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An exploration of the relationships between young adult women and their sisters with intellectual disabilities

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An Exploration of the Relationships
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Abstract

This qualitative study explored the nature of the relationships between young adult women and their sisters with intellectual disabilities. This study sought to contribute to the growing body of literature on siblings of people with intellectual disabilities by addressing the dearth of research on sisters in young adulthood, and their experience of the sibling relationship. The narratives of twelve young adult sisters of women with intellectual disabilities were gathered through open-ended interviews. Research questions explored such topics as the level of contact participants had with their sisters, how their relationships had changed in adulthood, and the most fulfilling and challenging aspects of these relationships.

Findings suggest that the relationships between young adult sisters are significantly impacted when one sister has an intellectual disability. These relationships face barriers to connectedness and reciprocity, but are also, in many cases, marked by a unique type of closeness. Participants revealed that their relationships with their sisters had a profound impact on their lives, both emotionally and instrumentally. While most of the women in this study had not assumed primary responsibility for their sisters, many of them indicated that their current life choices are affected by potential future responsibilities. The finding that sisters of women with intellectual disabilities would benefit from both individual counseling and access to support groups has important implications for social work practice.

An Exploration of the Relationships Between Young Adult Women and their Sisters with Intellectual Disabilities

A project based upon an independent investigation, submitted in partial fulfillment of the requirements for the degree of Master of Social Work.

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Chapter I

Introduction

The purpose of this qualitative study is to explore the experiences of young adult women who have sisters with intellectual disabilities. Specifically, this study investigates the quality and nature of their relationships with their sisters. It seeks to understand the fulfilling and challenging aspects of these relationships, the level and type of contact between sisters, and the ways that these relationships are unique. According to Seligman and Darling (2007), "Sibling relationships are usually the longest and most enduring of family relationships. This long-term relationship makes it possible for two individuals to exert considerable influence over each other through longitudinal interactions (p. 234)." This study seeks to understand more about this phenomenon when it pertains to a population that has not yet received adequate attention by researchers.

An increasing amount of research exists on the siblings of people with disabilities. However, a review of the literature reveals significant gaps. The majority of studies focus on the sibling's experiences during childhood, and those that focus on adulthood rarely differentiate between the challenges faced by younger and older adults. Most studies group findings on male and female nondisabled siblings, as well as male and female disabled siblings. Similarly, research has often grouped siblings of people with a wide array of both physical and intellectual disabilities. Finally, a review of the literature shows a lack of emphasis on the relationship itself, as studies tend to focus on the impact of the relationship on the nondisabled sibling. This study sought to add to the body of research in these neglected areas by focusing specifically on the young adult sisters of women with intellectual disabilities. The researcher hoped to lend a voice to women who are rarely heard from, and ultimately help the social work profession better serve their needs.

This thesis begins with an introduction which states the purpose of the study. Following this is a literature review that summarizes past research that has been conducted in the area of siblings of people with disabilities, while further illuminating some of the gaps. In the methodology section, the way in which the study was undertaken is elaborated. The findings section details the major themes which emerged from interviews with twelve young adult sisters of women with intellectual disabilities. Finally the discussion chapter seeks to explain the importance of the findings and the ways in which they fit in with past research.

Chapter II

Literature Review

The purpose of this study is to explore the relationships between young adult women and their sisters with intellectual disabilities. Over the past thirty years, a substantial number of studies have been conducted on the experiences of siblings of people with disabilities. Research demonstrates that these siblings have distinct experiences that may affect their functioning, development, and sense of wellbeing (Seligman & Darling, 2007). This literature review will highlight the dearth of studies that explore the sibling relationship, particularly between sisters. Four main areas of research are addressed: adult siblings, female siblings, siblings of people with intellectual disabilities, and the sibling relationship when one sibling has a disability. As shown, there is a need for more information in all of these areas, thus inspiring the present study.

Adult Siblings

The majority of existing research on siblings of people with disabilities focuses on experiences during childhood (Abrams, 2009; Azeez, 2001; King, 2007; Labato, Kao, & Plant, 2005; Seligman & Darling, 2007; Strohm, 2005). Studies tend to highlight the detrimental effects of the relationship, finding that nondisabled siblings often become overly responsible caretakers (Abrams, 2009; King, 2007; Seligman & Darling, 2007), cope with increased tension in the home (King, 2007), and mature prematurely (Abrams, 2009). Existing research also asserts that nondisabled siblings experience a number of negative emotional responses, including guilt (Abrams, 2009; Labato et al., 2005; Seligman & Darling, 2007), feeling neglected by parents

(Abrams, 2009; Labato et al., 2005) as well as by mental health and healthcare systems (Abrams, 2009), isolation (Strohm, 2005), and heightened levels of depression and anxiety (Labato et al., 2005; Seligman & Darling, 2007). Finally, several studies have demonstrated that nondisabled siblings often lack accurate information about their sibling's disability (Seligman & Darling, 2007; Labato et al., 2005).

There is need for further research on adult siblings (Azeez, 2001; Seligman & Darling, 2007). This population has been overlooked both by professions helping people with special needs, and by researchers (Azeez, 2001). Over the past ten years, studies have begun to focus, or include portions, on the unique experiences of adult siblings of people with disabilities (Azeez, 2001; Heller & Kramer, 2009; Orsmond & Seltzer, 2007; Hodapp, Urbano, & Burke, 2010; McGraw & Walker, 2007) These studies tend to be less concerned with the over-arching effects, either negative or positive, of having a sibling with disabilities, and more focused on the challenges that become prevalent in adulthood.

Research reveals the common expectation that nondisabled siblings will assume a parental role when the parent dies or is no longer able to care for their disabled child (Azeez, 2001; Heller & Kramer, 2009). In many cases, this means taking on primary caretaking responsibilities. Some disparity exists concerning how often nondisabled siblings become primary caretakers. In a survey of 139 adult siblings of people with disabilities, Heller and Kramer (2009) found that only 38% expected to be primary caretakers, which was less than they anticipated. Caregiving responsibilities seem to be a major focus of literature pertaining to adult siblings, partly based on the increasing number of people with disabilities who are reaching old age (Hodapp et al., 2010). According to Hodapp et al. (2010), the population of people with intellectual disabilities who are over 60 is supposed to reach 1.5 million by 2030. Further, 60%

of these adults currently live with their parents in the family home (Hodapp et al., 2010). Given that these numbers do not even include older adults with other disabilities, they have major implications for siblings in the future.

Research indicates that siblings who do not anticipate taking on a primary caretaking role still have significant amounts of contact with their disabled sibling, and expect to take on other parental responsibilities (Krauss, Seltzer, Gordon, & Friedman, 1996). Krauss et al. (1996) found that half of the people in their study that did not plan to co-reside with their sibling still planned to become their legal guardian in the future. Nondisabled siblings may also become advocates, trustees (Heller & Kramer, 2009) or primary sources of emotional and social support. Despite the likelihood that they will assume at least some responsibility for their disabled sibling, Heller and Kramer (2009) found that nondisabled siblings are rarely involved in future planning, remaining unclear on the specific duties they will inherit until their parents can no longer perform them.

Beyond the new roles that adult siblings may inherit from their parents, the literature indicates that having a sibling with disabilities affects the life choices that they make. One study by Hodapp et al. (2010) found that adult siblings may be delaying their first marriage. This may be partly due to having to choose a partner willing to take on the added responsibility of their sibling (Seligman & Darling, 2007). Interestingly, the divorce rate of sisters of people with disabilities is slightly lower than that of sisters of people without disabilities, indicating that they may be making more cautious choices in who they marry (Hodapp et al., 2010). However, there is also some indication that siblings may gravitate to partners that need to be "fixed", due to being accustomed to a caretaking role (Seligman & Darling, 2007). Other studies suggest that siblings are more likely to enter helping professions (Azeez, 2001; Seligman & Darling, 2007).

As can be seen, adult siblings of people with disabilities often experience a unique level of responsibility. This can have a strong psychological impact. According to Seligman and Darling (2007), additional responsibilities may create feelings of "burden, guilt, and fear" (p. 240). Siblings may experience excessive worry as they look to the future and wonder how they will support their sibling, both emotionally and financially (Seligman & Darling, 2007). While the literature tends to focus on the negative emotions experienced by siblings both in childhood and adulthood, there is also some evidence that having a sibling with disabilities can have a positive impact. Siblings may develop an increased sense of self-esteem as a result of being helpful to their sibling with disabilities and needed by their family (Seligman & Darling, 2007). In an on-line survey of 1160 adult nondisabled siblings, participants were asked to comment on the positive attributes that they had gained as a result of growing up with a sibling with disabilities. According to the results of this study, 90% reported a greater sense of empathy, 94.4% reported better understanding people's differences, 87.2% reported increase compassion, and 83.2% reported being more responsible (Hodapp et al., 2010).

It is important to note that the experience of nondisabled siblings may be affected by a variety of factors that have not been adequately explored in the research literature, such as race, ethnicity, and socio-economic status. In the study by Hodapp et al., for example, over 90% of respondents were white. As Lobato et al. (2005) point out, "What is understood about sibling adjustment to chronic illness and disability is based almost exclusively on families of European American decent" (p. 625). While race and ethnicity are not a central focus of this study, it is still valuable to keep in mind that the existing literature is not necessarily generalizable to people of all backgrounds.

