their ability to support their brother/sister. Siblings also reported having a positive mindset about the role they play in their brother/sisters life, never perceiving it as a burden. Data about the barriers siblings face was also consistent. The minor differences in the future planning section related to the amount of experience and knowledge held by each group.

Siblings already holding supportive roles had participated in more future planning and had more information about family plans than did siblings with no current responsibilities. However, common among both groups was an acknowledgment that they had always been involved in planning conversations, mostly of an informal, indirect nature. The level of concrete family planning was relatively low within both groups, as was the number of specific details. Data also revealed ways to build the capacity of siblings so they are better able to fill supportive roles. The most common suggestions included training for siblings in a variety of key areas, involving other people in their sibling's support, ensuring there is a transition period for transfer of care from parents to siblings, and having clear, open communication within families about future plans.

DISCUSSION

The findings in this study and the literature review provide insight into the factors that influence sibling caregiving and the needs of siblings in supportive roles. This chapter integrates and interprets these findings, in relation to the research questions and project objective. Key topics will be discussed that are relevant to building the capacity of adult siblings in supportive roles and to enhance practices of organizations that serve people with intellectual disabilities and their families. Key considerations and action implications will be explored related to fostering supportive sibling relationships, enhancing future planning concerns, and meeting the needs of siblings in supportive roles.

Fostering Supportive Sibling Relationships

The importance of building relationships between siblings that will promote long-term supportive roles has surfaced as a theme and critical point of learning within this project. The literature and the findings of this study indicate that the quality of these relationships will influence the likelihood of future sibling involvement and will help sustain lifelong commitments. This section will describe characteristics and other factors related to relationships that could be intentionally fostered to promote supportive roles.

One characteristic that can be fostered is a close, loving relationship that involves typical and regular contact. Several of the studies reviewed report close relationships and regular contact between siblings, often facilitated by living in close proximity (Davys, Mitchell, & Haigh, 2010; Greenberg, Seltzer, Orsmond, & Krauss, 1999; Seltzer, Begun, Seltzer, & Krauss, 1991). These relationship characteristics were also consistently described within this study. Siblings reported typical, loving sibling relationships as children that grew into deep and committed adult relationships. Siblings cared deeply for their brother/sister and wanted to support their wellbeing.

Having direct involvement in support to their brother/sister as a child was another regularly appearing factor that had a positive influence on the relationship. Siblings in this study reported having an understanding of their brother/sister's disability and support needs, and even direct participation in their care in some cases. Siblings often reflected fondly about the support they provided to their brother/sister growing up. One sister noted the importance of such caring roles in childhood and urged parents to craft such roles for siblings. Coyle, Kramer, and Mutchler (2014, p. 303) noted that when siblings hold care providing roles it can positively affect the sibling relationship through the life course.

A positive mindset is another factor that influences a supportive relationship between siblings. Participants in this study did not possess the burden mindset that they described as being a major barrier to caregiving. As support was not seen as a burden, siblings were committed to supportive roles, even when there was a lack of clarity about specific responsibilities. Participants also noted that it is important that parents do foster these mindsets among siblings. Another positive mindset that surfaced within this study related to a deep understanding of the vulnerabilities associated with disability and the resulting need for advocacy. Bigby (1997) and Li and Ping (2006) also acknowledged this key advocacy role.

Even though not specifically a relationship characteristic, family culture emerged as theme within this study that has direct implications for sibling relationships. Overwhelmingly, siblings reported being raised as part of a family that valued each family member and fostered shared responsibility. Siblings grew up in a family culture where members cared for each other, so continuing that care into adulthood was a logical extension. Even in cases where it had not been explicitly stated, there was an underlying assumption that the sibling would take over the responsibilities, in whole or in part, previously held by parents.

Enhancing Future Planning

This study supports the importance of future planning and specifically the involvement of siblings in such planning, which is consistent with studies by Burke, Taylor, Urbano, and Hodapp (2012), Davys et al. (2010) and Seltzer et al. (1991). When siblings are involved in future planning it increases the likelihood that they will assume supportive roles, prepares them for future responsibilities and supports a smooth transition of care. A consolidation of the findings and literature review illustrates the following planning-related considerations for parents, siblings, and service organizations.

