

THE EARLY ADULTHOOD EXPERIENCE OF HAVING A SIBLING WITH A  
DEVELOPMENTAL DISABILITY

by  
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A thesis submitted to the faculty of The University of Mississippi in partial  
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## **ABSTRACT**

This qualitative study explored the early adult's experience of having a sibling with a developmental disability and influences on the experience. The phenomenological method was used, specifically the approach of hermeneutic phenomenology as discussed by van Manen. The phenomenological investigation included the collection of data from the experiential descriptions of the participants gathered during interviews. Based on reflection on the data, essential themes of the experience and influences on the experience were identified. To describe the situational context of the participant, demographic data were collected.

Five essential themes of the early adulthood experience of having a sibling with a developmental disability were identified. There were lessons to be learned from their siblings. Knowledge of the experience of the early adults offered something for others to learn. The experience included contemplations on the future including: financial responsibility for, managing the care of, and living arrangements for their siblings with a developmental disability, and future children. The early adults in this study were pragmatic. The early adults in this study had intimate relationships with their siblings. Protectiveness was expressed by the early adults, which included advocating for their sibling and concern for their sibling.

Two influences were common among all early adults in the study. The early adult's perception of their sibling and their situation as normal to them while

growing up influenced their experience. Another influence was the parents of the early adult. This included their parents' mindset on, actions towards, and approach to the situation.

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## **CHAPTER 1**

### **INTRODUCTION**

The sibling relationship is different from other familial relationships. Siblings spend considerable time together throughout childhood and adolescence, and these relationships change and grow throughout adulthood. The sibling relationship is commonly characterized by a shared cultural background, shared experiences, and typically shared genetics. With increases in family mobility, divorce rate, and subsequent remarriages, it is possible that the sibling relationship has more chances to prevail as the stronger familial relationship. Factors such as parental absence, work stress, or marital stress may also contribute to the strength of the sibling bond (Goetting, 1986). Sibling relationships can show unique patterns throughout changes in developmental periods and can be one of the most enduring human relationships that a person can experience.

More specifically what does the sibling relationship look like in early adulthood? Early adulthood is a period of development characterized by many decisions about education, romantic relationships and spouse seeking, career planning, and even selecting city of residence (Graber & Brooks-Gunn, 1996). Young adults have vast opportunities ahead of them, and in this time they make many decisions regarding their future (Newman & Newman, 2012). One study reported that by the time of early adulthood most individuals have developed decision-

making skills to a peak and are more inclined to spend more time and consideration while making these decisions (Christakou et al., 2013).

Developmental disabilities are more prevalent in today's society than ever before. A developmental disability is any of a group of conditions that are due to impairment in physical, learning, language, or behavior aspects of an individual (The Centers for Disease Control and Prevention, 2013). According to the Centers for Disease Control and Prevention (CDC), these conditions start in the developmental period, may impact daily functioning, and persist throughout the individual's lifetime. A study completed for the CDC and the National Center for Health Statistics estimates that one out of six children aged 3-17 years, have one or more developmental disabilities (Boyle et al., 2011). In 2014, there was a 5.76% lifetime prevalence of developmental disabilities in children aged 3-17 as reported by parents in a National Health Interview Survey; this included children with intellectual disability, autism spectrum disorder, or other developmental delays (Zablotsky, Black, Maenner, Schieve, & Blumberg, 2015). Additionally, the trend in deinstitutionalization is increasing the number of individuals with a developmental disability residing both at home and in the community. In 1975, a daily average population of greater than 150,000 individuals with intellectual or developmental disabilities were in large state and psychiatric facilities; by 2009, that figure had decreased to less than 50,000 individuals (Lakin, Larson, Salmi, & Webster, 2010). Also, the life expectancy for individuals with developmental disabilities is now similar to that of the general population unlike in previous decades when individuals with developmental disabilities died at a younger age (Heller, Staffor,

Davis, Sedlezky, & Gaylord, 2010). Thus, more people than ever are living through early adulthood as siblings of a person with a developmental disability.

### Purpose

The purpose of this study was to explore the early adult's experience of having a sibling with a developmental disability. Gathering data from the early adult provided perspective into the relationship and experience of having a sibling with a developmental disability. From this study a descriptive theory of the meaning of the experience emerged. Influences on the experience also emerged.

### Research Question

The research question was:

1. What is the early adulthood experience of having a sibling with a developmental disability?

### Significance

It is important to learn about the early adult's experience of having a sibling with a developmental disability. The early adulthood stage of development is an important one. Many important life decisions are made in the period of early adulthood. Erikson (1963, 1964) believed the developmental stage of early adulthood to be from 20 years old to approximately 40 years old and labeled the developmental task of individuals in this range *Intimacy vs. Isolation*. This intimacy is defined as the ability to devote the self to affiliations and partnerships and then to remain loyal to these commitments even when sacrifice or compromise is required. Individuals who have attained a sense of intimacy are better equipped to accept others, and additionally himself or herself. Without this intimacy, individuals attain

a sense of isolation and are reluctant to establish commitments, because these commitments are seen as a risk to the identity formed in the previous developmental stage (Erikson, 1963, 1964). In a 1993 article, Chickering and Reisser (as cited in Glover, 2000) described seven vectors that together represent the psychosocial and cognitive transitions that occur as individuals enter young adulthood from late adolescence. The seven vectors include intellectual, physical, emotional, moral and interpersonal dimensions, with identity as the central theme. The first vector consists of the ability to contemplate multiple points of view regarding a singular issue, physical abilities including athletic and artistic feats, and interpersonal competence. This interpersonal competence includes the ability to hear others' opinions, respond appropriately, and work jointly as a part of a group. The second vector describes the ability of an individual to acknowledge and accept his or her emotions. Self-awareness and self-acceptance of emotions allows for the appropriate expression and control of emotions. The third vector involves an individual becoming more self-reliant in decision-making and taking responsibility for his or her actions. This also involves becoming less reliant on the opinions of others. The fourth vector is establishing interpersonal relationships. In order to develop mature interpersonal relationships, acceptance of the differences of others from the self is necessary. Identity is both the fifth vector and the central theme, recognizing that identity involves achievement in other vectors as well. Identity is the individual's acceptance of his or her own characteristics. Chickering and Reisser stated that identity is typically not developed until the late 20s and is never complete. The sixth vector includes the individual establishing a sense of purpose

based on his or her life roles, activities, commitments, and interests. The final vector involves emerging integrity, which requires the knowledge of what one should do and then taking suitable actions.

This research will contribute to the understanding of the early adult's experience of having a sibling with a developmental disability. Findings of this study may help professionals and parents better understand the early adult, specifically the early adult who has a sibling with a developmental disability. This research may help early adults better understand their own experience. The findings of this research can assist parents in understanding the relationship between their children, as well as better equip them to help their children through early adulthood. Furthermore, this investigation may facilitate future actions to enhance the experience for early adults who have a sibling with a developmental disability. This research can assist healthcare providers who work with the early adults and their families by increasing their understanding of the experience.

Considering the few studies related to individuals in early adulthood with a sibling with a developmental disability and the importance and uniqueness of this developmental stage, further research is warranted to increase the existing knowledge from this perspective.

#### Phenomenological Approach

The phenomenological approach was used in this qualitative study, specifically the hermeneutic phenomenology approach elucidated by van Manen (1990). This approach combines descriptive (phenomenological) methodology, in an attempt to remain loyal to how things appear, with interpretative (hermeneutic)

methodology, in accordance with the thought that all phenomena must be interpreted (van Manen, 1990). Aside from being considered a methodology, phenomenology is also considered a philosophy. The origins of the philosophy are attributed to Husserl who argues that the experiences of people must be initially described and then reflected on to infer the significance of the experiences (Dowling, 2007). In phenomenological research the researcher is not seeking to prove any preconceived hypothesis or theory. According to van Manen (1990), phenomenological research gives a description of the experience as it is lived and then inquires about the meaning of the experience. Likewise hermeneutic phenomenological research attempts to describe the way that the experience is lived in the world and its meaning without categorizing it in any way (van Manen, 1990).

#### Definition of Terms

The following definitions are listed to provide an understanding of the terminology and key words used in this study.

1. For the context of this study and as developed by the researcher, *early adulthood* is the time period of development between ages 21 and 35 years.
2. *A developmental disability* is, according to the Federal Developmental Disabilities Act, a severe and chronic disability experienced by an individual with the following characteristics: mental or physical impairment or a combination of both, is apparent prior to the age of 22, and reflects an individual's need for services and support. A developmental disability causes functional shortcomings in at least three of the following: self-care, language,

learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency (Developmental Disabilities Act, 2000).

### Assumptions

Assumptions of the study include (1) that there is no objective reality, because the observer's interpreted experience is reality (Munhall & Boyd, 1993), (2) developmental disability in a person has some effect on every member of his or her family and the family as a whole, (3) every member of the family has a unique and legitimate perspective on his or her own experience, (4) there may be both positive and negative outcomes from the experience of having a person with a developmental disability in the family, and (5) the participants were knowledgeable of their sibling's diagnosis and were honest to the best of their ability throughout the entirety of data collection.

### Limitations

This study extracted and analyzed descriptions of the early adult's experience of having a sibling with a developmental disability. Situational factors such as the location and time of the interview might have influenced the findings. To help minimize these factors, the participants were able to select the interview location and time to avoid inconvenient hours in their schedule that might cause anxiety or places in which the participants did not feel comfortable discussing their sibling. A reactive effect might have resulted from the presence of the tape recorder or knowledge that the interview was being recorded. This was expected to have minimal effect. Finally, misunderstanding of questions asked by the researcher



might have occurred during the interview. Intentionally clear wording and rephrasing of questions was implemented to minimize this effect.