Of the existing studies that focus on adult siblings, few specifically concentrate on early adulthood. As the literature demonstrates, parental roles are often assumed later in adulthood when parents are no longer able to fill their earlier functions. The focus of much of the literature on caretaking responsibilities is thus less relevant to young adulthood. Literature specific to young adulthood has been particularly sparse over the past ten years. Thus, this review of the literature includes findings from older studies.

There is some indication that sibling relationships may become less close in early adulthood, when many nondisabled siblings leave the family home and no longer live with their sibling with disabilities (Seligman & Darling, 2007). Cohabitating is known to contribute to the level of conflict and discrepancy in status in sibling relationships, but also necessitates constant interaction, which can foster closeness (Begun, 1989, p. 570). One study on sibling relationships when one sibling has intellectual disabilities found that siblings with disabilities viewed young adult nondisabled siblings as less reliable than middle-aged nondisabled siblings (Zetlin, 1986, p. 224). However, since few studies exist on the relationship between young adult siblings when one has a disability, this is not well understood. As they enter a new phase of their lives, young adults are often confronted for the first time with the prospect of acquiring more responsibility for their sibling in the future, and the ways that this affects their choices and feelings requires more research. By focusing on young adults, this study seeks to address this gap in the literature.

Female Siblings

Few of the studies on adult siblings make mention of gender, grouping findings on female and male nondisabled siblings and female and male disabled siblings. According to McGraw & Walker (2007), "the limited research that does exist tends to conceptualize nondisabled-disabled sibling ties as gender neutral; that is, researchers focus on siblings rather than on the gendered nature of being a brother or a sister to someone with a developmental disability" (p. 476). The few sources that do take gender into account tend to focus on the ways that it affects sibling experiences during childhood (Azeez, 2001; Seligman & Darling, 2007). These studies suggest that female siblings take on more caretaking responsibilities in their childhood homes (Azeez, 2001; Seligman & Darling, 2007). One study found that female siblings are treated as older even when they are younger than the child with disabilities (King, 2007).

In adulthood, the literature indicates that nondisabled sisters continue to take on more responsibility for their sibling with disabilities than nondisabled brothers (Hodapp et al., 2010; Heller & Kramer, 2009). Hodapp et al. (2010) found that females are "more likely to report that they provide to their brother-sister with disabilities greater amounts of caregiving, companionship, and positive affect" (p. 52). Interestingly, these researchers found that when there are more than two siblings in the family, women tend to consider themselves closest to the sibling with disabilities, whereas men do not (Hodapp et al., 2010). The same study found that after parents pass away, responsibility for the sibling with disabilities most often goes to the nondisabled sister in families with multiple siblings (Hodapp et al., 2010).

One of the only existing studies that focuses on female nondisabled siblings rather than mixing findings on nondisabled brothers and sisters found that, "Because care work is highly gendered, part of understanding the sociocultural boundaries of being a good sister to someone with a disability requires an understanding of the gendered nature of family care" (McGraw & Walker, 2007, p. 475). McGraw and Walker (2007) found the stories of the female nondisabled siblings in their sample to suggest that being a good sister to a sibling with disabilities "involves portraying the sibling as normal, emphasizing opportunities for moral enhancement, minimizing personal sacrifices, and accepting the ideology of gendered family care" (p. 487). This highlights an important point, in that nondisabled siblings may not always be entirely reliable historians when it comes to their own experiences. They may, as found in McGraw and Walker's study (2007) feel that portraying their experience as positive is part of being a "good sibling".

The literature that takes gender into account is mostly concerned with the gender of the nondisabled sibling. This is a significant gap, particularly in studies like that of McGraw and Walker (2007) that find fault with viewing sibling ties as gender neutral. Several studies do find that the gender of the sibling with disabilities plays a part in sibling dynamics. For instance, Heller & Kramer (2009) found that adult siblings are more likely to expect to be primary caretakers in the future when their sibling with disabilities is female.

Several studies emphasize the particular qualities of sister dyads. Some believe that bonds between nondisabled women and their sisters with disabilities are stronger than the bonds between any other sibling dyad when one sibling has a disability (Heller & Kramer, 2009). This is in keeping with the literature on female dyads when neither sister has a disability. According to Orsmond & Seltzer (2000), "sisters are the closest and most involved sibling dyads, followed by sister-brother pairs, with brother-brother dyads being the least close and emotionally involved (p. 489). There is a need for further research on siblings of people with disabilities that is gender specific. This study attempts to fill this need by focusing on sisterhoods when one sister had a disability.

Type of Disability

Many articles mix findings on siblings of people with a variety of different disabilities (Abrams, 2009; Azeez, 2001; Hodapp et al., 2010; King, 2007; Lobato et al., 2005; McGraw & Walker, 2007; Seligman & Darling, 2007). Discrepancy seems to exist about the extent to which type and severity of disability are significant (Rigney, 2009). While many studies group disabilities together, a survey of the literature indicates that nondisabled sibling experiences vary depending on the type and severity of the disability. For example, Heller and Kramer (2009) suggest that the severity of the disability may be a "pull factor" contributing to nondisabled siblings having less emotional and instrumental involvement, with involvement decreasing as level of disability increases (p. 209).

Orsmond and Seltzers' study (2007) is useful in conceptualizing the ways that sibling experiences vary depending on the specific type of disability because it makes a direct comparison. The researchers studied siblings of adults with autism (ASD) and siblings of adults with Down syndrome (DS). Orsmond and Seltzer (2007) found that in their subject pool of 154 siblings, those with a brother or sister with ASD had less contact with their sibling than those with a brother or sister with DS. Siblings of people with DS reported higher positive affect in the relationship and a more positive outlook on their sibling's future (Orsmond & Seltzer, 2007). The researchers suggest that this may be partly due to social and communication impairments implicit in ASD, which make positive relationships more difficult (Orsmond & Seltzer, 2007). Orsmond and Seltzer (2007) also find evidence that the severity of the disability plays a part in the experiences of nondisabled siblings in both groups. The less severe the disability, the more activities can be shared between siblings, and this may increase the positive experience of the relationship.

Keeping in mind the evidence that type of disability makes a difference in the sibling relationship, the present study chooses to focus solely on the siblings of people with intellectual disabilities. The body of research focusing on this population has been particularly limited over the last ten years (Rossiter & Sharpe, 2001). A review of the literature pertaining to this population by Rossiter and Sharpe (2001) found evidence of a small negative effect of having a sibling with intellectual disabilities. Research on siblings of people with intellectual disabilities from more than ten years ago indicates a relatively high level of involvement between siblings continuing into adulthood (Krauss et al., 1996, Zetlin, 1986). Overall, more studies are needed that focus on a specific disability, rather than grouping various disabilities together. The present study will seek to contribute to the understanding of siblings of people with intellectual disabilities.

Nature of the Relationship

Sibling relationships usually last the longest of all family relationships (Seligman & Darling, 2007). Abrams (2009) elaborates on their importance during childhood: "The sibling relationship is the connection in which the child learns to interact with peers, tries on different roles, manages disagreements, handles rivalry, and learns to share secrets as well as belongings, laughs, cries, loves, hates" (p. 306). These relationships can serve as models for future relationships outside of the family (Abrams, 2009, p. 306). Numerous studies have shown that while sibling relationships change with age, they continue to be significant in adulthood (Hodapp, Urbano, and Burke, 2010).

Despite the importance of sibling relationships, the literature exploring siblings when one sibling has a disability tends to be more concerned with understanding the effects of the relationship on the nondisabled sibling, rather than the relationship itself (Rigney, 2009). A review of literature pertaining to the relationship from the past ten years yields only limited results. However, an exploration of studies from over a decade ago shows some important trends in sibling relationships.

Among studies that address the relationship itself, there are conflicting opinions about whether this relationship is hindered by the presence of a disability. According to Rigney (2009) the relationship is prevented from being equal in the same way it would be between nondisabled siblings. She goes on to say that the "disability inhibits the kind of intimacy in which one feels deeply known" (p. 24). There is also evidence that these relationships are more hierarchical than relationships between nondisabled siblings, with the nondisabled sibling supporting the sibling with disabilities (Zetlin, 1986). In her qualitative study of forty-six sisters of siblings with developmental disabilities, Begun (1989) compared the relationships her subjects had with their siblings with disabilities to the relationships they had with their other siblings. Her research found them to be neither more negative nor more positive, but instead more affectively neutral (Begun, 1989). As she explains, "not only is there less intimacy, perception of similarity, and admiration, there is also less competition" (p. 571). However, she also found that the relationships participants had with their siblings with disabilities contained the same amount of affection and companionship as their relationships with their other siblings.

According to Seltzer & Krauss (1993), there is evidence to suggest that in relationships between nondisabled siblings there is little exchange of aid. These relationships are important due to the emotional connection between siblings, rather than because they rely on each other for instrumental help. In times of crisis, nondisabled adults are more likely to turn to a spouse or adult child (Seltzer & Krauss, 1993). When support is required from siblings, it tends to be exchanged in a reciprocal manner. However, when one sibling has a disability, studies indicate that the sibling relationship tends to be less reciprocal (defined by Seltzer and Krauss, 1993, as "support provided without the expectation of equal repayment"), with the sibling with disabilities relying on the nondisabled sibling for instrumental aid (Seltzer & Krauss, 1993).