To build the capacity of sibling caregivers, families need to engage in planning at higher rates than has been reported. Even though 100% of siblings currently holding supportive roles in this study reported an awareness of the future plan, 55% could articulate any type of concrete plan made by parents. Of the participants intending to support their sibling in the future, 37% reported knowledge of specific plans. Much of the planning that was reported by participants was informal and could not be described as concrete given details were often based on assumptions or intentions. Planning among participant families was also at various stages of implementation, ranging from beginning stages to full implementation, which may have had an impact on the amount of information known by siblings. These planning rates were relatively consistent with ranges reported in the literature review, which varied from 27 % (Hole, Stainton, & Wilson, 2013) to 45% (Bigby, 1996). This study found that 10% of current caregiving siblings had engaged in planning for a time when they could no longer provide support, which is lower than the 30% reported by Egan and Walsh (2001). The plans reported in this study indicate a preference for family-based options, with parents making financial plans more than other types

like living arrangements or legal decision-making (See Table 2). These findings are consistent with those reported in Bigby (1996) and Heller and Factor (1991).

Table 2: *Future plans reported by nine siblings already holding supportive roles*

Living Arrangements		
With Sibling	Residential Service	Undecided
4	3	2
Financial Arrangements		
Will and/or trust	Managed by sibling(s)	Undecided
9	9	0
Decision-making Arrangements		
No legal/formal arrangement	Sibling as legal guardian	
8	1	

Relationships and family culture appear to mitigate the lack of planning within this study.

Participants did not raise the lack of a concrete plan as a major concern, including siblings facing increased responsibilities in the near future. The siblings who intended to assume supportive roles in the distant future indicated a greater need for detail, but did not report feeling worried about the lack of specifics. Overall, siblings were guided largely by their intentions and assumptions or those of their parents.

Siblings want and need to be involved in planning processes. The literature highlights that sibling involvement in planning increases the likelihood that they will support their brother/sister in the future (Davys et al., 2010; Griffiths & Unger, 1994). Such involvement appears to be an influential factor in this study, which found that all participants had been involved in some type of future planning discussion, compared to rates of around 50% reported by Griffiths and Unger (1994) and Davys et al. (2010). Participants articulated the importance of their early involvement and the impact it had within their families. In addition to future planning

discussions, siblings also highlighted the benefits of participation in conversations about disability-related issues from a young age.

Although the levels of participation were high, discussions were largely informal and indirect. Much of the detail reported by siblings was based on assumptions and intentions. Siblings appeared to be able to act on the basis of those assumptions and intentions, however it can be assumed that they would be in a better position to support their brother/sister if those ideas were converted into specific plans. This notion is supported by the literature which recommends sibling engagement in formalized planning processes and direct roles in the creation and implementation of future plans (Davys et al., 2010; Heller, 2000; Seltzer et al., 1991).

Participants focussed on the need for open, clear conversations between parents and siblings and were less concerned with the specific process. Formal processes could be helpful, but were not seen as a requirement.

These findings lead to potential action implications for service organizations that commonly have a role in assisting people with intellectual disabilities and their families to plan for the future. In addition to early engagement of parents in planning discussions, participants felt organizations could promote, actively recruit and support the involvement of siblings. The findings also highlight the benefits of informal processes, in addition to the formal ones typically utilized by organizations. Formal planning processes do not always translate into the creation of actual plans (Heller, 2000), therefore organizations could incorporate various methods of engagement. The understanding of the benefits of early informal discussions and an appreciation for the importance of sibling involvement could help alleviate some of the hesitation and fears parents have about future planning. Organizations could help foster such an environment.

Regardless of the specific planning process, open, clear conversations about the future that

incorporates specific detail is important. Siblings' need for information and inclusion in the process could be facilitated by the service organization.

Meeting the Needs of Siblings in Supportive Roles

The first generation of parents who raised their disabled children at home are aging and siblings are assuming supportive roles at higher rates than before. Consideration needs to be given to addressing the needs of siblings so they are able to effectively support their brother/sister.