### Summary

There has been very little published research exploring the early adult's experience of having a sibling with a developmental disability. As more people are living through this experience, there is much to be gained by more research on the topic. With more available research, health care professionals and families of individuals with a developmental disability may be able to enhance both relationships between early adults and their sibling with a developmental disability and their experiences.

## **CHAPTER 2**

### **REVIEW OF LITERATURE**

A review of literature revealed few studies that focused on the experience of early adults who have a sibling with a developmental disability. The literature review includes research related to sibling relationships in early adulthood as well as sibling relationships in adulthood when a sibling has a developmental disability.

#### Sibling Relationships in Early Adulthood

Siblings provide the longest-lasting relationships within the family and frequently develop closeness as other family members age and extended family members die (Goetting, 1986; White, 2001). Siblings in early adulthood have the choice to have as much or as little interaction as they desire, and thus they can establish their own quality of relationship. They also have the unique aspect of rivaling for parental affection and attention that is not typical of other familial relationships (Furman, Lanthier, & Stocker, 1997). The study by Furman, Lanthier, and Stocker (1997) used a self-report questionnaire and analyzed reports on three categories of sibling relationships: warmth, conflict, and rivalry. The researchers reported the following correlations: the perception of warmth in the sibling relationship was positively correlated to how often the siblings had contact; the number of siblings (children within the family) was positively correlated with the perception of conflict and rivalry and negatively correlated with the perception of

warmth; and people with high scores of psychological functioning and mental health reported less conflict in their sibling relationships (Furman, Lanthier, & Stocker, 1997).

Research conducted by Conger and Little (2010) focused on how sibling relationships change during early adulthood. Several of the transitions occurring in this developmental period include: pursuing or finishing education, job seeking, establishing romantic relationships, perhaps even marriage, childbearing decisions, and moving away from the natal home. The experience may be different among siblings due to the fact that one sibling may experience this period at a different time than the other sibling or both siblings may experience early adulthood simultaneously. In typical sibling relationships, there is also a certain amount of competition during this period of development. One sibling may feel less adequate based on his or her success in job seeking or job-attaining or in finishing their education when compared to their sibling (Conger & Little, 2010).

A panel analysis conducted by White (2001) used pooled time series techniques on a national panel sampled by the National Survey of Families and Households to investigate sibling relationships of the life course. It was reported that in a typical relationship, communication and closeness between siblings decreases during early adulthood, most likely attributed to one or both siblings leaving home and establishing a family of their own that consumes more of their time (White, 2001). However, researchers reported that one sibling having children strengthened sibling relationships, perhaps due to parents desiring their children to have relationships with aunts, uncles, and cousins (White, 2001). Researchers also

reported that across all groups, sisters were the most inclined to maintain and strengthen their sibling relationships (White, 2001).

### Sibling Relationships in Adulthood with a Sibling with a Developmental Disability

There have been a number of studies in the adult sibling relationship in which one sibling has an intellectual or developmental disability; many of these studies focus on a specific disability (Cuskelly, 2016; Seltzer, Greenberg, Krauss, Gordon, & Judge, 1997; Seltzer, Orsmond, & Esbensen, 2009). For example, in one study including individuals with a sibling with Down syndrome, more than half of the adult siblings of persons with Down syndrome viewed their relationships as moderately warm with low levels of conflict and had the intention to provide direct care for their sibling (Cuskelly, 2016). In a longitudinal study of adult siblings of individuals with autism spectrum disorder, the sibling dyad shared more activities when the sibling with autism spectrum disorder was younger in age and had fewer behavior problems. Also, higher levels of positive affect were correlated with greater parental support (Seltzer, Orsmond, & Esbensen, 2009). Researchers have also studied the experience of having a sibling with a developmental disability focusing on childhood and adolescence (Smith, Elder, Storch, & Rowe, 2015). However, there is a paucity in literature available on the early adult experience of having a sibling with a developmental disability.

A study conducted by Floyd, Costigan, and Richardson (2016) focused on the progression of the sibling relationship over the life course and sibling relationships in which one sibling had an intellectual disability. Researchers in the study reported that sibling relationships in which one sibling has an intellectual disability, when

studied during adolescence and young adulthood, had a strengthening of the emotional bond and a reduction in sibling conflict as the dyad progresses through the development (Floyd, Costigan, & Richardson, 2016). Researchers from the study reported that the closeness of the sibling relationship was not related to co-residence; thus they predicted that siblings should be able to pursue career and relationship interests outside the family while balancing their responsibilities at home with their sibling with an intellectual disability (Floyd, Costigan, & Richardson, 2016).

A study by Heller and Kramer (2009) focused on the sibling involvement in future planning. In their study, they reported that 38% of siblings anticipated becoming the primary caregiver to their sibling with a developmental disability. The sibling respondents in the study ranged from ages 18-62 with a mean age of 37 years old. Several factors influenced this anticipation and included the gender of each sibling, the proximity of the living situation of both siblings, and the amount of contact and support between siblings. In this study, sisters were closer to their sibling with a disability than brothers. The most involved siblings lived closer and shared in more personal contact with their sibling. In most situations parents had discussed future plans with the non-disabled sibling, but no concrete plans had been established (Heller & Kramer, 2009).

Two studies compared sibling dyads in which one adult sibling was diagnosed with either autism spectrum disorder or Down syndrome. A study by Orsmond and Seltzer (2007) focused on the adult sibling relationships occurring when one sibling has either an autism spectrum disorder or Down syndrome. The

study included a series of questionnaires involving more than 150 siblings between the ages of 21-56 years. In this study adult siblings of a person with an autism spectrum disorder more often had feelings of pessimism about the sibling's future, less personal contact, and effects reaching outside the sibling relationship occurred. However, they found that siblings of adults with autism spectrum disorder reported that their sibling relationship had positive effects on their relationship with their parents. The researchers also reported that in both cases of autism spectrum disorder and Down syndrome adult siblings had better relationships with their sibling with a disability if the non-disabled sibling chose to live closer to his/her sibling with the disability, decided not to have children, had a lower education level, and used more problem-focused coping methods (Orsmond & Seltzer, 2007).

The second study was a large web-based study using questionnaires. The study included 460 adult siblings of persons with disabilities: 284 were adult siblings of individuals with Down syndrome, and 176 were adult siblings of individuals with autism. The average age of the adult siblings of individuals with Down syndrome was 36.7 ( $\pm$  13.9), and the average age of the adult siblings of individuals with autism was 30.6 ( $\pm$  12.6) (Hodapp & Urbano, 2007). In this study, the researchers reported that the majority of siblings of adults with developmental disabilities gave reports of positive effects on their sibling relationship. These included: functioning well, having good health, low reports of depressive symptoms, and feeling a significant level of reward from having a sibling with a developmental disability. More specifically, they found that individuals with an adult sibling with Down syndrome had better health and lower levels of depressive symptoms

compared to individuals with adults with Autism spectrum disorder (Hodapp & Urbano, 2007).

A study conducted by Burbidge and Minnes (2014) investigated the similarities and differences of relationship quality of siblings without a developmental disability and that of siblings in which one sibling has a developmental disability. The study was conducted in two parts and used a questionnaire. A person with one sibling with a developmental disability as well as another sibling without a developmental disability filled out two separate questionnaires about his/her relationships with each of the siblings. The research reported that in-person and telephone contact between siblings was greater when one sibling had a developmental disability. Participants also rated their closeness to their sibling with a developmental disability as greater than their sibling without a developmental disability, but rated their closeness in behaviors, referring to shared activities, as greater in similarity to their sibling without a developmental disability (Burbidge & Minnes, 2014).

O'Neill and Murray (2016) conducted a study focusing on the prevalence and symptomatology of anxiety and depression in adult siblings of individuals with developmental disabilities including Down syndrome, autism spectrum disorder, Prader-Willi syndrome, and those with a developmental disability of unknown etiology. The study included 132 non-disabled siblings of individuals with the aforementioned disabilities who were 18 years or older and 132 non-disabled control group participants. The mean age for the sibling group was 33.83 ( $\pm 10.69$ ) and for the control group 37.03 ( $\pm 12.34$ ). The data were gathered via

questionnaires sent to disability charities. The researchers reported that all of the sibling groups who had a sibling with a disability reported elevated levels of anxiety and depression symptoms compared to the control group based on the siblings' reports of their symptoms. Siblings of individuals with autism spectrum disorder or Prader-Willi syndrome were reported to be significantly higher for anxiety than the control group, while siblings of individuals with autism spectrum disorder and developmental disabilities of an unknown etiology were reported to be significantly higher for depression compared to the control group. Siblings of individuals with Down syndrome were not significantly different from the control group for either depression or anxiety. In most sibling groups, siblings younger than their sibling with a disability displayed a trend towards anxiety and depression (O'Neill & Murray, 2016). The researchers reported that having a sibling with a developmental disability of an unknown etiology may be particularly stressful because they have no actual prognosis and have limits for participation in specific support groups. While their reported depression was not in the clinical range, siblings of individuals with a developmental disability of an unknown etiology reported higher levels of depressive symptomatology (O'Neill & Murray, 2016).