A study by Zetlin (1986) differs from the vast majority of existing research in that it focuses on the perspective of the sibling with disabilities. The researchers studied 46 adults with mild intellectual disabilities living outside the family home over an 18-month period, and took note of any interaction that they had with their nondisabled siblings. Zetlin (1986) evaluated these relationships based on warmth, frequency of contact, and degree of involvement. Relationship types were divided into five categories: "very warm feelings/frequent contact/extensive involvement," "warm feelings/regular contact/ moderate involvement," "warm feelings/minimal contact/minimal involvement," "resentful feelings/minimal contact/minimal involvement", and "hostile feelings/rare or no contact/no involvement" (Zetlin, 1986, p. 222). Sibling pairs were found to fit into all of the categories, with the highest incidence of relationships with "warm feelings/minimal contact/minimal involvement" (Zetlin, 1986, p. 220).

As the research literature demonstrates, relationships between siblings when one sibling has a disability can be partially determined by the desires and expectations of both people (Zetlin, 1986). Furthermore, in some cases these desires and expectations can be in disagreement (Zetlin, 1986). Zetlin (1986) found evidence of sibling relationships where the sibling with disabilities wanted more contact and closeness than the sibling without disabilities. Very little has been explored about how siblings in this situation negotiate their relational connection with each other. The present study seeks to place an emphasis on this topic.

Evidence also exists that these relationships may be more affected by the desires and expectations of the parents than a relationship between two nondisabled siblings. As Davis and Salking (2005) say in an exploration of Davis' relationship with her sister with disabilities, Kathy, "What seems clear to me is that any disability Kathy had was a 'family disability,' experienced in relationship with our family members" (p. 206). Studies show that the unique culture of the family of origin has a profound impact on the relationship (Seltzer & Krauss, 1993). Disabled and nondisabled siblings who have little contact are found to come from families marked by less expressiveness and more conflict than the families of siblings with close connections (Seltzer & Krauss, 1993). This contrasts data on sibling relationships where neither sibling has a disability, which finds that these relationships are more independent of the family of origin in adulthood (Seltzer & Krauss, 1993). Nondisabled siblings are also often directly influenced by the expectations of their parents. Zetlin (1986) found that nondisabled sibling involvement in the lives of their siblings with disabilities was closely in keeping with what their parents wanted from them, and also reflective of the style of involvement of the parents themselves. The present study attempts to better understand this phenomenon by asking participants to discuss their family's expectations for their relationships with their sisters.

As this review of the literature demonstrates, studies that explore the relational connection between nondisabled women and their sisters with intellectual disabilities are largely non-existent. Research in this area has been particularly lacking over the last ten years. This study attempts to illuminate the experiences of these women, and help to give them a voice.

Chapter III

Methodology

The purpose of this study is to explore the experiences of young adult women who have sisters with intellectual disabilities. Specifically, it seeks to investigate the quality and nature of their sibling relationships. The research questions for this study include: 1. What level of contact do adult women have with their sisters with intellectual disabilities? 2. How have these relationships changed in adulthood? 3. What are the most fulfilling and challenging aspects of these relationships? An exploratory, qualitative research method was chosen because a review of the existing literature revealed that few studies aimed to capture in-depth information from participant narratives (Creswell, 2007).

Researcher Statement

I was inspired to research this topic because I myself am a young adult sister of a woman with intellectual disabilities. My sister Annie, who is less than two years younger than me, was born with Cerebral Palsy as well as severe intellectual disabilities. Throughout our lives I have been keenly aware that our relationship is different, both in its challenging and rewarding aspects, from the relationships that my peers have with their sisters without disabilities. My relationship with my sister has affected me in profound ways. I have also noticed that both the nature of the relationship, and its implications for the rest of my life, have changed in early adulthood. This motivated me to explore if research has been conducted on this topic, and finding that there was little I decided to conduct my own.

Because the topic I chose to study is extremely personal, this research has been rewarding in many ways. I have had the opportunity to talk to women in a similar situation to me, really for the first time in my life. I have felt validated by the ways that their experiences mirror mine, and learned from the ways that they have coped with them differently. However, my personal connection to the material has also presented me with challenges. As elaborated in my discussion chapter, I have had to take special care to remain objective.

I also encountered a specific hurtle early on in the research which I no doubt took more to heart due to my situation. I decided to base my recruitment criteria on the DSM diagnosis, which still uses the term "Mental Retardation." My aim was to be specific, and I used this term in my recruitment letter. However, once I had sent it out I immediately received several strong responses. This terminology has become outdated since the publication of the DSM, and replaced with the term "Intellectual Disability" due to the hard work of advocates in the field. The thought that I had inadvertently offended the very community that I sought to help, and that I consider myself a part of, was deeply upsetting to me. Switching to the term "intellectual disability," which is often used more broadly, meant sacrificing specificity in my recruitment. However, I ultimately decided that it was more important to use current language, and I changed my recruitment materials.

Sample

The selection criteria for this study required that participants be female, between the ages of 18 and 35, and have a sister with an intellectual disability. When the recruitment process began, participants were also required to have a sister whose disability had been present since birth, and to no longer live with their family of origin. However, both of these criteria were later changed to include siblings of women who had acquired an intellectual disability at any point before the age of 18, and who continued to live in the family home. This change was made with the approval of the HSR committee, in order to broaden opportunities for recruitment of potential participants. Exclusion criteria consisted of sisters of women with non-intellectual disabilities, brothers of people with disabilities, sisters of men with disabilities, and women who did not meet the specific age requirement for participation in this study.

Two different sampling strategies were used in order to recruit participants for this study. Utilizing criterion sampling (Creswell, 2007, p. 127), a recruitment letter was posted on both the listserv and the Facebook page of an on-line support group for adult siblings of people with disabilities (www.siblingsupport.org). In addition, snowball sampling was used (Creswell, 2007, p. 127). An e-mail was sent to contacts of the researcher who may have been aware of potential participants. A copy of the recruitment letter was attached to the e-mail, and recipients were asked to forward it to people they knew who might be interested.

Potential participants underwent an initial screening via phone or e-mail to make sure that they met the inclusion criteria. If they were found to qualify for the study, their mailing address was obtained. Two copies of the consent form (see attached) were sent to all participants in self-addressed stamped envelopes, and participants were asked to return one copy signed before data collection could commence. A list of national referral resources for mental health services was also included in this mailing. Upon receipt of the signed consent form, participants were contacted in order to schedule an interview time, and were instructed in using Skype if they chose that as an option instead of a phone interview.

Overall, a total of 23 potential participants contacted the researcher. However, only 12 of these potential participants met criteria for involvement in the study.

Study Participants

This study included twelve participants, all female and between the ages of 22 and 34. Participants lived in nine different States and Provinces, with the highest number from the east coast of the United States. Nine participants identified as white, one as Eurasian, and two as Hispanic. Four participants were married, and six others were engaged or in a relationship. Two participants had one or more children of their own.

All of the participants had a sister with an intellectual disability, but the specific nature of these disabilities varied greatly. Almost all of the participant's sisters had some level of co-occurring physical disability. Specific disabilities included Prader Willi Syndrome, seizure disorders, Cerebral Palsy, and brain damage resulting from specific childhood events. Six of the participant's sisters lived in group homes, three lived with one or both parents, and three lived in other situations. One of the participant's sisters was married.

Data Collection

Data was collected from open-ended, semi-structured interviews that lasted approximately one hour per participant. At the beginning of each interview, participants were told that they had the option to request to turn off the recorder and terminate the interview at any point. They were then asked a series of demographic questions about both themselves and their sisters, with the option of not answering any questions that made them uncomfortable. Following the demographic questions, interviews used a protocol designed specifically for the study, which sought to elicit narratives of the participants. The interview protocol (see Appendix C) included twelve open-ended questions (Creswell, 2007), and served as a tool for initial discussion. The open-ended nature of the interviews allowed the researcher to follow the lead of participants in order to explore issues as they came up (Creswell, 2007).

Interviews were conducted over the phone or via Skype, a free computer program that allows people to have conversations over the Internet. Potential participants had the option to choose the method that was most convenient for them. The link to the Skype website was provided in the initial recruitment letter, allowing potential participants to explore this as an option. Instructions on how to use Skype were provided to all participants who preferred to use this as an interview method.

Interviews were recorded using the Call Recorder from ecamm.com. This computer recording device created audio files from all Skype calls. The researcher transcribed each interview concurrently with interviewing. This method was used instead of transcribing all the interviews at the end in order to let each interview inform the next, in the hopes of enriching the process. The researcher also kept a journal after each interview in order to maintain awareness of potential researcher bias.

In order to safeguard identifiable information, names were removed from interview transcripts and replaced with identification numbers, as proposed by Rubin & Babby (2007). Signed consent forms were kept separate from interview recordings. Names or identifying information of respondents were not used in the thesis, and all illustrative vignettes and quoted comments were disguised using pseudonyms. All data and tapes will be kept secure for three years as required by Federal regulations and after that time, will be destroyed or continue to be kept secured in the event that they are still needed for the purposes of an audit trail.