One strategy is to ensure that the working definitions of 'family' within organizations are inclusive of siblings. Participants noted that despite an organization's intentions or claims to support families, its service practices, including training and planning processes, are typically geared towards parents. The literature reports similar concerns with family definitions and calls for more family-centered approaches (Arnold, Heller, & Kramer, 2012; Conway & Meyer, 2008; Tozer, Atkin, & Wenham, 2013). As parents age, organizations will begin to work more directly with siblings. Organizations would benefit from a review of their family support approaches to ensure that sibling needs are considered and that services are not designed solely for parents.

A second strategy is to provide and promote training and information. The importance and benefits of providing siblings with information and training is clearly reported in the literature. Studies illustrate that siblings will be better prepared to support their brother/sister if they have access to information and training related to important disability-related topics like advocacy, financial planning, legal issues, and navigating the service system (Arnold et al., 2012; Li & Ping, 2006; Rawson, 2009). This study found similar information needs among siblings, but participants also described the importance of values training, which helps siblings understand

how to assist their brother/sister to have a good life. The findings also highlight that training contributes to positive mindsets about disability and is an influential factor in sibling caregiving. Service organizations play a fundamental role in meeting the information and training needs of siblings. Organizations can conduct training on topics of specific interest to siblings and siblings can be actively recruited to participate in training that the organization typically offers to parents. Organizations can provide financial support for registration fees or travel expenses to siblings enabling them to attend costly training events. Some participants expressed gratitude for the financial support received from organizations, as they would not have been able to participate in the training otherwise. Organizations can also provide a mechanism for the distribution or sharing of information among siblings, as some may not be able to attend training events. Resource manuals or information booklets, as described by Conway and Meyer (2008) and Rawson (2009), could be an effective distribution method used by organizations.

Providing siblings with the practical assistance they need to fulfil their supportive role is another key strategy. A common concern among siblings relates to their ability to be in a supportive role to their brother/sister while managing other responsibilities. Accessing paid services, like respite supports, has been described as a useful strategy for helping siblings manage multiple responsibilities (Arnold et al., 2012; Meyer & Holl, 2014). Respite services will help siblings maintain work roles and provide assistance to siblings caring for their own children in addition to the support provided to their brother/sister with a disability. Even though some studies report sibling caregivers as being less likely to have children of their own (Greenberg et al., 1999), others report high rates of up to 75% of siblings having children (Krauss, Seltzer, Gordon, & Friedman, 1996). These higher rates were also reflected in this study with 77% of caregiving siblings having children.

The benefit of paid supports was voiced among participants as well but a few siblings warned against relying too heavily on paid services. Support from other family members, friends and neighbours was described as natural ways to help siblings with various practical needs and to balance multiple responsibilities. Participants also noted that organizations might need to adapt provision of respite services to accommodate the needs of siblings, which may be different than those of a parent.

A fourth strategy is to foster connections between siblings and advocacy organizations as such connections are highly conducive to capacity building. Connections between siblings has been reported as helpful within this study and in the literature reviewed, though there was some variation in methods. Studies commonly recommend support groups as a way for siblings to connect (Arnold et al., 2012; Heller & Kramer, 2009) and that such groups will prepare siblings for future caregiving roles (Burke et al., 2012). However, siblings had concerns about a support group model that could promote unhelpful mindsets. Instead, siblings preferred informal opportunities to gather, share experiences with a focus on learning from each other. Social events were seen as one way that siblings could interact in a fun, natural environment, especially at a young age. Heller et al. (2008) promote sibling networks, which a model more closely aligned with participant views. Such networks, which exist less extensively in Canada than in the United States, would be an important capacity building strategy for siblings.

Another type of helpful connection is to be active in disability advocacy organizations, through leadership roles and participation in advocacy activities. These connections build sibling capacities through membership in the broader disability movement and by increasing awareness of important disability-related issues. Research indicates that involvement in advocacy activities and/or leadership roles within disability organizations is an influential factor among siblings in

supportive roles (Heller & Kramer, 2009; Tozer et al., 2013). About 95% of participants either had direct involvement with disability organizations or had been exposed through the work of parents.