Arnold, Heller, & Kramer (2012) conducted a study regarding the support needs of individuals who have a sibling with a developmental disability. The participants in this study were 18 or older with an average age of 37 years old. The study was conducted using two open-ended questions attached to a questionnaire. The researchers reported three overarching themes: Include Me, Start Spreading the News, and Fix the Mess. The first theme "Include Me" encompassed the participants'



wishes to have support groups of their own and to be included in family support groups. The researchers stated, “Numerous respondents shared the importance of targeting siblings as a group with support needs because they have felt neglected and desperately wanted to be included” (Arnold, Heller, & Kramer, 2012, p. 377). The second theme “Start Spreading the News” related the participants’ desires for more education and training opportunities for themselves, more opportunities to develop future plans with their family members, more available information on how to navigate different systems involved when a sibling has a developmental disability (for example, Medicaid programs and day services), and also more disability awareness education for the public. Highlighted in the study were participants’ sentiments that getting the conversation started about future planning was the biggest step and then worry about what will occur when parents die could be discussed (Arnold, Heller, & Kramer, 2012). The third theme “Fix the Mess” involved participants’ desire for system improvement, additional funding for families, and the need for respite services. The highest ranking need in the study was sibling support services. The participants’ inquiries for more education and training opportunities, such as conferences, workshops, and seminars, demonstrates their desire to connect with others in similar situations, share needed information, and aid in supporting one another (Arnold, Heller, & Kramer, 2012). It was evident in the study that individuals with siblings with a developmental disability were eager to gain knowledge regarding their situation in order to better prepare themselves for the future and also to better assist their sibling.

The early adulthood time period is especially relevant when considering a review of adult sibling literature conducted by Heller & Arnold (2010). The review of literature included 23 studies published between 1970 and 2008 on adult siblings over 21 years of age who had a sibling with a developmental disability. The review focused on three main topics: (1) the psychosocial outcomes of having a sibling with an intellectual and developmental disability on the non-disabled sibling; (2) factors relating to the nature of the sibling relationship; and (3) factors relating to future planning. The literature review reported a mixture of positive and negative psychosocial outcomes. The researchers reported eight studies in which researchers found positive psychosocial impacts for siblings of adults with a developmental disability, and five studies in which researchers found negative psychosocial impacts for siblings of adults with a developmental disability (Heller & Arnold, 2010). The researchers reported that the majority of siblings studied in more than 20 studies expect to take on an increased supportive role for their sibling with a disability in the future. The researchers found that among all studies reviewed, 19% of siblings intended to co-reside with their sibling with a disability in the future, 44% of siblings were willing to be a future caregiver, and 60% intended to be a future carer for their sibling with a disability (Heller & Arnold, 2010). The researchers reported that non-disabled siblings felt knowledgeable about the needs of their sibling with a disability and that the majority of studies reviewed reported that non-disabled siblings had positive relationships with their sibling with a disability (Heller & Arnold, 2010). Researchers reported that several factors may

affect the sibling relationship, including the type of disability, degree of disability, sex and age of each sibling, and proximity of residence (Heller & Arnold, 2010).

In relationship to common developmental tasks relevant to early adulthood, there has been no conclusive research findings regarding the influence of a sibling with an intellectual disability on life course decisions including marriage, career choice, and the decision to have children (Burton & Parks, 1994; Davys, Mitchell, & Haigh, 2016). Several studies specifically researched the effect of having a sibling with a disability on career choice, a choice that is very prominent in early adulthood (Burton & Parks, 1994; Marks, Matson, & Barraza, 2005; Davys, Mitchell, & Haigh, 2016). Burton and Parks (1994) conducted a study with college students and found that no significant differences in career aspirations existed between individuals with siblings with or without disabilities. In another study conducted by Marks, Matson, & Barraza (2005), the researchers reported that siblings did choose their career path based on their experience with their sibling with a disability; however, their study population consisted entirely of individuals already working in the special education field. These siblings expressed that their experience with their sibling led to an interest in that specific field and instilled in them a desire to help others in similar situations (Marks, Matson, & Barraza, 2005).

Davys, Mitchell, and Haigh (2016) conducted a study using semi-structured interviews with 15 participants aged 30-64 years and reported 9 of 15 participants in adulthood had a degree of engagement with health and social care either by a paying job or volunteer services, which suggested a link between career choice and intellectual disability for some siblings. The results from Davys, Mitchell, and

Haigh's study (2016) on the influence of a sibling with an intellectual disability on the decisions in partners and in whether or not to have children were mixed. For three of 15 participants the willingness of the partner or spouse to live with the sibling was a primary determining factor for the continuance of the relationship. For one participant, a long-term live-in relationship was not possible because the sibling with the intellectual disability reportedly would not tolerate another woman in the house. For one participant, the decision to refrain from having children was due to having the sibling with an intellectual disability (Davys, Mitchell, & Haigh, 2016). Two of the 15 participants in the study reported obtaining counseling for mental health needs while in adulthood due to the presence of the sibling with an intellectual disability, thus providing evidence that more sources of information during early adulthood may be beneficial to this population to help prevent reported feelings of guilt, anger, a sense of loss, and jealousy (Davys, Mitchell, & Haigh, 2016).

There was evidence that the gender of the sibling of the individual with a developmental disability played a role in the sibling relationship quality and experience (Greenberg, Seltzer, Orsmond, & Krauss, 1999; Orsmond & Seltzer, 2000). It was more prevalent for sisters of individuals with disabilities to be involved in their siblings' lives as compared to brothers of individuals with disabilities. In the study by Greenberg, Seltzer, Orsmond, and Krauss (1999), sisters provided more emotional care for their siblings than brothers provided for their siblings with either an intellectual disability or mental illness. Similarly, in the study conducted by Orsmond and Seltzer (2000), sister siblings of individuals with mental

retardation provided more caregiving, companionship, and positive affect than brothers of individuals with mental retardation. It was also reported that brothers are more likely to be involved with brothers with mental retardation than with sisters (Orsmond & Seltzer, 2000).

### Summary

The literature review evidences the need for more research on the early adult's experience of having a sibling with a developmental disability. Research related to this experience will contribute to the knowledge base regarding the sibling experience of having a sibling with a developmental disability, particularly during early adulthood. There is some research regarding the experience of having a sibling with a developmental disability when in adulthood, but early adulthood is a unique stage and the siblings may have different experiences. Qualitative research, containing rich data, specifically has the potential to increase knowledge of the early adult's experience. Only two qualitative studies were found by the researcher on individuals who have a sibling with a developmental disability. The researcher found no qualitative studies specifically on early adults who have a sibling with a developmental disability. This increased knowledge has the opportunity to help inform families who have a child with a developmental disability and professionals who work with families who have a member with a developmental disability in order to optimize the experience for each member of the family. This knowledge also has the potential to better inform policy makers and those who provide resources to families of those with a developmental disability.

## **CHAPTER 3**

### **METHODOLOGY**

The purpose of this study was to explore the early adult's experience of having a sibling with a developmental disability. The research question was: What is the early adulthood experience of having a sibling with a developmental disability? This chapter will include a description of the research design, setting, participants, instruments, procedure for the data collection, and protection of human subjects.

#### Design of the Study

Phenomenological methodology was used in this qualitative study, specifically the method of hermeneutic phenomenology described by van Manen (1990). Through phenomenology, the researcher described and unfolded the early adulthood experience of having a sibling with a developmental disability. According to van Manen, hermeneutic phenomenology involves six methodological activities: 1) selecting phenomenon which genuinely interests us and commits us to the world, or turning to the nature of lived experience; 2) exploring experience as we live it rather than how we think about it, or existential investigation; 3) contemplating the themes which characterize the phenomenon, or phenomenological reflection; 4) transcribing the phenomenon in writing, or phenomenological writing; 5) maintaining a strong relation to the phenomenon; and 6) balancing the research

context by reflecting on parts and the whole (Polit & Beck, 2010). Phenomenological reflection includes thematic analysis and determination and results in an understanding of the meaning of an experience. These essential themes are what define and compose the experience. Van Manen explicates that these themes are what “make a phenomenon what it is and without which the phenomenon could not be what it is” (van Manen, 1990, p. 107).

Following the first three methodological activities, writing about the essential themes is done to describe the themes more clearly. This phenomenological writing is a description of the human experience of interest, and the process of phenomenological writing utilizes careful contemplation to allow the meaning of the experience to emerge. The intention of this process is to reflect the meaning of the experience in a manner that can be understood by the reader (van Manen, 1990).

### Setting

Data collection took place in a location of the participant’s choosing or by phone. Only the participant and the researcher were present for the interviews. The interviews were conducted in a room in which the confidentiality of the participant’s conversation was ensured.

### Instruments

In phenomenological study, the researcher is the main instrument for collecting data. The phenomenological investigation included the collection of data from the experiential descriptions obtained from the participants during interviews

using the phenomenological method described by van Manen (1990). The interviews were recorded using the AudioNote application for iPads for later transcription and analysis.

### Participants

There were six participants in the study. There were no exclusions related to race or gender. Participants in the research study met the following criteria: (1) were between the ages of 21 and 35 years old, (2) had a sibling with a diagnosed developmental disability according to the guidelines set by the Federal Developmental Disabilities Act (2000), per self-report, (3) were able to communicate efficiently in the English language, (4) were able to hear (with or without assistive devices). It was assumed that the participants were accurately aware of the diagnosis of their sibling(s). Demographic data for the participants were collected including: age, gender, ethnicity, city of permanent residence, education, total number of siblings with/without a developmental disability, and total number of years lived in same household as sibling. Also data about the sibling were collected including: diagnosis as reported by participant and major life activities impacted by the developmental disability as listed in the Federal Developmental Disabilities Act (2000) (Appendix B).

The participants included persons aged 22 years to 28 years. Four participants were 22 years old, one participant was 25 years old, and one participant was 28 years old. Three participants were female, and three participants were male. Four participants had earned a bachelor's degree. One participant had earned a master's degree. One participant had completed some



college. Five participants were White, and one participant was multiracial. All participants' siblings met the criteria established by the Federal Disabilities Act (2000) for a developmental disability, and information about the diagnosis of each participant's sibling is discussed in Chapter 4.