Data Analysis

Data was analyzed and coded in keeping with the Data Analysis Spiral outlined by Creswell (2007, p. 150). First, interview transcripts were organized as numbered computer files. The interviews were then read through in their entirety several times, in order to get a sense of major themes. This process was reflective of open-coding, a system in which themes are derived from the data rather than pre-existing theory (Creswell, 2007). Interview transcripts were then color-coded based on these themes. A review of the color-coded data was useful in establishing which themes were most significant. New files were then created for each theme, and excerpts from the interview transcripts relevant to each theme were cut and pasted into these files. For example, the recurring theme "yearning for a deeper connection" was coded in red. The red passages from each interview transcript were cut and pasted into a "yearning for a deeper connection" document, which was then used to create a narrative about the theme. Afterwards, an outline was formed, in which color-coded themes were arranged into larger sections of the findings. Thus, "yearning for a deeper connection" became a sub-theme of the section on "emotional impact", along with other themes like "sadness" and "guilt".

Chapter IV

Findings

The purpose of this qualitative study was to explore the experiences of young adult women who have sisters with intellectual disabilities. Specifically, this study sought to investigate the quality and nature of their relationships with their sisters. Open-ended questions were used to gain insight into the fulfilling and challenging aspects of these relationships, the level and type of contact between sisters, and the hopes that the nondisabled sisters have for the future of their relationships.

This chapter contains the findings from twelve interviews conducted with young adult sisters of women with intellectual disabilities. The data from these interviews has been organized according to the major themes that emerged. Findings are presented on both the nature of the relationship itself, and the impact on the nondisabled sisters interviewed.

Nature of the Relationship

Participants discussed many of the components that characterized their relationships with their sisters. They spoke to the level of contact that they had with their sisters, and the quality and nature of their communication. Many described regular phone contact in which conversations often revolved around recurring topics, and they often took more of a listening role. Participants also discussed both the things that drew them closer to their sisters, and the things that made closeness difficult. Long distance and the nature and severity of their sisters' disabilities emerged as common barriers to closeness. These findings are organized into three subthemes: Communication, Experiences of Connection, and Experiences of Disconnection.

Communication: "She'll ask me some questions but it's mostly focused on what's going on with her".

Of the twelve study participants, seven lived in a different State or Province than their sister with intellectual disabilities, and only three lived within a half hour drive. One participant lived and shared a bedroom with her sister. Thus, the majority of participants reported keeping in touch with their sisters primarily by phone and e-mail, with occasional visits. The nine participants who lived at a distance from their sisters reported phone contact ranging in frequency from once a week to once a month, with one reporting that she and her sister preferred to stay in touch by e-mail. In the vast majority of cases, phone calls, e-mails, and visits were initiated by the nondisabled sister.

When asked what these contacts were like, the majority of participants described conversations revolving around recurring themes such as family relationships and, in a number of cases, pets. Abby said "When I talked to her before the baby was born all we talked about was my cat. And after my baby was born all we talk about is my baby. And the cat." Similarly, Emily described phone communication with her sister:

> We don't really feel the need to talk a lot on the phone unless we're planning for something. So she'll call me if we're trying to coordinate gifts for someone's birthday, or trying to coordinate a visit, or she'll call to say happy birthday to my dog. Like she calls to… she called me one day and I was like, 'oh hey you wanna….' Like I thought she was

> calling to chat with me and she was like, 'are you home? I wanna talk to Mack.' I was like, 'oh, you're not calling to talk to me… okay.

Many participants described taking a listening and mediating role in conversations. Heidi explained,

> Um we talk about… you know, what's going on in her life. She likes animals, so we'll talk about her pets, or um traveling… she wants to travel, so… I pretty much just let her dominate the conversations. Um, she is interested in my life. She'll ask me some questions, but it's mostly focused on what's going on with her.

Similar to Emily, Grace said,

> Yeah I just listen to her talk, and sometimes I'll tell her random funny stories of what have happened to me. So, whatever, I love to make her laugh, she loves to laugh, so anytime I can make her laugh is a good thing.

A sense of responsibility was a predominant theme among many of the interviews. This often affected the level of contact that participants had with their sisters. For example, Abby described having an appointment set up in her Microsoft Outlook that reminded her to call her sister at a certain time each week. She also stated that "There have been times when my dad has called and written to his, um all his children, well written to me and (my brothers), 'you *need* to communicate with Diana. Because she's feeling all alone.' Beth said, "I try to make a real effort to call my sister once a month… I'm an adult with a family of my own and a job and you know, I just start feeling guilty I guess if I don't call her once a month".

Participants described in person contact as being largely activity based, and many portrayed it as fun and enjoyable. When asked what the most positive aspect of her relationship with her sister was, Laura said,

> Probably just hanging out, you know? Being at the cottage, sitting in the sunshine, and doing the crossword. Taking the dog for a walk, going to visit my grandmother, you know? Having her same jokes that she's been making since she was five years old.

When describing in person contact, Kristen said, "Well, this is part of my fantasy of what I want to have happen. In reality it's probably happened like three or four times in the last year when she's come up to stay with my boyfriend and I. And, you know, we've gone out to dinner and done the whole thing, kind of created like a little vacation weekend for her." Other participants mentioned activities such as playing video games, shopping, getting ice cream, playing tic-tac-toe, watching movies or cartoons, and attending family birthdays and holidays.

Experiences of connection: "The fact that she trusts me is very important."

Interviews revealed a lot of disparity in the connectedness that participants felt with their sisters. Five participants used the word "close" to describe their relationships with their sisters, and two others described what seemed to be a close relationship. Whether or not they considered their relationships with their sisters close, many of the stories and anecdotes that participants shared revealed a unique bond. For example, Nicole said, "I've always been really able to understand how she's thinking about things, and when my parents would say something even and she didn't understand, I was always able to reword it for her so that she would understand it." She elaborated, "I have my entire life always been able to really understand where Margie is coming from and how she's seeing things." Interestingly, some participants reported that others did not always understand their connectedness with their sisters, and sometimes misinterpreted it. Emily said,

> I've never babied her in any way, and to some people I think that has been perceived as being mean to her, and then I'm all confused because I'm like, 'I don't know what you're talking about, like I don't see this as being mean, I don't think she needs my help.' I'm not trying… you know… I think that I see her… it's tough because in some of those situations I'm like 'you're the one that's seeing her differently… you're the one that is treating her differently… not me, and this is not, I'm not being mean to her, like I'm being a normal sister.'

Carrie, who spent several years caring for her sister before she recently moved to a group home, described a scene at the doctor's office when her sister had become extremely upset before she arrived and "had a fit":

> And so finally I got there and all I did… you know I walked in the door, and she couldn't quite see me yet because she was kneeling on the floor, you know looking down, very angry. And I knelt on the ground, took her hand, and she stood up and calmed down. And it was just very interesting to see you know, just that reaction, you know, and um realize what our relationship is really like. You know as far as the trusting area. So I think that the fact that she trusts me is very important.

Experiences of disconnection.

The nature and severity of the disability: "She isn't capable really of giving me…"

Participants discussed several major barriers to connectedness in their relationships with their sisters. One of these was the nature and severity of their sister's intellectual disabilities. More that half of the participants felt that their sister's intellectual disabilities prevented the type of closeness in their relationship that might exist otherwise. For instance, when asked if she had expectations for what her sister contributed to the relationship, Nicole explained,

> It's really hard to say because, you know, she's my sister and I love her and you know… but um, I don't… I don't know how to answer this one. Um, she isn't capable really of giving me… you know what you would think of with, you know, in terms of a sister relationship. Um, you know she'll ask… if she knows that I'm going through a particularly stressful time or something when we first talk you know she'll say how are you doing, and that's it. Which, you know, I don't hold against her or anything. But that's how it is.

Similarly, Grace said, "She's not really at a level where she could understand very much, you know? So if I was to say, you know, 'oh I'm having a bad day' she wouldn't be able to say, 'why's that?'" When asked if she had confided in her sister during their parent's divorce, Cassidy answered, "I think I was more there to just calm her down and protect her, more than really discuss. I don't think I ever discussed, you know, our parents aren't getting along, I don't know if she'd really understand that." In her description of phone conversations with her sister, Liz offers a revealing picture:

> Um… there's initial excitement, which is good, and then there's um… I usually ask her about work, and ummm… and she usually knows, it's all about food, she's very fixated on food, so I'll ask her what she had for dinner, she'll ask me. Um… and depending, if she's seizing a lot, I mean we'll go back, she'll greet me, she'll say 'Hi!' all over again because she forgot that we said hi already. Umm… and if she's doing a bit better than I might ask if she's got, you know if she's got plans coming up, if she's going on vacation.

Long distance and living apart: "Phone conversations… it's like pulling teeth."

Long distance was also a significant barrier to connectedness that emerged in many of the interviews. When asked how their relationships with their sisters had changed in adulthood, four participants referred to the effects of living far away from each other. In addition to simply reducing the amount of time that they could spend with their sisters, participants found that distance also made communication more difficult. As Kristen suggested, "With me she doesn't volunteer information nearly as freely as she does with my mother. So like, phone conversations… it's like pulling teeth. Yeah, it's brutal". Speaking of her sister's tendency to develop false ideas of what was going on, Liz added,

> When I was younger and I was around her a lot more I could sometimes figure out where her confusion came from, but now being so far away it's really hard, and borderline impossible for me to have any clue where she came up with this idea, or if she just decides it on her own.