Summary

This chapter reflected on key considerations and action implications to build the capacity of siblings. It considered the relationship between siblings, which emerged as a key theme that influences and sustains supportive roles. Such relationships can be fostered through the promotion of meaningful sibling interactions, positive mindsets about disability, and sibling support, and a family culture that promotes shared responsibility. It further suggested that enhancing future planning within families could be a means of building sibling capacity as findings indicate the importance of engaging in direct discussions about the future and actively involving siblings in planning processes that result in clear expectations. Finally, it highlighted some of the unique needs of siblings and the resulting action implications for families and service organizations. Specific strategies included definitions of family that are inclusive of siblings, providing siblings with information, training, and other services that will support their roles with their brother/sister. Supporting connections to other siblings and advocacy organizations was another effective strategy.

RECOMMENDATIONS

Based on the research and analysis conducted in the project, this section provides recommendations that are relevant to the capacity building of siblings and the improvement of service practices of the Brockville and District Association for Community Involvement. This section offers 15 recommendations within three broad categories: membership engagement and leadership development, training and information, and organizational practices. Within each category, recommendations are ordered in terms of priority within two time frames, namely short-term (within 1 year) and long-term (with 2 years) implementation goals.

Member Engagement and Leadership Development

Short-term implementation

1. Establish a BDACI Sibling Leadership Network. The group of siblings who were involved in the BDACI “Engage” event could serve as the founding members of this network, playing a key organizing role. Local parent networks, like the previous Leeds and Grenville Family Network, could serve as a model in the design of this network. Large-scale sibling leadership networks, like those in the United States, could also serve as an important reference point. This network could provide a mechanism for:
 - a) Engaging siblings in the Association’s advocacy efforts and developing their leadership skills. Network members could actively participate in the Association’s local and/or provincial advocacy activities.
 - b) Providing opportunities for networking among siblings through regular meetings, social events, or social media outlets.
 - c) Assisting BDACI in the organizing and/or conducting of sibling-specific training events.

- d) Voicing the needs of siblings within the Association through a liaison relationship with the Board of Directors.
2. Disseminate the results of this project to the Association's membership, highlighting themes and the considerations discussed in the report. The full report can be made available, however more user-friendly formats could be pursued, such as a short article or presentation.
3. Revisit the Board decision made in 2013-2014 to discontinue large-scale social events like the Christmas party. Focus group members, most of whom have attended such events, described them as an important means of sibling engagement.

Long-term implementation

4. Review and amend organizational by-laws related to the composition of the Board of Directors to ensure that at least one director position is reserved for a sibling. Sibling involvement should be a priority for the Nomination Committee. Sibling representation could be a requirement for committee membership. As it may be difficult to recruit multiple siblings, ensuring a sibling is on at least one committee seems like a reasonable expectation.
5. Host social events for members, at least three per year that foster the participation of the whole family. Emphasis could be placed on children-friendly activities that will engage young siblings.
6. Recruit sibling guest speakers for membership engagement events, family retreats, or the annual general meeting.

Training and Information

Short-term implementation

7. Provide sibling-specific training opportunities that will address the key information needs of siblings. The training could be conducted through an information series, spanning several months, or during a multi-day retreat event. Siblings could be involved in the organization of this training and when possible, sibling trainers could be accessed. Minimally, this training could include:
 - a) A form of values training that will help siblings explore issues of visioning and creating a good life for their brother/sister.
 - b) A brief overview of the developmental services sector focusing on the program and funding sources most commonly used by families.
 - c) An introduction to essential elements of financial planning, including information about wills, trusts, and potential implications of the Ontario Disability Support Program.
 - d) An overview of the current legal decision-making processes in Ontario.
8. Review and update the organization's mailing lists to include contact information for adult siblings. This will ensure siblings receive training and event notifications.

Long-term implementation

9. Enhance the organization's website and Facebook page by adding information and resources that may be of interest to siblings. This could include articles written by siblings, stories of siblings who are successfully navigating supportive roles, and links to relevant websites.

10. Ensure siblings have knowledge of and access to the financial subsidies BDACI provides to families for external training events.

11. Purchase sibling focused resources for the organization's library. Resources written by siblings would be an asset, as would materials suitable for various age groups. Young siblings could benefit from resources that help foster positive mindsets about disabilities, while adult siblings would benefit from guides written for sibling caregivers.

Organizational Practices

Short-term implementation

12. Review and revise the current planning process used by the Family Support Program to:

- a) Optimize sibling involvement
- b) Ensure planning documents are detailed and actionable
- c) Promote the early establishment of support circles

13. Hold a Board/staff retreat to review the research findings and discuss possible action implications. Part of this retreat could be devoted to reviewing the Association's operational definition of 'family', with a goal of assessing the degree to which siblings are considered and included in the organization's practices.