The method used for attracting participants was snowball (nominated) sampling. The researcher asked the initial participants to refer later study candidates. Qualitative studies do not claim generalization covering a greater population; therefore, if the participants are in fact members of a small group of acquaintances, then the credibility and trustworthiness of the study is not necessarily compromised. The researcher also shared, by word of mouth and e-mail newsletter, information on the study within the Sally McDonnell Barksdale Honors College. The researcher also shared information by word of mouth in the Psychology Department of the University of Mississippi to recruit participants. The researcher stood before psychology classes, as permitted by the professors, and announced the study being conducted and shared an e-mail address as a method of contacting the researcher. If the potential participant indicated interest in participating in the study, contact was made by the researcher to verify inclusion criteria and then schedule an interview.

### Procedure

The phenomenological study included the collection of data from experiential descriptions obtained from the participants through interviews using the phenomenological method described by van Manen (1990). Based on reflection on the data, a phenomenological writing regarding the early adulthood experience of

having a sibling with a developmental disability was composed and analyzed for themes (van Manen 1990).

After the University of Mississippi Institutional Review Board approved the study (Appendix E), experiential descriptions were obtained from the participants via interviews. The researcher recruited participants by announcements in person or in the Sally McDonnell Barksdale Honors College e-mail newsletter and also through snowball sampling. The participants were asked to participate in a singular interview lasting for one to two hours. The intention of the interviews was to allow freedom and flexibility to elicit individual stories, while collecting information with sufficient consistency to make comparisons between participants. Each interview was recorded for later accurate transcription and analysis. Once the participant expressed clear interest in participation and the interview was coordinated, the participant was asked to give consent for the recording of their interview to be used and also consent that they were over the age of 21 and agreed to participate in the study. These consents required the participants' signatures, or checkmarks, on an Institutional Review Board Recording Release form (Appendix D) and the Information Sheet (Appendix C), respectively. Once consent was obtained and prior to the interview, demographic data was obtained from the participant (Appendix A) and also the data about the sibling were collected including: diagnosis as reported by participant and major life activities impacted by the developmental disability as listed in the Federal Developmental Disabilities Act of 2000 (Appendix B). The researcher began the interview with the question: "What is your experience in early adulthood of having a sibling with a developmental disability?" All other questions

evolved as the interview proceeded. The follow-up questions were intended to encourage the participant to more fully explain or clarify his or her experience. Each interview was transcribed verbatim and verified for accuracy. The recordings were preserved on the iPad device. The transcripts were preserved on a Universal Serial Bus storage device and printed copies were used for analysis of data.

### Protection of Participants

Approval of this research was obtained from the University of Mississippi Institutional Review Board (Appendix E). Informed consent was obtained from the participant prior to the initiation of the interview (Appendix C). The study was verbally explained to the participant and written assent was obtained. Each participant was assigned a unique participant number, and only the participant number was attached to the data to protect the confidentiality of the participants. Participants were also assigned a pseudonym. A chart connecting participant name, pseudonym, and participant number was kept safely. All data were kept in a locked file. Consent forms and the chart containing participant name, pseudonym, and participant number were kept in a separate locked file.

### Analysis

The researcher began phenomenological reflection during the verification of the transcription. No attempts were made to document these reflections; however, this was the first reflection of the researcher. The researcher identifying thematic aspects in the participants' descriptions, highlighting thematic statements, and creating linguistic transformations constituted thematic analysis. An elaboration of each step follows.

Each interview transcription was read multiple times. Three approaches explicated by van Manen (1990) were used in the thematic analysis: the holistic approach, the selective approach, and the detail approach. The holistic, or the sententious, approach involved reflecting on the description as a whole to discern the overall meaning. The meaning was summed into a phrase that encompassed the fundamentals of the experience. The selective, or highlighting, approach involved reading the transcript multiple times to find the aspects of the description that were essential to the phenomenon and then highlighting those specific statements or phrases. The detailed, or line by line, approach involved reading cautiously each line of the description to reflect on how the participant worded or phrased the description revealed the phenomenon.

Following the hermeneutic process of van Manen (1990), linguistic transformations were made in the form of notes and paragraphs as themes and thematic statements were encountered and identified. This involved the researcher reflecting on the participant's experience and transforming them into the words of the researcher. The adviser of the researcher separately analyzed the data using the same techniques. Following separate analysis, the researcher and adviser jointly discussed the individual themes of the participants.

Certain experiential themes were common or possibly common among all participants; therefore, these themes were compared across interview transcripts to look for similarities and differences. The researcher then selected which themes, common among participants, emerged as representing the meaning of the phenomenon of the early adulthood experience of having a sibling with a

developmental disability. The adviser of the researcher separately identified common themes. Together, the researcher and adviser discussed and selected the common and emergent themes across participants. Following the conclusion of reflective analysis and definition of essential themes, phenomenological writing began. The researcher wrote multiple attempts and versions of the text until satisfied that the writings accurately and meaningfully represented the early adulthood experience of having a sibling with a developmental disability. After completion of phenomenological writing, participants in the study were asked if the writing accurately reflected the experience (the phenomenological nod). The purpose was a member check to ascertain credibility of the research findings.

#### Methodological Rigor

Rigor in qualitative research is important to the practice of good research. Trustworthiness is assured through the criteria of credibility, transferability, and confirmability (Lincoln & Guba, 1985).

#### Credibility and Dependability

Credibility and dependability of the findings were based on the trustworthiness of the phenomenological writing. Consistent use of the method helped to ensure pure description of the data.

In qualitative research it is assumed that there is no objective position from which to study human beings. The researcher is a self-interpreting being, as is the participant in the study. The researcher did not identify meanings in the participant descriptions that were not supported by textual evidence. To establish credibility and dependability, the researcher must demonstrate that the findings and analyses

of the data are credible to the participants who described their experiences. To increase credibility and dependability, the adviser of the researcher analyzed the data for individual and common themes separately from the researcher, and later the adviser and researcher together discussed and selected the individual and common themes.

For this study, the phenomenological nod was used to establish credibility. The phenomenological nod is the agreement of others reading or hearing the phenomenological writing of the investigation (Munhall, 1994). For the purpose of methodological rigor the phenomenological nod needed to be obtained from the participants, because they are the only ones who could answer the question of whether the writing reflected what the experience was like for them. Participants should see reflections of their experience somewhere in the writing, if not in the totality of the writing (Munhall, 1994). All participants contacted concurred with the findings of the study.

#### Transferability

In a qualitative study, the researcher cannot specify the transferability of the findings. The task of transferability is that of the person seeking to apply the research elsewhere. The sample and setting of the study were described in detail and data from interviews included in the report of the findings, so that others may make their own transferability judgments.

#### Confirmability

Data and analyses of a study must be based on the participants' experiences. Findings should be based in the data, and interpretations made by the researcher

must be logical (Lincoln & Guba, 1985). Confirmability in this study was established by following closely the analysis process and the endorsement of the findings with the participants through the phenomenological nod.

### Summary

This hermeneutic phenomenological study (van Manen, 1990) was designed to acquire an understanding of what it is like to experience early adulthood while having a sibling with a developmental disability. Data were obtained through participant interviews. Through this research, analysis of the meaning of the phenomenon began with each interview and proceeded through data collection and writing. The findings of the data analysis are explored in the next chapter as well as themes and their variations. These themes are reinforced by direct quotes from the participant interviews.

## **CHAPTER 4**

### **DATA ANALYSIS**

In this chapter, the researcher presents the phenomenological reflection of the experiential descriptions gathered from the participants. There was one research question for this study: What is the early adulthood experience of having a sibling with a developmental disability? The situational context of each participant and the themes present in each interview are discussed individually with a focus on answering the research question. Themes and influences identified for each participant are found in Table 1. Essential themes across the participants' experiences are described in Chapter 5.



Table 1. Participant Themes and Influences

Participant	Themes	Influences
Sara	<ul style="list-style-type: none"> <li>• Protective</li> <li>• Involvement of Spouse</li> <li>• Role Model for her Sibling</li> <li>• Lessons Learned</li> <li>• Intimate with Sibling</li> <li>• Pragmatism</li> <li>• The Future</li> </ul>	<ul style="list-style-type: none"> <li>• Normal to Me</li> <li>• Parents</li> </ul>
Kara	<ul style="list-style-type: none"> <li>• Lessons Learned</li> <li>• Involvement of Spouse</li> <li>• Pragmatism</li> <li>• Protective</li> <li>• The Future</li> <li>• Guilt</li> <li>• Intimate with Sibling</li> </ul>	<ul style="list-style-type: none"> <li>• Normal to Me</li> <li>• Parents</li> </ul>
Harley	<ul style="list-style-type: none"> <li>• Intimate with Sibling</li> <li>• Pragmatism</li> <li>• Lessons Learned</li> <li>• Guilt</li> <li>• Protective</li> <li>• The Future</li> </ul>	<ul style="list-style-type: none"> <li>• Normal to Me</li> <li>• Parents</li> </ul>
Brad	<ul style="list-style-type: none"> <li>• Intimate with Sibling</li> <li>• Pragmatism</li> <li>• Lessons Learned</li> <li>• The Future</li> </ul>	<ul style="list-style-type: none"> <li>• Normal to Me</li> <li>• Parents</li> </ul>
Regan	<ul style="list-style-type: none"> <li>• Pragmatism</li> <li>• Realizations</li> <li>• Choosing College</li> <li>• The Future</li> <li>• Guilt</li> <li>• Protective</li> <li>• Lessons Learned</li> <li>• Misunderstood</li> </ul>	<ul style="list-style-type: none"> <li>• Jamaica</li> <li>• Adolescence</li> <li>• Normal to Me</li> <li>• Parents</li> </ul>
Brandon	<ul style="list-style-type: none"> <li>• Guilt</li> <li>• Protective</li> <li>• Intimate with Sibling</li> <li>• Frustration</li> <li>• The Future</li> <li>• Pragmatism</li> <li>• Embarrassed</li> </ul>	<ul style="list-style-type: none"> <li>• Normal for Me</li> <li>• Parents</li> </ul>