Cassidy described how her relationship with her sister changes depending on geographic distance:

> I think, you know, when I speak to her on the phone it's still more of a very positive… you know how are things going? Good, you know like a very… I don't know, maybe on the surface relationship, more. And then when I'm home, which is, when I'm home maybe two or three times a year… then I feel like maybe we talk a little bit more about um… like deeper issues.

In this study distance was also found to have positive aspects. For example, Grace described:

> I'm not so much in the day to day, in the trenches as it were sometimes. Um you know, so I can kind of benefit just from the good side, you know because when she's upset she

> doesn't talk on the phone anyway. She's like, 'No! I don't want to talk!' and so it's like, 'Okay well I'll come back when she's having a better time' you know whereas before when I was at home, you can't escape as easily. It's like, 'okay let's deal with this, how do we deal with this?'

One participant, Ana, lived with her sister at the time of the interview, and her experience served as a contrast to those living far away from their sisters. As she explained,

> I do have school, I do have work, but we share a room. So I see her every day, every night. Um… yeah there's not really a day that goes by that I don't see her or talk to her or anything. That would just be weird. Like when I'm not sleeping at home it's definitely like something's missing almost, you know?

Lack of Reciprocity: "My main expectation is of myself."

During the interviews, participants were asked about their expectations for their relationship with their sisters. Six of the eleven participants who answered the question listed their own expectations for themselves, without mentioning their expectations for their sisters. As Nicole said,

> I guess my main expectation is that… my main expectation is of myself, that I'm there for her. That, you know, if somebody at the school drops the ball, or that my parents drop the ball somehow that I'd be there, that you know if she you know needs any type of advice or help or whatever that I'd be there.

This was also true when participants were asked how they hoped to see their relationships with their sisters five and ten years in the future. Many focused on the ways they hoped to change their own behavior or attitudes. According to Heidi,

> I guess I expect for us to stay close, and for me, and I know it's kind of my problem, to let her be independent and not to try to be so controlling over her when we're together. Because that's definitely been a problem in our relationship, and I know she gets frustrated with me when I try to tell her what to do. But… I've gotta learn to step off a bit.

This type of response seemed to indicate a lack of reciprocity in some of the participant's relationships with their sisters. However, it's important to emphasize that this was not evident in all of the interviews. Several participants in particular, when asked what their expectations were for the relationship, strayed from answers that solely focused on their own role. According to Emily, "A very tangible thing that I think has really been a part of our relationship is she's very organized and keeps track of everyone's birthdays, and of holidays, and gift-giving, and everything like that, and I… I mean that's one expectation I always have of her, like she's gonna take care of that stuff."

Many participants described how the limitations imposed by their sister's disability made the relationship less reciprocal in some ways. Four participants said the relationship had parent-child aspects, and three said that they felt like the older sibling despite the fact that they were younger. Several participants indicated that this lack of reciprocity had increased in adulthood. Nicole described the moment at which she became aware of the relationship changing:

> When we were really young, probably up until around six or seven or eight, um, you know we were sort of peers, because her stuff, you know her learning stuff and social interaction stuff really didn't come out so strongly until later. Um… because, you know, when everybody's younger they all have those things. But it's funny, I remember really clearly one day, in my backyard, I think I was about seven or eight. And she was, you know, maybe twenty feet away from me doing something else, and I just looked at her,

> and I had this really bizarre realization that she… you know I had been growing up as much as an eight-year-old could, and I felt like I was leaving her behind. And I remember that day, and like that one minute so clearly.

Beth described a similar transformation in the relationship:

> When I was really small as a kid, she did get to be a little bit of the older sister, like my mom has stories that she taught me how to read, and you know stuff like that. You know, I found out, you know, what a woman's menstrual period was because I had an older sister. I remember stuff like that. But as I became older it became real clear that I was kind of the older sister in a sense.

Liz also remembered realizing that she and her sister were growing up in different ways. She said,

> As I got older, as we got older, it created all kinds of dynamics. Of me wanting to connect to her and not being able to because there's just… she's not… like she's not my sister the way my wife's sister and her have a connection… we don't have… that's just not the kind of connection that's possible. So then there becomes this strange… sibling-like but then mixed in with the parent-child because I'm trying to, you know, guide her and protect her as well.

The amalgam of different roles that Liz described was evident in many of the participant's descriptions of their relationships with their sisters. Carrie, who took care of her sister for two years before her recent placement in a group home, said of her visits to her sister in her new setting:

> Now what's nice about it is we can actually be sisters, you know what I mean? The way that it was supposed to be, you know, um so that's what I'm really embracing right now

> and really liking. Yeah so we get to have fun, there isn't this looming oh my gosh this is so much responsibility I feel trapped blahhhh kind of feeling.

At the same time, she explained,

> I think I'll always feel like a parent, sort of, because I do control a lot of… you know I have the final say, I have to sign documents all the time, giving permission to do whatever, changing doctors, and kind of handling all the medical stuff, I still do that. there's always going to be that element of responsibility. But at least daily, you know, when I go see her, the sister relationship comes out so… that's the fun stuff.

Impact on the Self

During the course of discussing their relationships with their sisters with intellectual disabilities, participants described the impact that these relationships have had on their lives. Many discussed feelings that commonly came up in connection to their relationships with their sisters, such as guilt and acceptance. Others described the practical ways that these relationships had influenced their lives, for instance in influencing where they chose to live. These findings are divided into two main categories: emotional impact and instrumental impact.

Emotional impact: "To know that she had to deal with that, and I didn't…"

Guilt was a prominent theme that came up in eight out of twelve interviews. Many participants felt guilt about not doing more for their siblings, or not being further involved in their lives. Interestingly, the four participants who did not talk about guilt included the participant who lived with her sister, and the participant who had singlehandedly cared for her sister for two years. Heidi, who lives a day's drive from her sister and also has a brother with intellectual disabilities, said, "Sometimes I don't feel like I do enough, or since I do live far away, you know, I feel like I'm not there enough for them. And I do understand that I do need the distance sometimes and to, you know, do my own thing. But um, yeah, there is that guilt." Similarly, Cassidy said, "You know sometimes I do feel, like, guilty in a way that I moved on. I went to college, I went to grad school, I'm moving on. And I know that's what my parents you know would want too, but I do… I feel bad sometimes. Should I have been there more? Should I have stayed to help out?" When discussing the guilt that she sees her parents experiencing, Liz said,

> I suppose when my mom's expressing her guilt, I feel my own sense of guilt that's… you know, sort of inevitable, right? Because she's a dependent, she's depending on us to shape her life the best we can. And you know, it's the perennial parent worry that you know, um, we're not going to do a good enough job. And so I feel that as a sibling, you know, I let her down in some way shape or form. But you know, every time I see her again and she's got a great big smile and excited to see me and gives me a great big hug, it's awesome.

Siblings also voiced regrets about not doing more to alleviate the struggles they had witnessed their sisters go through in the past. Emily explained,

> Sometimes I wish I had been more protective of her, and that I had sort of like beat up the people who were mean to her. Because I didn't…you know, I stood up for her as much as I could, but I didn't stand up for her every single time. And a lot of… I feel really guilty about that and wish that I had. And wish that I could have been there every time and could have been brave enough and strong enough to protect her.

Another major source of guilt amongst participants was the knowledge that their sisters were not able to experience some of the things that they could due to their disabilities. Nicole said,

> The guilt is pretty huge. Um, it's pretty much with me all the time. You know I feel guilty coming into my apartment because I can have an apartment, I feel guilty driving because I can drive, I feel guilty in my friendships, you know with people, and my relationship with my boyfriend, because I'm capable of having those relationships, I feel guilty buying things for myself because I have disposable income… it's just always, everywhere.

Emily described the pain of watching her sister be ostracized by other people and struggle to make friends:

> To know that she had to deal with that, and I didn't, and that's not her fault, and that it's society's fault kind of thing. I've always felt just super guilty about all that. And felt like, 'Is there something I could have done in the past or could do in the future to try and change that? You know, am I doing enough to try and change that?'

Cassidy described how the ability to do things that her sister is unable to can create pressure rather than guilt:

> I don't know how it is with other siblings, but I think there's just this incredible sense of responsibility. And you know I feel that towards her, but I feel like in life, like I felt like a lot of times that I don't think my parents expected it of me, but I felt a lot of times that like okay, I'm the only one who's going to do these things, I'm the only one who's going to graduate from high school, college, I'm the only one who's going to get married, drive a car, so it felt like, wow it's a lot of pressure, to complete those things and do them well".

Many participants also expressed sadness, grief, and loss during their interviews. Some discussed their sadness about their sister's situations and the things that they had watched them endure. For Abby, whose sister had been victimized by sexual predators on more than one occasion, this was particularly acute. She referred to the knowledge that the perpetrators were still at large, and the realization that the world is full of people capable of doing that sort of thing, as a "wound that won't heal." For others, simply seeing the struggles that their sisters had gone through as a result of their disabilities was difficult. Heidi described feeling:

> Some sadness, because um of the way she was treated, and the way she feels about herself. She's, you know, a beautiful woman. She got all the good genes when it comes to looks. But she just, you know, she doesn't have a lot of friends… now she's making more friends which makes me very happy. But, um, she's always been kind of a loner. And that always made me really sad.