Long-term implementation

14. In their work with parents, Family Support Coordinators could engage in discussions about key themes that emerged in this project, including the importance of typical sibling relationships, shared responsibility, and early involvement in disability-related and future discussions.

15. Participate in provincial events or projects to increase awareness about the needs of siblings who are in supportive roles. For example, the siblings involved in the BDACI Sibling Leadership Network could present at the Community Living Ontario conference or a Family Alliance Ontario gathering. BDACI could also promote sibling issues through its membership to Community Living Ontario.

Summary

Within this section, parallel recommendations have been provided in three categories. The highest prioritized recommendations within the respective categories included establishing a Sibling Leadership Network, providing training to siblings, and improving the organization's planning processes. As implementation efforts may be constrained by resources, BDACI may need to focus its efforts on one specific recommendation. If so, it is suggested that sibling training be addressed first as this could have an immediate impact on sibling preparedness. Training events also create meaningful engagement and networking opportunities, which will be beneficial in the creation of a sibling network in the future. Given this networking potential, it is suggested that training occur through a series of sessions or a retreat, not as one stand alone event.

CONCLUSION

The life circumstances of people with intellectual disabilities have changed significantly in the past several decades. Deinstitutionalization has allowed people with disabilities to live in their family home and experience community life. With these positive changes, come new parental concerns about who will care for their son/daughter when they are no longer able. Siblings commonly assume these supportive roles that enhance and safeguard the life of their brother/sister, but are not always prepared to take on these responsibilities.

To address the issue of preparedness and investigate capacity building strategies, this research examined factors that influence siblings to hold supportive roles and the needs of siblings in such roles. Through interviews and a focus group data was gathered from siblings who already held supportive roles and from siblings who intended to assume such roles in the future. These research methods provided an effective means for siblings to share their thoughts, feelings and experiences related to supportive roles.

Research data was analyzed in four areas: relationships, influential factors, future planning, and capacity building strategies to reveal themes relevant to the research questions and project objective. Among these themes some powerful messages emerged about the importance of close sibling relationships, family cultures that promote shared responsibility, exposure to influential ideas that shape mindsets, being included early in conversations about the future and the need for siblings to surround themselves with supportive people. When integrated with the literature review, these findings informed the following key considerations and action implications: sibling relationships can be fostered to promote supportive roles, improving planning processes will better prepare siblings for future responsibilities, and meeting the needs of siblings will build capacity and promote the sustainability of supportive relationships.

This analysis led to 15 recommendations that could enhance the service practices of the Brockville and District Association for Community Involvement (BDACI). The recommendations focused on actions in three areas: membership engagement and leadership development, training and information, and organizational practices. Even though each recommendation plays an important role in meeting the project objective, recommendations were organized into short-term and long-term implementation goals. Of the short-term goals, priority was given to establishing a Sibling Leadership Network, providing training to siblings, and improving the organization's planning processes. To further explore this topic, additional research could be conducted that includes the perspectives of siblings who may be hesitant to assume supportive roles.

The Brockville and District Association for Community Involvement has always been a family-driven organization that is committed to meeting the needs of people with intellectual disabilities and their families. The organization's interest in this project and recognition of the important role that siblings play highlights this commitment to families. This project created an opportunity for BDACI to learn from the perspectives and experiences of siblings, which the organization believed was an essential element in improving overall support to families.