## Sara: First and Foremost Sisters

The first participant was Sara. She is a White female and was 28 years old at the time of the interview. She lived within approximately an hour and a half of her sibling with a developmental disability. She is the middle sibling with one older sister and one younger sister. Her younger sister is her only sibling with a developmental disability. She was raised in the same household as her sibling with a developmental disability for 18 years, or until Sara left for college. Sara participated in taking care of her sister while growing up. Sara has earned both a bachelor's and a master's degree, and at the time of the interview was working on a doctoral degree. Sara was married and lived separately from her sibling with a developmental disability. Her sister with a developmental disability has been diagnosed with the following: hydrocephalus, craniosynostosis, agenesis corpus callosum, autism, and acquired Chiari malformation. Her sister with a developmental disability was impacted in the following life activities listed in the Federal Definition of a Developmental Disability (2000): self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency. Her sibling with a developmental disability lived at home with their parents, and at the time of the interview she was 20 years old. Her sibling with a developmental disability had a cell phone of her own, and Sara contacted her daily with frequent in-person visits and overnight stays. Her sibling with a developmental disability regularly attended a program geared for persons with disabilities and has earned a high school diploma.

## Themes

Protective: advocating & concern. Sara displayed a protective attitude towards her sister through advocating on behalf of her sister and expressing concern for her sister. Sara felt offended by the use of the “r-word” and felt strongly that people-first language should always be used. She believed that the use of these in language stemmed from a form of ignorance and did not want her sibling to be exposed to them. She was very vocal during her college experience about these topics. She felt strongly that she should advocate for her sister by spreading awareness. Sara’s advocating was intended to affect the actions of others around her sister and other individuals with disabilities. Sara also felt compelled to advocate for the intelligence of her sister while aware she was living with a developmental disability, which was interpreted by the researcher as a form of protection. Sara was realistic about the abilities of her sibling, while also defending aspects of her sibling’s intelligence.

*So on Friday night football games my sister would come, and there would be some people, not all... I use the term “ignorance”, not in a negative way, just they truly did not know, because they weren’t around it. So that kind of was something that I struggled with, and I was very vocal, even later in college, you know if people used the “r-word” even just for joking. If they said “Oh that’s so retarded.” I would immediately say, “Please don’t use that word around me.” I would be very quick, and you know people would always feel bad. But that’s a precedence I set early on.*

*She actually has a full high school diploma, which is very rare, because of her IQ and adaptability scores. For example, she can do algebra, but she couldn’t tell you that “x” stood for anything. She may not understand the concept, but she can memorize. That’s probably one of her biggest strengths, is memorization, but generalizing is an issue. So things are absolute: black and white.*

She expressed concerns about her sister’s safety as a female with a developmental disability. She thought that her sister’s safety could potentially be

compromised by her gaining independence. Sara also displayed a level of concern for her sister and her emotional well-being. This concern was apparent throughout all of the topics that Sara discussed; however, it was particularly relevant to Sara's leaving home to go to another city to attend graduate school. Sara displayed knowledge of the negative effects of an empty nest on other individuals in her sister's situation and expressed worry over her sister experiencing the same effects.

*The goal is for her independence to grow, but at the same time one of the biggest fears is her being taken advantage of. Obviously it happens to females, but can happen to males. I worked in adult programs, and I've heard horrific stories, just horrific stories.*

*Now that it's an empty nest though, I am concerned about depression and things like that with her, which a lot of people don't see that aspect. There are a lot of studies out there, such with individuals with Down syndrome. People automatically assume "Oh they are so nice, so sweet, and happy all the time." There is a rise in depression once they get older, because their involvement is limited, unfortunately, with society.*

Involvement of spouse. Sara expressed how important she thought it was to have her boyfriend, now spouse, be involved and informed regarding her sibling with a developmental disability throughout all of their relationship. She explained that she acquainted her boyfriend with her sibling early on so that the two could develop a comfortable relationship with one another. She expressed her own comfort in knowing that they have a relationship and that her sibling with a developmental disability responds well to the male authority figure she sees in Sara's husband. She expressed her gratitude for the fact that her husband can now share in the disciplining responsibility for her sibling with a developmental disability, so that Sara can shift her focus more toward being her sibling's sister versus being her sibling's caretaker.

*That was a big part of when we got engaged. That was something that I wanted to have a serious conversation with him about. You know she will be treated as if she were one of our children. We're making decisions on the family... And that's something to which he said, "Of course, of course." But I really would explain worst-case scenarios and really wanted him to be aware of how this was asking a lot. This is a big deal. The older she gets, the more people are involved in the stakes, which I think is good for her because she has a good support system I feel like. But that is asking a lot of spouses with those kinds of things.*

Role model for her sibling. Sara believed that her sister with a developmental disability modeled Sara's behavior, and so she often tried to include her sister in activities. Sara invited her sister to stay with her in her sorority house in college so that she could have more appropriate interactions with people similar to her age. Sara felt strongly that her sister with a developmental disability should be included in her activities so that Sara could set a social example for her sister.

*In college a lot of times, she would come over and spend the night with me in the sorority house, or come eat lunch with me. I would try to facilitate more, because it was easier for me to take her out, or at least I think it was more appropriate for her to go out with me versus mom and dad all the time, just to have someone closer to her age.*

Lessons learned: a lesson to learn from my sibling. Sara also believed that her sister with a developmental disability was a role model for her. She credited her sister for setting an example for the perspective that Sara should have on life. She thought that the simplicity and wholesomeness of her sister's perspective were commendable. Sara made it clear that she admired her sister and that she had lessons to learn from her sister.

*Because she is in a way my role model for life with the way she is into her things, her perspective on life, and the purity of her heart kind of thing.*

Intimate with her sibling. Sara talks with her sister with a developmental disability on a daily basis and the two have in-person visits frequently. Sara thought

that her relationship with her sister with a developmental disability was very similar to other sister relationships: with feelings of being best friends and being very close to one another. Sara expressed clearly that the two of them were very close with one another.

*She gets a little headstrong. I think we both do, because it is hard because in a way first and foremost we are sisters but at the same time I'm caretaker-ish. I'm very momma-bear, even though she already has a momma-bear.*

*So when I moved away from home, I think we both went through bouts of depression. I told my husband that we were not moving. Even though it's only an hour away, you would have thought it was half way across the world.*

Pragmatism. Sara showed a very practical attitude towards her experience with her sister. She shared examples of practical accommodations she and her family made for her sister such as going to restaurants early in the evening and avoiding standing in lines. She did not express any negative feelings towards the adjustments that she and her family made, and currently make, for her sister. She also maintained a very sensible stance on how situations regarding her sister are handled in early adulthood.

*But there are just certain things we couldn't do or had to do in a different way. You know, going out to dinner, we would go early. We would always be the early birds, with the people who were older for the early bird special, because putting your name in and having to wait, and those kinds of things. Going to stores, having to be in line, we would tag team and have someone walk around the store with her while someone else waited in line.*

*... we try to teach [my sister] through realistic settings. So when she was approaching puberty, we were trying to prepare her for what a period was and things like that. When the dog was in heat, we talked about that. Everything is a learning situation.*

The Future: financial responsibility. Sara had impressive knowledge of her status in plans for the future in her sister's life. Sara was aware of their family's

financial situation and that her sister had a special needs trust. She also was aware that she was the designated person in charge of her sister's finances. Sara displayed confidence in her family's plan and also in her abilities to fulfill her part of the plan. Sara discussed their plans for her sister with ease and never described stress from thinking about the future.

*So if something were to happen to my parents, let's say there are three of us siblings so technically a family would divide things three ways in their will. Well if anything is left under her [sister with developmental disability] name, then she will not qualify for services, and she will be kicked out of services. There is something going through legislation now called the Able Act that has been passed and looks to help in that area. I am the executor of the special needs will and trust, so it is basically money allocated to her but not under her name. I am also the guardian or conservatorship, if something were to happen to my parents.*

### Influences

Normal to me. Sara discussed her sentiments that her sibling and her experience were normal to her. She had a positive attitude about the situation as she recognized that others' lives are different from hers, but she also acknowledged that her sibling and the accommodations that she and her family make for her sibling are their normal. She did not express bitterness toward the fact that there were differences between her lifestyle, accommodating to her sibling with a developmental disability, and others' lifestyles. She expressed without frustration that her family frequently adjusted their plans or goals to fit her sibling's needs, and she thought that that became their normal routine.

*I was probably 8 or 9 years old, so we understood that she you know needed more attention. So it was never something. We never had resentment or anything like that, you know, it was just how [she] is, and I never knew anything different.*

Parents. Sara shared more than once that her parents' relationship and their faith had a lasting impact on how she viewed having a sibling with a developmental

disability. She credited her parents' efforts to facilitate her sibling with a developmental disability in their family environment as being the biggest impact on her experience. She said that these efforts enabled her to understand her situation better and have had a lasting impact on how she views relationships and marriages now. She credited her sibling's progress to her parent's decisions regarding early intervention in her sibling's life. She recognized the struggles her parents faced and the benefits of those struggles. She showed great admiration for the manner in which her parents handled the situation and clearly looked up to their example for working together when facing challenges. She said that watching her parents handle the situation eventually led to her career choice in special education as well.