Nicole referred to the sadness she felt about not being able to change her sister's life for the better, which led to a sense of helplessness.

Participants also discussed a sense of loss of the relationships they might have had with their sisters had they not had intellectual disabilities. As Grace explained,

> I see friends who have sisters near their age and they're just… you know they're best friends. They're always there, and you know you stay up late at night talking, and you just know each other, like inside and out. Or that's what it seems like. So sometimes, especially when I was younger, I would think about that, and just be like you know, yeah, you know I wish that we could have a normal talk. And I wish that we could make cookies together. You know, like really basic stuff sometimes. You know?

Similarly, Nicole said,

> I do think about the fact that I basically had to you know, give up and lose this idea of a sister relationship kind of thing. Um… because I started my life out with that, um, that's

> what my life was for a few years, you know having that, and then… you know, it's obviously not you know like… I mean she's not even two years younger than me so, it's clearly not that kind of close sisterly relationship that people think of or idealize.

Other negative emotions reported by siblings included frustration, anger, and a sense that no one could understand their experience. However, interviews also indicated that young adulthood was a time of healing and making peace with the situation for many participants. According to Emily,

> I definitely used to have the feeling of 'I wish I could have known what my life would have been like if I didn't have a sister with a disability'. Or, 'I wish that I had another sibling who didn't have a disability.' I remember feeling that pretty intensely, but I just don't feel that at all anymore. And I don't know what happened to make that go away… but it just… yeah I just don't have that feeling anymore. I feel generally good about our relationship and the experience that I've had.

As Liz put it, "I wanna make peace with my teenage self that keeps saying, 'I'm not calling Allison because that's what I have to do.' That's not the point! The point is that she's my sister, and she's still a part of me and a part of my family and a part of my world." Four of the participants were working either in helping professions or specifically with disability rights. Three out of four mentioned that their career had helped them in the process of making peace. According to Cassidy,

> Sometimes it's almost like an accepting how it is and having to move on, hoping that through my field that I'm in, and hopefully, you know, in the future we'll financially be able to help out more. I mean that's what I guess I hope for now, is that maybe some great opportunities will really open up, and I'll be able to, you know, give back.

Despite the guilt, worry, and sadness that participants reported, many positive emotions came through in the interviews as well, in some cases overwhelmingly. Many participants expressed happiness about their relationships with their sisters. When asked what the primary emotions were that came up for her when talking about her sister, Emily said,

> I think that I feel… um… I mean I feel good. I don't know what emotions to attribute to that. I don't know if it's happiness, or just like general contentment. I feel… um… I feel… I don't know. I like her. So I feel great that I have had the experience I've had growing up.

Carrie said, while answering the same question, "Now that we have what she needs um, you know it's quite different, and now it's more of a just calm, happy, love, all that."

When asked what they found to be the most fulfilling aspect of their relationships with their sisters, many participants also expressed admiration and appreciation. Cassidy said, "Overall she's pretty talkative, loves music, loves plays, loves animals, and you know those aspects of just smiling a lot, those aspects I think are great, I think are great strengths that she has." Ana said,

> Whatever I do, and it doesn't matter if it's like recognized by anyone… she's my number one fan. For everything… everything… like I could get a good grade on a paper and she goes crazy because it was such a good thing that I got a good grade. Um… that is probably… probably the biggest. Well, not the biggest. She's just so compassionate, and so… she's just a great person, through and through, and she doesn't change with the next person, you know what I mean?

A number of participants described the ways that they felt that their relationships with their sisters had made them better people. Grace said, in response to a question about how her relationship with her sister would have been different had her sister not had intellectual disabilities,

> It would definitely be different. But I think, honestly, I prefer what I have now. Because it's opened my eyes to so much that wouldn't have even been on my radar. Just to understand what people go through having a sibling with special needs. And to understand what those special needs people themselves go through.

She added, "Um and just to… yeah, to learn to be kind, and patient, and manage stress. You know… all sorts of things. Like I would not be anywhere near the person I am without all of that." Carrie said, "Growing up with a special needs sibling, you know it helps you understand others. You know with special needs. You know I noticed that a lot of other people are just so uncomfortable, and they don't know what to do." She later added,

> I think growing up like that has just been a continuous enlightenment. You know, because she's always surprising us, um with what she does, and what she comes up with. You know she makes jokes, and you know has a great sense of humor. And everyone is just so pleased to be around her. Um, so I think that's helped too… just having that comfort, and understanding of differences between everybody.

Similarly, Kristen said, "It forced me really to be empathetic and mature in a way that perhaps I wouldn't be otherwise. And it's forced me to be responsible for myself and for others in a way."

Instrumental impact.

In this study exploring the experience of being a sister of a woman with an intellectual disability, themes of instrumental care and support, as well as stories of responsibility, emerged in the interviews. Participants discussed both their current responsibilities for their siblings and the responsibilities that they expected to have in the future. Their expectations for the future had a strong influence on the ways that they planned for and thought about their lives.

Current roles: "I'm the sister and I should be responsible for her."

The twelve participants had varying levels of current responsibility for their sisters. Many described what one called "taking a supportive role" while their parents took care of the vast majority of case management and in some cases day-to-day care. According to Emily, "I don't take on the roles like planning, and getting all the paperwork in, and getting things done. But I'm there, usually for my sister or for my mom or dad, to sort of bounce ideas off of, and just to give general input, and try and ask, um, think of good questions to ask." When asked what her involvement had been in her sister's recent move to a special community, Kristen said, "I would call it more like watching from the periphery. Like I knew where she was going and I went down and visited her. And I still participate a little bit." While in this supportive role, many participants described being the first to be called on after their parents. According to Ana,

> When it comes to my sister, I mean there's always just that understanding that if something, like if they need my sister to go this place, or they need someone to ride, they can always come to me and ask me first and then go down the line. I mean, they don't necessarily force that on me it's just something… it's just natural I guess.

Others described how, in the absence of many instrumental responsibilities in the present, they were able to focus on their emotional connection with their sister. Cassidy said, "I just want to be something happy in her life, I guess. That's what I kind of see our relationship as." Laura described herself as "more in a sister role than in a caregiving role."

Despite many similarities across the twelve interviews, each participant had her own specific role in her sister's life, determined by myriad variables such as how far away she lived, family make-up, age difference between her and her sister, and the nature of her sister's disability and level of need. Laura described publishing a regular newsletter about her sister's progress, as well as writing grants. Ana, who resides with her sister, talked about helping her sister with personal care tasks such as washing her hair and shaving.

Most participants discussed expecting to take on a greater instrumental role at some point in the future, when their parents were no longer able to. However, for three participants, this process had been expedited by parent illness or death. Kristen said,

> The timeline of when my parents were going to get older and Caitlin was kind of going to become my responsibility somehow got moved up when my Dad got sick. And so, I am trying to play a greater role in her life, thinking that this all is going to happen like soon kind of a thing.

She described how this gave her a "sense that I need to start building a foundation of a relationship with her… now." Another participant, Heidi, was going through a similar transition. She said of her mother, "She's been going through some health problems lately and so… I don't think she's been there as much as she wanted to, you know, so I've stepped in, or had to step in for some of that." Finally, Carrie had become her sister's primary caregiver after her grandparents, who had custody of her sister, became too old to perform this role.

Future roles: "I've always known that I'll take care of Valerie.

Many participants remained unclear on the specific details of their future responsibility for their sisters. Anticipated roles varied, and included becoming a legal guardian, being in charge of case management, helping financially, and providing emotional support. As Grace expressed, "I've always known that I'll take care of Valerie, you know if and when something happens to my parents. Um, I think maybe it was something that I just kind of assumed." Speaking to the way this knowledge has changed in early adulthood, she said,

> You know it's one thing to say when you're like fifteen years old, and you're like, 'oh yeah, I'll take care of Valerie if anything happens' um and then, yeah, you know it's very different when you're like, you know you are an adult, and you're out on your own, and you're like, okay, what would that practically look like.

In keeping with this, many participants expressed worries about how exactly their relationships with their sisters would affect their future, and whether they would be able to adequately fulfill their roles. Nicole said, "I worry that I won't… I won't understand. I guess paperwork is honestly a big part of it, that I won't be able to understand that stuff enough to do right by her, um and make sure she's getting what she deserves." Beth mentioned, when talking about finances, "my parents obviously put away nothing for that, so I don't even know how it would work."

Parental expectations: "We haven't said 'this is the year' or 'this is the age' but we have said it will happen."

When describing the responsibilities they would have in the future, participants were clearly heavily influenced by parental expectations (with the exception of Carrie, who had already taken on primary caretaking responsibilities). When asked if these expectations and plans had been explicitly discussed, participant's responses varied. Kristen said, "Overtly, no, but… um… I would say it's… you know, I have copies of her guardianship papers and I know where I need to go to switch that when and if the time comes. And yeah, I mean we haven't really… just because I don't… we haven't said, 'this is the year' or 'this is the age' but we have said it will happen." As Kristen's response indicates, many participants said that specific plans had not been made because the time when they would need to assume responsibilities from their parents was still in the future, and thus many variables were unknown. As Kristen put it, "There is this sort of question mark about what's going to happen and what the expectations are."