REFERENCES

- Arnold, K., Heller, T., & Kramer, J. (2012). Support needs of siblings of people with developmental disabilities. *Intellectual and Developmental Disabilities, 50*(5), 373-382.
- Bigby, C. (1996). Transferring responsibility: The nature and effectiveness of parental planning for the future of adults with intellectual disabilities who remain at home until mid-life. *Journal of Intellectual & Developmental Disability, 21*(4), 295-312.
- Bigby, C. (1997). When parents relinquish care: informal support networks of older people with intellectual disability. *Journal of Applied Research in Intellectual Disabilities, 10*(4), 333-344.
- Braddock, D. (2013, February 27). Intellectual and developmental disabilities services in the US. *AAIDD Webinar* [slideshow]. Retrieved January 2, 2016, from http://www.acphd.org/media/292360/webinar_intellectual_and_dds.pdf
- Braddock, D., Emerson, E., Felce, D., & Stancliffe, R. (2001). Living circumstances of children and adults with mental retardation or developmental disabilities in the United States, Canada, England and Wales, and Australia. *Mental Retardation and Developmental Disabilities Research Review, 7*, 115-121.
- Brockville and District Association for Community Involvement. (2006). *Towards Inclusive Community: the first fifty years*. Brockville, ON.
- Brockville and District Association for Community Involvement. (2013). Service purpose and principles policy. *Program and Services Policies and Procedures*. Brockville, ON.

- Brockville and District Association for Community Involvement. (2015). *Family support coordination program*. Retrieved November 7, 2015, from <http://bdaci.com/association-outreach-cl.php>
- Burke, M., Taylor, J., Urbano, R., & Hodapp, R. (2012). Predictors of future caregiving by adult siblings of individuals with intellectual and developmental disabilities. *American Journal of Intellectual and Developmental Disabilities, 117*(1), 33-47.
- Canadian Association for Community Living. (2010). *Position paper on legal capacity*. Retrieved December 12, 2015, from <http://www.cacl.ca/sites/default/files/uploads/docs/CACL%20Policy%20Position%20legal%20capacity.pdf>
- Canadian Association for Community Living. (2016). *History*. Retrieved January 3, 2016, from <http://www.cacl.ca/about-us/history>
- Canada Housing and Mortgage Corporation. (2006). *Housing for adults with intellectual disabilities*. Retrieved December 12, 2015, from http://www.cmhc.ca/en/inpr/rehi/rehi_018.cfm
- Carney, T., & Keyzer, P. (2007). Planning for the future: Arrangements for the assistance of people planning for the future of people with impaired capacity. *Queensland University of Technology Law and Justice Journal, 7*, 255 – 278.
- Chadwick, D., Mannan, H., Iriarte, G., McConkey, R., O'Brien, P., Finlay, F., Lawlor, A., & Harrington, G. (2013). Family voice: life for family carers of people with intellectual disabilities in Ireland. *Journal of Applied Research in Intellectual Disabilities, 26*, 119-132.

- Community Living Ontario. (2015). *What is an intellectual disability?* Retrieved November 7, 2015, from <http://www.communitylivingontario.ca/about-us/what-intellectual-disability>
- Conway, S., & Meyer, S. (2008). Developing support for siblings of young people with disabilities. *Support for Learning, 23*(3), 113-117.
- Coyle, C., Kramer, J., & Mutchler, J. (2014). Aging together: sibling cares of adults with intellectual and developmental disabilities. *Journal of Policy and Practice in Intellectual Disabilities, 11*(4), 302-312.
- Dang, M. (2010). The history of legislation and regulations related to children with developmental disabilities; implications for school nursing practice today. *The Journal of School Nursing, 26*(4), 252-259.
- Davys, D., Mitchell, D., & Haigh, C. (2010). Future planning, parental expectations and sibling concern for people who have a learning disability. *Journal of Intellectual Disabilities, 14*(3), 167-183.
- DiCicco-Bloom, B., & Crabtree, B. (2006). The qualitative research interview. *Medical Education, 40*, 314-321.
- Egan, J., & Walsh, P. (2001). Sources of stress among adult siblings of Irish people with intellectual disability. *The Irish Journal of Psychology, 22*(1), 28-38.
- Flynn, E. (2010) A socio-legal analysis of advocacy for people with disabilities – competing concepts of ‘best interests’ and empowerment in legislation and policy on statutory advocacy services. *Journal of Social Welfare and Family Law, 32*(1), 23-36.