*I think my parents have done an amazing job always being advocates for her, and that's what has gotten me into the field. I think the reason she has progressed as much as she has is because we do know her rights. My parents have always killed with kindness... They were always well educated and worked together. I do see an impact that it had on my parents' marriage. I do think that that's something just like with any children. But their faith was a firm foundation, which taught me a lot of things now that I'm married, you know, how to approach relationships. I generalize what they went through and how they dealt with things, and I think it's a testimony to their faith.*

*So it was really kind of collaborative, and we all worked together. That was just our norm... But I think that was all facilitated by my family.*

#### Kara: Don't Take Things for Granted

The second participant was Kara. Kara is a White female and was 22 years old at the time of the interview. Kara is the youngest child with an older brother and an older sister. Her older sister is her only sibling with a developmental disability. She was raised in the same household as her sibling with a developmental disability for 18 years. Kara participated in taking care of her sibling while growing up. Kara earned a bachelor's degree, and at the time of the interview



was working on a second bachelor's degree. Kara was married and living separately from her sister; however, Kara lived in the same city as her sister. Kara's sibling with a developmental disability has been diagnosed with hydrocephalus and has suffered several strokes. Her sibling with a developmental disability was impacted in the following life activities listed in the Federal Definition of a Developmental Disability (2000): self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency. Her sibling with a developmental disability lived at home with their parents and was 31 years old at the time of the interview. Her sister had her own cell phone that she used to text Kara, and the two saw each other frequently. Her sister with a developmental disability earned a high school diploma.

### Themes

Lessons learned: a lesson to learn from my sibling. Kara shared a humbling realization that her sister lived a different life than Kara was able to, and Kara said the acknowledgement of these differences kept her thankful for the life she had. Kara felt constantly reminded of how appreciative she should be of her abilities, both mental and physical. She also shared her gratefulness towards the doctors and medicine that help keep her sister as healthy as she can be. Having a sister with developmental disabilities gave her a different perspective on life and the things that many take for granted. Kara said repeatedly how grateful she was for her life because of her sister's influence and the lessons that her sister has taught her.

*My main thing that I learned with her being my sister is just don't take stuff for granted. You don't take the medicine for granted. It's not always going to work. You know, she's not always going to be okay. I mean I hope so. You can hope and pray all*

*day long, but the next day she's in the hospital. You know you pray that nothing like that ever happens again and that she lives a long time.*

*It's made me very thankful for, you know, I used to wake up and grumble that I'm going to school. I think everybody does that. It makes you realize that your sister downstairs, or just the door right beside you, I mean she graduated high school but not with the same capability that we can. She didn't have that option, doesn't have that ability actually... But then it's a very big reality check. You are a lot more blessed than you really think you are, and you need to quit complaining. It makes you very thankful for what you have and just in general... She reminds you- just her presence reminds you how thankful you should be.*

*I know for a fact that if she was not my sister that I'm pretty sure I would be a lot more selfish. I guess I would take a lot of stuff for granted honestly, I know I would. I mean I'm not proud of that at all. I just don't feel like- it's been a lot easier as a teaching lesson for her to be my sister to learn: don't take stuff for granted.*

Kara acknowledged that her sister made life harder, but she believed that there were more benefits to having a sibling with a developmental disability than negative consequences. She thought that her sister's impact on her and others around her was significant. She said that her sister helped to teach them a lesson in humility. She felt strongly that her sister was not a burden despite the challenges that she may have brought to their family, which reflected her optimistic outlook on her experience.

*There are so many more positives. I don't think there's really any negatives, honestly. There are so many more positives that people don't see, and so many more blessings. I mean, she touches people at our church all the time, makes them cry, and everything. She is a very good life blessing and reminder of what our whole purpose of here is anyway... Just the benefit of her being here totally outweighs the so-called burden everyone may see.*

Involvement of spouse. Kara explained that she thought it was important to have a talk with her boyfriend, now husband, before he met her sister. She has already discussed future plans with her husband regarding their taking care of her sister. She spoke with positivity about her husband's relationship with her sister.

She said that they get along very well and that her husband loves to joke around with her sister. She mentioned how tedious her process was regarding deciding to be with her husband, but never discussed her sister's influence on this decision.

*But when he first met her, I think he was still trying to figure out where she was. I had talked about her some and given him a heads up like, "Hey, this is where her mentality is, but you won't really understand her until you meet her, like how she is." But it was no problem.*

*[My husband] loves her [sister], and he'd be more than happy to have [her] at the house. I love that, because you know some people are like that's more responsibility or something to make it harder.*

Pragmatism. Kara had a practical mindset about her situation. She acknowledged that her sister required adjustments to their daily lives. However, she expressed feelings that these adjustments were not an inconvenience. She believed that the adjustments were so ingrained in their schedules and routines that she didn't necessarily think about them. She compared the extra care and attention that her sister required to having a sibling that remains in the life stage of a young child. She expressed clearly that she did not view her sister as an imposition in this way.

*...some people might see her as- I can't think of the word! I guess like an obstacle, makes life harder. And I'm not saying that she doesn't make life harder. I mean you have to set a little more time to make two people like more, make sure that she's fine. You can't always get up and go to the grocery store, if you're the only one at the house. You know to stay there. Burden! Some people think she's a burden. That's the word! I feel like what's the difference in just having a younger child? Anybody can view them as a burden interrupting conversations or anything. It's just like taking care of a younger child, but forever.*

Protective: advocating. Kara shared more than once that her family attempts to make her sister more independent when they are able. She said that they often make her sister prepare her own breakfast cereal and drinks. She and her brother

also frequently encouraged her not to watch “baby shows”, such as Sesame Street, and to instead watch television shows in which the characters talk more frequently. Her sister is also asked to fold laundry. Kara had a very matter-of-fact attitude regarding her family’s efforts to maximize her sister’s abilities. She expressed that they were not satisfied at letting her sister rest in her comfort zone of her abilities and that they wanted to push her to attain new abilities. She felt frustrated that sometimes others did not share their family’s attitude and didn’t push her sister to do tasks for herself, but she claimed that other people just didn’t know she was capable of more. Kara stood up for her sister’s intelligence despite knowing that her sister had a developmental disability. She expressed that she thought teachers in her sister’s school weren’t teaching her as many things as they could and were degrading her sister’s intellect. Kara expressed her awareness that her sister was incapable of some things intellectually, but felt strongly that there were other things she was intellectually capable of that others didn’t know about. She stated that her sister was smarter than the majority of people thought.

*She has a lot more cognitive ability than a lot of teachers thought that she had, and my mom knew that and she was mad that they weren’t trying. They were teaching her how to wash dishes, stuff like that, and it’s like okay she knows how to memorize some Spanish. She knows Spanish pretty darn well, which is crazy. She can do simple math, but she has a hard time writing. Anything you try to teach her with complex ideas or discussion, she doesn’t follow. She knows very basic stuff, like in the math area or Spanish- different areas that you wouldn’t think they get or understand she does really well in.*

*I don’t let a lot of my friends kind of baby her, or be easy with her, because I know they’re not here 24/7. I know that she can do this stuff.*

The future: managing care, living arrangements, & children. Kara and her brother have loosely established a plan for their sister’s future care; however, they

have never had a conversation about this with their parents. She expressed that their parents have never approached her or her brother about future plans. She and her brother both felt that they were willing to accept the responsibility for their sister and each were willing to have their sister co-reside with them and their spouse. Each of them had discussed the possibility with their spouses as well. Kara expressed that she would prefer that her sister co-reside with her and her husband. Although Kara and her brother had talked and formed a loose plan, she felt that they would make decisions and talk more seriously about it when their parents were no longer able to care for their sister. Kara expressed her concern for her future children: if any parts of her sister's disabilities or her mother's complications during pregnancy were genetic. She sought medical advice regarding this, which indicates thinking about the future and pragmatism.

*When I want kids, not any time soon, but when I do that will be in the back of my mind. Nothing is genetic. I've talked to the doctor about it, because I wasn't really sure... I was wanting to know if complications of pregnancy were genetic or if I was having any risk factor of having it, but he said no.*

*They [parents] haven't really sat me and my brother down and said anything. [My brother] has already said like, "Hey if [sister with developmental disability] ever needs to come anywhere, she is welcome to come stay with us for the rest of her life or whatever." I would feel better if she came to stay with me and my husband. So I know once my parents get to the point where they can't take care of her or even if they need help, she's more than welcome to stay at our house, or just live there or whatever.*

*I've mentioned it to my brother, and he's said she is welcome to stay there or it depends on the situation, if she stayed with us for a year or two and then went over there for a year or two. He seemed okay with it, so if something ever happened she was with one of us. That's the most extent that we've talked about it, but I guess when that bridge comes we'll have to make a decision.*

Kara expressed a fear of initiating conversation with her parents regarding the future of her sister. Kara felt that she had more to learn about her sister's

prognosis and future care, but felt intimidated by asking her parents. She thought that her asking could make her parents upset.

*I don't know the life expectancy for her. I don't know if even my parents or even the doctors know, but I would assume just because she has the shunt that she would have a pretty normal life expectancy. That's never been discussed, and it's one of those things that I don't want to discuss with my parents because it's kind of like you're pushing boundaries a little. Because no parents want to see their children die, so I've never asked. But I've always been a little curious, because I kind of wanted to be prepared.*

Guilt. Kara expressed several times that her sister brings out humility and gratefulness in her, but this appeared to come with some feelings similar to guilt. Kara seemed to feel guilty for her attitude after contemplating her sister's situation. She was upset with herself for thinking negative thoughts or ever feeling unappreciative of things.