Interestingly, half of the participants specifically referred to their parents not wanting their relationships with their sisters to be a "burden" to them in the future, without prompting. In some cases, this meant that parents had done a significant amount of concrete planning. As Emily said,

> I think that they expect that I'll be her primary like, caregiver doesn't sound like the right word to me, I think like primary supporter, primary family person, just to take care of anything that needs to be taken care of. So they have their wills all written out, and they've done a lot of future planning for her and for me, to try and make sure that I'm not left with a huge burden, and that I'm not left with a financial legal mess to take care of after they've gone. So, I think their expectation is that when they pass away I'll take on any responsibility for her, and they've done a lot to try to make sure that that responsibility won't be overwhelming.

In other cases, the desire to avoid this "burden" had led parents to prevent their nondisabled daughter from being as involved as she would like to be. As Cassidy said,

> They want her to be taken care of so that I don't ever feel burdened. Which is hard because, you know, I try to tell them if I ever need to come home and help, please let me.

> Um, so I think it's sometimes like a struggle, because they don't want to put too much on me, but I think it would be nice to also have some help, because it is a big challenge.

Impact on life decisions: "It's making the world a whole lot more complicated a place."

A major concern that participants voiced was where they would need to live in relationship to their sister in the future. While many expressed a desire to live close to their sister in the present, or misgivings about the fact that they didn't, most seemed to feel that they had a certain amount of freedom to live where they chose while their parents still remained in the picture. However, many seemed to feel that geographic proximity would become more important in the future, and expressed confusion about planning for this. As Emily said,

> It's tough. I haven't been able to make any decision in my head about whether I would live close or whether I would live far, and how that would effect what might need to be taken care of for her. I think that with technology it might be a lot easier for me to live somewhere else and still be able to support her in every way that I can. But then on another day I might not think that at all, and I think no I'll have to live in (city near her sister) so that I can drive up if anything happens."

Nicole said, "I worry about where I am geographically when my parents aren't you know around anymore, how that's going to work, what's going to happen", adding, "In the future it's possible that I could theoretically live in a different state from her and it would be okay. But I don't know that now." When discussing her concern about having to leave the city she was currently settled in, Liz commented, "It's making the world a lot more complicated a place when you have to make room for… there's no winner, right?"

Another significant theme that emerged in the interviews was the impact of participant's relationships with their sisters on their romantic relationships. Of the twelve participants, only two described themselves as single. Four were married, and one was engaged. One difficulty that many discussed was balancing their sense of needing to be geographically close to their sisters in the future with their partner's needs and desires. As Emily said,

> It definitely effects future planning with them. And you know, I always want my relationships to be equal, and for us to be making equal compromises, and I really worry that in the future I'm gonna have to ask for more compromise from my partner because I need to be closer to my sister and closer to my family. And I really want them to be with me for that, and I worry so much that that's going to be really hard to do.

When asked what the most challenging aspect of her relationship with her sister was, Laura said,

> I'd say worrying about the future… worrying about what would happen if… what will happen if the plan falls through. And the fact that, you know, I sort of have to negotiate my personal relationships on two levels. I mean I don't think I would be with my partner if he didn't like my sister… if they didn't get along… because that's too important to me. And I don't think that I would be with my partner if he hadn't committed to moving across the country to be with me. Um… and that's all because of my sister.

Other participants echoed Laura's feeling that their partner liking their sister had the potential to make or break the relationship. Emily said,

> One of the greatest moments I think in my current relationship was when my partner was able to meet my sister, and it was amazing… like, I… you know, it was, she didn't even skip a beat, she just, you know, started talking to her, and it was just like she would talk to anyone else. And it was just an amazing moment that solidified a lot of… just a lot of

> feelings in me about um… just wanting to be with somebody who was comfortable with my sister.

Summary

Overall, the findings of this study suggest that the relationships between young adult sisters are significantly impacted when one sister has an intellectual disability. These relationships face barriers to connectedness and reciprocity that might not exist otherwise, but are also in many cases marked by a unique type of closeness. The twelve interviews also reveal that these relationships have a profound effect on the nondisabled sister, both emotionally and instrumentally. The implications of these findings, as well as generalizability, will be further explored in the discussion chapter.

Chapter V

Discussion

The purpose of this qualitative study was to explore the experiences of young adult women who have sisters with intellectual disabilities. Specifically, this study sought to investigate the quality and nature of their relationships with their sisters. Open-ended questions were used to gain insight into the fulfilling and challenging aspects of these relationships, the level and type of contact between sisters, and the hopes that nondisabled sisters have for the future. The findings were divided into two main themes: nature of the relationship and impact on the self. In this section these findings will be discussed in terms of the ways they both supported and differed from research in these areas, while also suggesting areas for further research.

Nature of the Relationship

This study sought to learn more about the relationships between sisters when one sister has a disability, rather than solely the effect on the nondisabled sibling. Interviews suggested that the contact that most participants had with their sisters consisted of weekly to monthly phone or e-mail conversations, and occasional visits. In person contact seemed to revolve around activities such as games, outings, and attending family parties. The accounts that participants gave of their relationships reflected disparity in the connectedness that participants felt with their sisters. This seemed to be based on a variety of factors including the level and nature of their sister's disability, age difference, and individual personalities.

This study supported Rigney's (2009) belief that sibling relationships when one sibling has an intellectual disability may be less equal, or reciprocal, than relationships between nondisabled siblings. However, this was not true in the experiences of all of the participants. As already discussed, despite the barriers to connectedness that participants reported, many still characterized their relationships with their sisters as close. The vast majority of participants seemed to view these relationships as significant, regardless of the level of emotional connectedness that they felt was possible.

One objective of this study was to fill the gap in existing literature pertaining specifically to young adult siblings. The findings suggest that young adult siblings experience much of the instrumental and emotional impact that siblings of all ages do. However, because they are poised at a unique time in their lives, their experiences also differ in some ways. Seven out of twelve participants lived at a significant geographic distance from their sisters, a situation that contrasts the cohabitation of childhood. However, many anticipated that they would need to live closer to their sisters in the future, suggesting that the geographic distance they currently maintain might be specific to early adulthood. As the study showed, this distance had major implications for their relationships with their sisters. Many participants expressed that living far away, and the difficulties in communication that it often produced, was a barrier to connectedness. Others mentioned the positive aspects of long distance, such as having space from some of the challenging aspect of having a sibling with intellectual disabilities.

Despite some of the barriers to connectedness that participants discussed, the findings of this study do not necessarily support the indication in existing literature that emotional closeness decreases during early adulthood (Begun, 1989; Orsmond & Seltzer, 2000). Many participants characterized their relationships with their sisters as "close" and described a unique bond with them. Some also described making peace during this phase of life with these relationships and their implications for the future. Overall this study suggests that young adulthood is a transitional time in the relationships between sisters when one sister has an intellectual disability, in which they are negotiating a new adult relationship and preparing for further changes later on.

Another objective of this study was to lend a voice to female siblings. According to McGraw and Walker (2007) the existing literature "tends to conceptualize nondisabled-disabled sibling ties as gender neutral" (p. 476). This study focused specifically on the relationships between women: sisterhoods where one sister has a disability. Because brothers were not included in this study, the findings preclude making a direct comparison between the relationships between sister dyads and the relationships between brother dyads when one sibling has a disability. However, some comparative information can be gleaned from participants who were able to contrast their own roles in their sisters' lives to those of their brothers. Of the twelve participants in the study, six had siblings in addition to their sister with intellectual disabilities, and all six of these participants had at least one brother. Only one participant reported that her brother had more of an emotional or instrumental role in her sister's life than she did. This supports the findings of Hodapp et al. that women tend to be more involved in these ways (2010). However, comparing the roles of participants to those of their brothers was not the focus of this study.

This study suggests that there is a unique bond between sisters when one sister has an intellectual disability. Some participants reported helping their sisters with things that they wouldn't have if they were male, such as showering and shaving. The vast majority of participants also reported that their mother was the primary person in charge of their sister's care, which may have major implications for the role they are expected to inherit later in life. The ways that female roles are passed through generations in this context would be an interesting area to research further.

Rather than grouping findings on siblings of individuals with both intellectual and physical disabilities, this study focused solely on sisters of women with intellectual disabilities. It supports the findings of Krauss et al. (1996) that the siblings of individuals with intellectual disabilities continue to have extensive roles in their lives during adulthood. This study also suggests that the intellectual disability of one sibling creates some major barriers to connectedness in the sibling relationship. Many participants reported having a difficult time communicating with their sisters, feeling unable to turn to them for emotional support, and not feeling that they had the relationship with them that they would have in the absence of an intellectual disability.

While the participants in this study all had sisters with an intellectual disability of some kind, their sister's disabilities varied greatly in level of severity, and in the specific ways that they affected behavior and interpersonal contact. These differences were found to greatly impact the relationship. Some participants, for example, reported a greater level of reciprocity in the relationship than others, and the level of reciprocity seemed to be partially tied to the extent of their sister's intellectual disability.