- Freedman, R., Krauss, M., & Seltzer, M. (1997). Aging parents' residential plans for adult children with mental retardation. *Mental Retardation*, 35(2), 114-123.
- Golstein, J., & Godement, M. (2003). The legend and lessons of Geel, Belgium: a 1500-year-old legend, a 21st century model. *Community Mental Health Journal*, 39(5), 441-458.
- Gordon, R. (2000). The emergence of assisted (supported) decision-making in the Canadian law of adult guardianship and substitute decision-making. *International Journal of Law and Psychiatry*, 23(1), 61-77.
- Greenberg, J., Seltzer, M., Orsmond, M., & Krauss, M. (1999). Siblings of adults with mental illness or mental retardation: current involvement and expectation of future caregiving. *Psychiatric Services* 50(9), 1214–1219.
- Griffiths, D., & Unger, D. (1994). Views about planning for the future among parents and siblings of adults with mental retardation. *Family Relations*, 43(2), 221-227.
- Grossoehme, D. (2014). Overview of qualitative research. *Journal of Health Care Chaplaincy*, 20(3), 109-122.
- Heller, T. (2000). Supporting adults with intellectual disabilities and their families in planning and advocacy. *Physical & Occupational Therapy in Geriatrics*, 18(1), 59-73.
- Heller, T., & Arnold, C. (2010). Siblings of adults with developmental disabilities: psychosocial outcomes, relationships, and future planning. *Journal of Policy and Practice in Intellectual Disabilities*, 7(1), 16-25.
- Heller, T., & Caldwell, J. (2006). Supporting aging caregivers and adults with developmental disabilities in future planning. *Mental Retardation*, 44, 189-202.

- Heller, T., & Factor, A. (1991). Permanency planning for adults with mental retardation living with family caregivers. *American Journal on Mental Retardation*, 96(2), 163-176.
- Heller, T., & Factor, A. (2008). Family support and intergenerational caregiving: report from the state of the science in aging with developmental disabilities conference. *Disability and Health Journal 1*, 131-135.
- Heller, T., Kaiser, A., Meyer, D., Fish, T., Kramer, J., & Dufresne, D. (2008). The Sibling Leadership Network: recommendations for research, advocacy, and supports related to siblings of people with development disabilities. Available from <http://www.rrtcadd.org/blog/files/efebf03a51d7e56895dec39050c0118f-80.html>
- Heller, T., & Kramer, J. (2006) Involvement of adult siblings of people with developmental disabilities in future planning. *Disability Research Brief*, 2(2). Chicago: Institute on Disability and Human Development, University of Illinois at Chicago.
- Heller, T., & Kramer, J. (2009). Involvement of adult siblings of people with developmental disabilities in future planning. *Intellectual and Developmental Disabilities*, 47, 208–219.
- Heller, T., & Schindler, A. (2009). Family support interventions for families of adults with intellectual and developmental disabilities. *International Review of Research in Mental Retardation*, 37, 299-332. doi: 10.1016/S0074-7750(09)37009-3
- Hole, R., Stainton, T., & Wilson, L. (2013). Ageing adults with intellectual disabilities: self-advocates and family members' perspectives about the future. *Australian Social Work*, 66(4), 571-589.

- Krauss, M., & Seltzer, M. M. (1993). Current well-being and future plans of older caregiving mothers, *The Irish Journal of Psychology*, *14*(1),48-63, DOI: 10.1080/03033910.1993.10557914
- Krauss, M., Seltzer, M. M., Gordon, R., & Friedman, D. (1996). Binding ties: the roles of adult siblings of persons with mental retardation. *Mental Retardation*, *34*(2), 83-93.
- Krauss, M., Seltzer, M. M., & Jacobson, H. T. (2005). Adults with autism living at home or in non-family setting: positive and negative aspects of residential status. *Journal of Intellectual Disability Research*, *49*(2), 111-124.
- Li Y., & Ping E. (2006). Sibling advocates of people with intellectual disabilities. *International Journal of Rehabilitation Research*, *29*(2), 175-178.
- Meyer, D., & Holl, E. (2014). *The sibling survival guide: indispensable information for brothers and sisters of adults with disabilities*. Bethesda, MD: Woodbine House, Inc.
- McConkey, R., Sowney, M., Milligan, V., & Barr, O. (2004). Views of people with intellectual disabilities of their present and future living arrangements. *Journal of Policy and Practice in Intellectual Disabilities*, *1*(3/4), 115-125.
- O'Rourke, A., Grey, I., Fuller, R., & McClean, B. (2004). Satisfaction with living arrangements of older adults with intellectual disabilities. *Journal of Learning Disabilities*, *8*(1) 12-29.
- Orsmond, G., & Seltzer, M. M. (2000). Brothers and sisters of adults with mental retardation: gendered nature of the sibling relationship. *American Journal on Mental Retardation*, *105*, 486-508.