*She's always excited and happy. And I know she isn't really aware of her problem, and for her to be so happy all the time, it's like why am I always so mad. It's interesting. I think she touches a lot of people in that way.*

Intimate with sibling. Kara displayed a very intimate relationship with her sister. The two of them talked and visited each other frequently. She thought that they had a close relationship. Kara very fondly recalled how often she and her husband go to her parents' house to eat dinner and play games or watch TV with her sister and family.

*We at least go over there once, maybe once or twice a week. We'll eat dinner or something. Sometimes we'll play games with Kristy, or we all like watching The Voice and she'll sit there and watch with us. But it's usually like dinner and TV or a game or something. She'll still text us and ask us, "Where are y'all?" "What are y'all doing?"*

### Influences

Normal to her. Kara expressed that she thought her family and their situation was very normal to her growing up. She recalled that she never felt

negatively about her sister or their childhood, because she didn't realize how different her experience was from that of others. Kara straightforwardly discussed her perception of her childhood as normal. Kara shared that her experience was completely normal to her even now in early adulthood. Although she recognized that she knew other people were not having to make the sacrifices her family was, she felt that her family's lifestyle was all she had ever known personally. She didn't express any feelings of resentment or bitterness toward the situation, only calling the experience "different." She had a positive outlook on her experience and her family's routine adjustments to complement her sister's needs, including the fact that she plays the role of an older sibling when in fact she is younger than her sister.

*... I never looked down upon her. It was just- I don't know how to explain it- like I guess I just felt like it was normal, you know. I didn't think that- I mean, I know that other kids didn't have siblings that had cognitive disabilities, but for us it was normal. So I didn't think anything was abnormal about it.*

*I mean people ask me, "Is it different being the younger sibling taking care of your older sibling?" It is different, but it's never been any other way so it's normal for me.*

Parents. Kara was very admirable of her parents' efforts on behalf of her sister. She discussed the fact that they knew her sister was going to have serious disabilities before birth and chose not to abort the pregnancy. Kara says that if in the same situation, she would do the same because she believes in the same principles that her parents did and has witnessed their experience in parenting a child with a developmental disability. Kara was very aware of the battle her parents faced in rearing her sister: in coordinating their work schedules so that her sister was never alone, not finding adequate special education in the public school system,

her mother having to become a special education instructor, and the testing of their faith.

*She [mother] went back to school, because [my sister] got into, I think, elementary like 3<sup>rd</sup> or 4<sup>th</sup> grade, and the teacher was like, "I don't have time for her." My mom was like, "Excuse you?" So she went back to school and got her special education degree here [University of Mississippi], and she started teaching at Tupelo. She didn't like it at Tupelo, because they were mixing the kids with discipline problems with the ones that had disabilities.*

*It shows their faith, their Christian faith, and how they value things in life. I wouldn't change my parents for anything, or the situation at all. I look up to them.*

Kara believed that she had learned a valuable life lesson through her mother's experience in having a child with a developmental disability. She thought that now she knew that life is not always fair and that she should always be prepared for an undesirable outcome in situations. She expressed that her mother had given her advice on multiple occasions to this extent. Kara didn't have a negative attitude as she expressed that she had learned this hard life lesson, but instead she seemed to believe that it was just true of life and it was better for her to recognize that sooner rather than later.

*Like my mom, you're not always going to have the best outcome. Don't expect or assume everything is going to be okay. Always be prepared for the worst, even if it comes out the best. Always be prepared for the worst.*

#### Harley: Brotherly Love

The third participant was Harley. Harley is a White male and was 22 years old at the time of the interview. Harley is the oldest child with a younger brother. His younger brother is his only sibling with a developmental disability. He was raised in the same household as his brother for 18 years. Harley participated in some aspects of taking care of his brother while growing up. Harley earned a



bachelor's degree, and at the time of the interview held a job. Harley was single and living separately from his brother, approximately 9 hours away. Harley's brother has been diagnosed with Down syndrome. His brother was impacted in the following life activities listed in the Federal Definition of a Developmental Disability (2000): self-care, receptive and expressive language, learning, mobility, self-direction, and capacity for independent living. His brother lived at home with their father and was 20 years old at the time of the interview. His brother had his own cell phone that he contacts Harley with daily, and the two saw each other occasionally. His brother was working on earning a high school diploma at the time of the interview.

### Themes

Intimate with sibling. Harley thought that he is the closest person to his brother and felt that he is frequently there for him for advice. Harley described his relationship with his brother as being very close and dependent. He said that he helps his brother to make decisions. He described his role as a confidant and adviser for all things in his brother's life, and he feels responsible for maintaining that role. Harley reported that the two of them talk every day on the phone or FaceTime. Harley believed that his leaving for college was an experience that really highlighted how close they were. The dyad adjusted to talking on the phone every day instead of in person. Harley had his brother come stay with him more than once in college, because Harley wanted his brother to get to see what his life was like. Harley explained that they are similarly adjusting to his living 9 hours away now for work.

*It was tough at first. He called me a lot. He has a cell phone, which by the way he can operate masterfully. He called me a lot, like every single day. It took him a while to really kind of grasp what I was doing there, why I left, why I wasn't coming home every day. Then it just became that he wanted to do it too. He's always looked up to me and always kind of wanted to do what I'm doing. Then he got it in his mind like, "Well I want to move out and go to college too." The hardest part was him understanding what I was doing and why I was there.*

*But it's another thing having to explain why I'm so far away and why I don't get to see him as much. The thing is now he's 20 years old, so he tends to understand real world concepts a lot better. So he understands that I'm out here working and the reasons, but it's definitely even harder than when I went to college just because, like I said, I'm his primary person that if he has something he wants to tell somebody, he wants to tell it to me. We're both kind of having to adjust to being able to do that on the phone a little bit better.*

Lessons learned: a lesson to learn from my sibling. Harley remembered having to adjust to having a sibling with a developmental disability. He called this a "huge learning curve". He recalled his parents having to assist him in gaining patience and adaptability. He thought that it took extra patience to handle the situation, and that this patience was something he had to work towards having. He claimed that this patience is one of the most prominent gains from his experience and something he still benefits from currently in early adulthood.

*So I definitely had to learn a lot of patience, kind of adaptability to that situation. You know, I didn't know anybody that had a sibling with Down syndrome. I didn't know anybody with Down syndrome, except him. So it was all brand new to me, and it was all brand new to my parents as well. So it was kind of a learning curve, adapting to that situation, and kind of having to understand that most things aren't going to come easy. It's going to take a lot more time and patience and a lot more work for him to accomplish the things that somebody his age normally would. That's pretty much how it always was. It was just kind of having to learn to slow down. The patience was the biggest virtue, or attribute, that I had to learn.*

Guilt. Harley reported feeling guilty about leaving for college, even though he remained close, because he knew his brother always wanted him around. Harley said that the dyad has experienced even more difficulty in adjusting to his now

living 9 hours away. He said that he moved strictly for the purpose of a job and that it upset him to be so far from his brother. Harley felt guilty that he was not around to help his brother and be there for him.

*I always felt guilty, just because I knew that he always wanted me around. It's best for him when I'm around, because I can understand him better than anyone else can. I always take the time more than anybody else will with him. So I feel like he develops a lot better, and he learns a lot more, and I feel like he performs a lot better in the world when I'm there to help him, help guide him through. So I've always felt kind of guilty about that.*

Protective: advocating & concern. Harley thought that college was a significant decision in his life and that his brother heavily impacted this decision. His parents had opposing views on whether or not Harley should go far for college or stay near to home for the sake of his brother. He chose to stay close to home for his brother, because he had concern that his brother would not handle well Harley's leaving to go to college far away. The transition was tough for the dyad, since they are so close to one another. He has never regretted his decision to go to college close to his brother and said that he believes it was the right decision even when he looks back on it.

*And a big part of that decision was because of [my brother]. I didn't want to move too far away from him too fast just because, like I told you, I'm a huge factor and influence in his life and it was going to be tough enough for both of us to be apart the majority of the time, but I definitely didn't want to do anything too rash and go too far away. So I made the decision to stay in state.*

Harley knew that he was his brother's role model and best friend, so he tried to nurture their relationship even while he was away in college. He invited his brother to come spend the weekend with him and introduced him to his friends. He wanted his brother to be able to see what Harley does at college and also to be able to feel included, since Harley knew his brother wanted to be in college with him.

Harley expressed his concern for his brother through his worrying about his brother once he left for college and worrying about his brother when meeting new people or going new places. Harley described some of the great efforts he made to facilitate his brother into his social life to help their transition. He invited his brother to stay with him in college and to meet his girlfriends. Harley described doing his best to advocate for his brother and the other parties to prepare for their meeting. He said that the social encounters have been a significant experience for his girlfriends and friends and that they have expressed nervousness to meet his brother.

*Me, being a little nervous and [my brother] excited, because he's always wanted to get to do what I do. He gets really excited and overly amped up over these things. I was nervous that my friends were going to freak out. Before that I had to kind of sit down with them and explain to them what it was going to be like and what to expect and how to deal with that situation. That was a really interesting experience, just because introducing somebody to that, I think, is a pretty significant deal in their life. I've always grown up around it, so it's not that strange to me, but that interaction with somebody with Down syndrome for somebody who has never been around it is a pretty big deal.*

*Sometimes I worry that Spencer gets too excited and a little too aggressive with people, by aggressive I just mean like overly excited, and I'm always kind of afraid that that will freak them out a little bit.*

Harley's concern for his brother was also apparent when he discussed his brother moving to another city to attend an Access program. His brother had been recently accepted into the Access program for persons with disabilities that helps them to gain skills for contributing to society and living independently. Harley's parents recognized Harley's level of concern and did not tell him that his brother was applying to the program in order to keep Harley from getting his hopes up or becoming stressed.