Impact on the Self

This study supports the findings of Krauss et al. (1996) that adult siblings anticipate playing a major instrumental role in the lives of their siblings with disabilities in the future, whether this entails primary caretaking or other duties such as becoming an advocate, trustee, or primary source of emotional support (Heller & Kramer, 2009). All twelve participants expected to inherit some degree of responsibility for their sisters from their parents or other guardians, and three participants had already begun to assume this responsibility due to parent illness or death.

Interviews with participants also supported literature indicating that adult siblings experience a wide spectrum of psychological impact (Seligman & Darling, 2007). The most common emotions expressed by participants were guilt, sadness, worry, contentment, and joy.

The findings of this study suggest that while most young adult women have not yet taken on primary responsibility for their sisters with intellectual disabilities (only one of twelve participants in this study), the anticipation of having this role in the future greatly affects them in the present. This impact was shown to be both instrumental and emotional. Participants reported feeling worry and confusion about future plans. They also discussed the ways that the anticipated need to be closer to their sisters geographically, or have a greater role in their lives, affected their current choice in partners, careers, and places to live.

Limitations

This study provides a picture of the relationships between sisters when one sister has an intellectual disability. However, there are some important limitations to generalizability. First, it is important to note that this study is limited to the perspectives of nondisabled sisters, and thus gives a one-sided view of these relationships.

While the participants in this study all had a sister with a diagnosis of intellectual disability, significant variation existed between their cognitive abilities and whether they had co-occurring physical disabilities. This may mean that the findings would not be generalizable to other groups of sisters of women with intellectual disabilities. It is difficult to avoid this sort of disparity in sampling due to the extremely individual nature of intellectual disability. It is also impossible to thoroughly separate varying levels of intellectual disabilities from the vast differences between all people, and thus one cannot say with certainty what differences in relationships are based on factors such as disability and what are based solely on the individuals.

Because a major recruitment method for this research was posting on sibling support websites, it may show a bias for women who not only had access to e-mail, but who were proactive in trying to make sense of their experiences and reach out to other siblings. However, given that participants were also recruited through snowball sampling, this was not true of all participants.

Another possible source of bias was the interpretation of participant interviews by the researcher. As an adult sister of a woman with intellectual disabilities, it is possible that I was inadvertently looking for certain themes that were in keeping with my own experience. In order to decrease this bias, I kept a log of my own reactions during the interview process, and showed an interview transcript to my research advisor to see if we had similar interpretations of the data.

Implications for Future Research

Further research is needed on these relationships as seen by both participants. This study focuses on sibling experiences in the United States and Canada, and does not reflect significant racial or cultural diversity. Some aspects of the experiences reported by nondisabled sisters, such as the roles that they are expected to play in their sister's lives, geographic distance, and common emotions are no doubt culturally bound. Further research is needed on the ways that relationships between young adult sisters when one sister has a disability are different in other cultures.

Interestingly, while the demographic questions included in this study did not include sexual orientation, three out of twelve participants identified as gay during the course of the interview. One mentioned that there were ways in which her sexual orientation had impacted her experience of having a sister with intellectual disabilities. She mentioned that this was something that she had discussed with other adult siblings who identify as gay, and agreed that this might be an interesting topic for further research.

Implications for Social Work Practice

This study has a number of implications for social work practice. It provides a much-needed picture of the relationships between women and their sisters with intellectual disabilities, and illuminates the ways that these relationships affect them. Participants revealed that their relationships with their sisters have a high level of emotional and instrumental impact on their lives. A particularly significant finding was that participants feel a sense of concern about the future, and that the choices they make in the present are affected by their anticipation of future responsibility. It is important that social workers not overlook young adult women when designing programs to support the families of adults with disabilities, simply because the majority of them have not yet taken on primary responsibility for their sisters with disabilities. Social workers should consider involving nondisabled sisters in discussions and planning, and connecting them with their own services.

Results of this study demonstrate that young adult sisters of women with disabilities often utilize self-help services. Participants reported seeking support services from and with other siblings who shared their lived experience. These informal networks proved to positively impact their sense of well-being. These findings suggest that sisters of women with intellectual disabilities would benefit from both individual counseling and access to support groups. It is the hope of this researcher that these findings will be used to inform further services for this population.

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Appendix A

Informed Consent

March 2011

Dear Participant,

My name is Kate Wilson. I am a student at Smith College School for Social Work. I am conducting research to use for my thesis, presentation, and possible publication. My hope is to interview adult sisters of women with intellectual disabilities. Specifically, I am interested in exploring the quality and nature of the sibling relationship between disabled and non-disabled women, and how non-disabled sisters experience and manage this relationship.

You are being asked to participate in this study if you are female, between the ages of 18 and 35, and you grew up with a sister with intellectual disabilities. As a subject in this study you will be asked to do a one-on-one audio interview either over the phone or using Skype, a free computer program that allows you to have voice conversations over the internet, depending on which is more convenient for you. Open-ended questions will focus on your experience as an adult sister of a woman with intellectual disabilities. Questions about personal information will also be asked. The interview will take approximately 60 minutes. I will transcribe the interview myself.

You will receive no financial benefit for your participation in this study. However, you may benefit from knowing that you have contributed to the knowledge of how to best provide support to siblings of people with disabilities. You may also benefit from being able to tell your story. The potential risk of participating in this study is the possibility that you might feel strong or uncomfortable emotions while talking about your experiences. If you become distressed at any point during the interview, you can ask to have the recorder turned off and the interview terminated. I have also included a list of resources from which information about services local to you can be obtained at the end of this consent form.

Your confidentiality will be maintained, as consistent with federal regulations and the mandates of the social work profession. Interviews will be recorded, and the recorded computer files will be coded numerically in order to ensure your confidentiality. Recordings will be destroyed after three years. No one else will be given access to the recordings while they are being transcribed. When presented in my thesis, any personal information in the way of quotes or vignettes will be carefully disguised. All data will be kept in a secure location for a period of three years, and data stored electronically will be protected.

Your participation is voluntary. You may withdraw from the study at any point during the data collection process, and you have the right to refuse to answer any question. If you wish to withdraw from the study after interview information has been collected, you may do so until May 1, 2011 and all materials pertaining to you will be immediately destroyed. After that date, data may have been incorporated into my thesis in an anonymous fashion. If you have any concerns about your rights or about any aspect of the study, you are encouraged to contact me, or contact the Chair of the Smith College School for Social Work Human Subjects Review Committee at 413-585-7974.

YOUR SIGNATURE INDICATES THAT YOU HAVE READ AND UNDERSTAND THE ABOVE INFORMATION AND THAT YOU HAVE HAD THE OPPORTUNITY TO ASK QUESTIONS ABOUT THE STUDY, YOUR PARTICIPATION, AND YOUR RIGHTS AND THAT YOU AGREE TO PARTICIPATE IN THE STUDY.

Signature of Participant **Date**

Signature of Researcher **Date**

Sincerely,

Kate Wilson

Appendix B

Human Subjects Review Approval Letter

SMITH COLLEGE
School for
Social Work

Smith College
Northampton, Massachusetts 01063
T (413) 585-7950
F (413) 585-7994

January 30, 2011

Kate Wilson

Dear Kate,

Your final revisions have been reviewed and they are fine. We are now glad to give final approval to your very interesting and useful study. I am glad you have such an excellent source for recruitment.

Please note the following requirements:

Consent Maintaining Data: You must retain all data and other documents for at least three (3) years past completion of the research activity.

In addition, these requirements may also be applicable:

Amendments: If you wish to change any aspect of the study (such as design, procedures, consent forms or subject population), please submit these changes to the Committee.

Renewal: You are required to apply for renewal of approval every year for as long as the study is active.

Completion: You are required to notify the Chair of the Human Subjects Review Committee when your study is completed (data collection finished). This requirement is met by completion of the thesis project during the Third Summer.

Good luck with your project.

Sincerely,

Ann Hartman | Chair

Ann Hartman, D.S.W.
Chair, Human Subjects Review Committee

CC: Rebecca Rivera, Research Advisor

Appendix C

Interview Protocol

Demographic Information:

Age:

Age of sister:

Race/ethnicity:

City/town of origin:

Employment status:

Educational attainment:

Economic background:

Number of siblings in family:

Relationship status:

Children:

Nature of sister's disability:

1. Where and with whom does your sister live? How far does she live from you?
2. How often do you talk to your sister on the phone or via e-mail? How often do you see each other? What do you do when you're together?
3. How has your relationship with your sister changed in adulthood?

4. What are your expectations for the relationship? How do you communicate these expectations to your sister?

5. What do you perceive to be your sister's expectations for the relationship? How does she communicate these expectations to you?

6. What are your family's expectations for your relationship with your sister? How have these expectations changed in adulthood?

7. Do you and your family communicate about your relationship with your sister?

8. What would you like to see happen in your relationship with your sister five years from now? How about ten years from now?

9. How do you imagine your relationship with your sister would be different if she did not have intellectual disabilities?

10. What aspects of your relationship with your sister do you find fulfilling? What aspects do you find challenging?

11. What are the primary emotions that come up for you when you talk about your relationship with your sister?

12. Are you in contact with other siblings of people with disabilities?

13. How do you think your experience has been different than it would have been if one or both of you were male?