- Osburn, J. (2011). *Report of an assessment of issues related to the model coherency of the Brockville and District Association for Community Involvement*. Bardstown, KY: Indiana Safeguards Initiative.
- Pedlar, A., Hutchison, P., Arai, S., & Dunn, P. (2000). Community services landscape in Canada: survey of developmental disability agencies. *Mental Retardation*, 38(4), 330-341.
- Rawson, H. (2009). I'm going to be here long after you've gone—sibling perspectives of the future. *British Journal of Learning Disabilities*, 38, 225-231.
- Schwartz, C. (2005) Parental involvement in residential care and perceptions of their offspring's life satisfaction in residential facilities for adults with intellectual disability, *Journal of Intellectual and Developmental Disability*, 30(3), 146-155.
- Seltzer, G., Begun, A., Seltzer, M. M., & Krauss, M. (1991). Adults with mental retardation and their aging mothers: impacts of siblings. *Family Relations*, 40(3), 310-317.
- Taggart, L., Truesdale-Kennedy, M., Ryan, A., & McConkey, R. (2012). Examining the support needs of ageing family carers in developing future plans for a relative with an intellectual disability. *Journal of Intellectual Disabilities*, 16(3), 217-234.
- Tozer, R., Atkin, K., & Wenham, A. (2013). Continuity, commitment and context: adult siblings of people with autism plus learning disability. *Health & Social Care in the Community*, 21(5), 480-488.
- Vaismoradi, M., Turunen, H., & Bondas, T. (2013). Content analysis and thematic analysis: implications for conducting a qualitative descriptive study. *Nursing & Health Sciences*, 15, 398-405).

Weeks, L., Nilsson, T., Bryanton, O., & Kozma, A. (2009). Current and future concerns of older parents of sons and daughters with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 6(3), 180-188.

Wolfensberger, W. (1975). *The origins and nature of our institutional models*. Syracuse, NY: Human Policy Press.

Wolfensberger, W. (2003). *The future of children with significant impairments: what parents fear and want, and what they and others may be able to do about it*. Syracuse, NY: Training Institute for Human Service Planning, Leadership and Change Agency (Syracuse University).

Wolfensberger, W., Thomas, S., & Caruso, G. (1996). Some of the universal good things of life which the implementation of Social Role Valorization can be expected to make more accessible to devalued people. *The International Social Role Valorization Journal*, 2(2), 12-14.

Appendix A: Interview Questions

1. Can you tell me a little bit about your brother/sister (age, type of disability, support needs, where he/she lives, etc.)?
2. Can you talk about your relationship with your brother/sister, while you were growing up and now?
3. Describe some ways that you currently provide assistance/support to your brother/sister?
4. Planning for the future can be very difficult for parents. Can you describe how your parent(s) handled (or are thinking about) future planning?
5. What was your involvement/role in these conversations?
6. Did your parent(s) talk about any specific roles you could/would fill or responsibilities they wanted you to take on? If so, can you tell me about those conversations? If not, do you know why this never happened?
7. Can you talk about when you first started to take on responsibilities in your brother/sister's life? Was there a specific reason?
8. Can you tell me what kinds of things have been helpful to you in carrying out these responsibilities?
9. Not all siblings fill supportive role in their brother/sister's life. What may have influenced your decision to do so?
10. What kinds of things did you (or do you) struggle with or find particularly difficult in your supportive role?
11. Thinking about this issue broadly, not specifically about your own situation, do you think there are any barriers that can get in the way of siblings being in supportive roles to their brother/sister?
12. Reflecting on your experience, what would have been helpful to you (that you didn't receive)?
13. What might a service organization do to build the capacity of siblings and/or support siblings to fill supportive roles?
14. What would you say are some of the biggest lessons you have learned about supporting your brother/sister?
15. When you think about the future, what do you see for your brother/sister and for you?

Appendix B: Focus Group Topics

1. Roles/responsibilities that sibling can hold in the future
2. Your knowledge/experience with future planning
3. Thoughts/feelings about your future role
4. Barriers/difficulties that get in the way of siblings filling future roles
5. What do siblings need?