*My parents actually didn't tell me about it until after his first interview, because they didn't know how qualified he would be for it. They didn't want me to get*

*really excited, and then get down about it if he wasn't qualified. So they kind of waited a ways into it before telling me about it... They just didn't want me to stress out about it.*

The future: managing care, living arrangement, & financial responsibility.

Harley expressed that he has a loose plan for his future regarding his brother. He wanted his brother to be able to gain independence to the best of his abilities.

Harley intended to be responsible for his brother and was willing to co-reside in some capacity some day. As Harley described his brother's abilities to care for himself, he said that he thought that his brother living on his own with supervision was possible. Harley had clearly given thought to his brother's future and his own involvement in his brother's care. Harley said he intends to assist financially with his brother's care and to live within a very close proximity to his brother.

*I mean the plan was always to find a way for him to learn to work and live independently and contribute to society, but there was never an institution that we knew of where he could do that. So once we found out about the Access program was a real blessing, and we are really, really excited that he met the criteria to be able to be a part of it.*

*Yeah, I mean my plan, and it has been for a while, is to hopefully, eventually by the time I'm 30 or so to be in a position, you know financially stable enough and things like that, to be his primary caretaker. The goal is to buy a house with like an apartment over the garage, or maybe buy two houses one a lot smaller, just so he can have his own place and take care of himself and live as independently as he possibly can, while I can still be nearby as a support system.*

Influences

Normal to me. Harley said that he thought he had a normal childhood. He reported that he and his brother were able to do some physical activity together, such as playing games outside, once his brother eventually developed his physical and coordination skills. He recognized some aspects of his family's situation that were different from his peers, such as he and his parents assisting his brother in

dressing and bathing. While he acknowledged that this kind of extra care and attention have always been required, he said these didn't have a lot of effect on his life being normal in his eyes. Harley shared that his perspective on their situation being normal to him has been sustained in his early adulthood experience.

*To be honest, looking back from my perspective it was a pretty normal childhood given the circumstances.*

*What I always try to tell people is that you don't have to interact in any kind of special or different way, just act as if he's a normal person, which you know he is.*

Parents. Harley's parents got divorced during his childhood, and Harley said that has had an impact on his relationship with his brother. The dyad traveled together between parents, and Harley said that he did his best to facilitate his brother's development during the divorce. He said that he did his best to explain to his brother what was happening and what life would be like after the divorce. Harley said the divorce was a contributing factor to their close bond.

*Our parents got divorced when we were younger, so that definitely drew us a lot closer. We've split time between our parents, like one week with mom and one week with dad, back and forth like that, but since me and him were always doing it together, I think that's what kind of established our bond so strongly because we were kind of in that together.*

#### Brad: All I've Ever Known

The fourth participant was Brad. Brad is a White male and was 25 years old at the time of the interview. Brad is the middle child with a younger brother and older sister. His younger brother was 15 years old, and his older sister is his only sibling with a developmental disability. He was raised in the same household as his sister for 18 years. Brad reported that he did not participate in taking care of his sister while growing up. Brad's highest level of education was some college, and at

the time of the interview held a job. Brad was single and living separately from his sister; however, he lived in the same neighborhood as his sister. Brad's sister has been diagnosed with Angelman syndrome. His sister was impacted in the following life activities listed in the Federal Definition of a Developmental Disability (2000): self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency. His sister lived at home with their mother and was 31 years old at the time of the interview. The two saw each other frequently. His sister earned a high school diploma and was a part of a daily program for individuals with disabilities.

### Themes

Intimate with sibling. Brad expressed that he is very close to his sister and that the two of them see each other almost every day. He said that he frequently goes to his mother's house to spend time with his sister. He also expressed that the two have fond feelings towards one another.

*I do see her almost every day. You know, I don't live with them. I do see her almost every day.*

*But she is happy to see me everyday when I see her.*

Pragmatism. Brad expressed a very pragmatic perspective on his experience and his situation having a sibling with a developmental disability. Brad did not think that anyone is to blame for his situation, and thus he took a very practical outlook on and approach to dealing with the situation. He expressed that he thought the situation is what it is and that there was nothing to be done to change it now. He discussed the practical ways in which he and his family have altered their routine to accommodate his sister and her needs. Brad talked about the

adjustments that he and his family have made to their lives in order to help fit his sister's needs. He reported that their family works very well together and often all take shifts in being responsible for his sister's care. He said that frequently one of them would tend to his sister so that another family member can go participate in an activity. He described their procedure for handling big groups of people, such as shopping centers and family gatherings. He said that for family gatherings, he or his mother will bring his sister after the rest of the family has eaten dinner and the bulk of the activity is over so that his sister will not become overly stimulated. Brad also displayed a pragmatic attitude as he discussed how grateful he is for the abilities his sister does have. He acknowledged that realistically the situation could be much worse. Brad expressed his appreciation for the fact that his sister was able to graduate from high school and walk in the graduation ceremony. He acknowledged that many people in her situation would not have been able to do that, and he said he is grateful for that now even though he was too young to realize the significance of it at the time. He also expressed gratitude for the physical abilities that she is able to do, like walking. He was very realistic about the difficulties that they do face with her situation, but was not lost to the fact that she has more abilities than others with disabilities.

*I was really the only person that had a sibling with a developmental disability, which is perfectly fine for me. I was not ashamed of her. Um, I didn't look down upon her. I didn't feel guilty, or I didn't want to feel sorry for her, or anything like that. I was perfectly fine with it, and I still am today. You know as far as people looking at people a certain way with disabilities, it's really a shame because you know it's not a choice there is. There isn't just one day that they wake up and say you know I think I'd rather be disabled than take care of myself.*

*I don't really feel guilty, because I guess because I don't think it's anybody's fault. You know, I don't think anybody kind of did this to themselves, or anything like*



*that. It's just the hand we were dealt. Like I said, for me it's all I've ever known, so it all just came naturally.*

*That's one reason I've never felt guilty, never felt ashamed to have a sister with a disability. For me I think it's always, I wouldn't say it's been an advantage, but I don't really look at it like it's a problem, you know what I mean. It's just how it is. I embrace it. I'm happy to have her, and I know she's happy to have us. So I don't really think that um... I'll put it like this: if I could go back and kind of pick and choose how life was, I don't really think I would change anything... we love her to death and wouldn't trade her for anything.*

*We really don't carry [my sister] to like Wal-Mart a lot, or out in public a lot of places, not because we don't want to, but she will get really excited when she gets like in a big crowd. More or less I think she just doesn't understand what's going on, and sometimes she'll get so excited she will cause herself to gag, and she'll just kind of stress herself out.*

*I will say for her personally, there are a lot of Angels [persons with Angelman syndrome] that we know about and are confined to a wheel chair. And she is not, so we feel very fortunate that she can walk on her own, because having someone in a wheelchair on top of not being able to talk and not being able to kind of explain yourself is you know, it just makes things harder. There's really no nice way of putting it, but it's just not great for anybody. We are definitely fortunate that she can walk on her own and get around on her own.*

Lessons learned: a lesson to learn from my sibling & something for others to learn from my experience. Brad mentioned multiple times how thankful he was for different aspects of his experience. He had an apparently genuine gratitude for his experience and reflected positively on his sister and their situation. He did not express frustration or bitterness. He believed that he has gained something on a personal level from having a sister with a developmental disability, and he said that he thought others have something to gain from the experience as well. Brad expressed gratitude for the research being done by the researcher. He said that he thought that not enough people know of experiences like his and that others could benefit from a better understanding of these experiences. He said that many people

don't acknowledge situations like his because it isn't their situation, but he believed that it could help people both like him and unlike him to have this research available

*...I consider myself a very humble person, because I appreciate everything that I have. I appreciate my mom. I appreciate my dad. I appreciate my sister. I appreciate everybody, even the people that I see from time to time and may do the smallest thing for us. There are still people today that I have no idea who they are when I see them, but they'll ask me how my sister is doing because they taught her in school or she went to daycare with them or they've got a son or daughter her age so they knew of her. So you know, you find people that are very caring...*

*I do think we all could learn something by living a day or two with somebody with a disability and seeing how life is with that and really just kind of seeing for the most part, like yourself, that might not have a sibling with a disability to understand and see just how life- you don't know how that life is until you're put into a position to where you know somebody else is dependent on you no matter what. And I'm not saying it's a bad thing. It's not, but it's just more- I consider it knowledge. You know, it's more knowledge for somebody to have to understand what it's like to have to go through life like that.*

*...but I am really glad that you did choose this topic. Um it's really an area that is overlooked in a lot of people's minds. A lot of people don't really pay attention to it. They just kind of turn a blind eye in a way, and I don't think it's something that should really be turned a blind eye to.*

The future: living arrangements and managing care. Brad said that he has never discussed the future care of his sister with either of his parents; however, he did mention that the topic is something that he should discuss with them soon. He did not seem compelled to be responsible for his sister at any point in the future, but hinted that he would always be involved in some capacity. Brad thought that his aunts were the more likely future caretakers for his sister, and he did not seem to feel any negative feelings about not intending to assume that role. Brad also discussed how his sister had influence on his job selection. He believed he should work in a job that allowed him to set his own schedule so that he would be available

to help with his sister at any time that he was needed. It was clear that Brad had put some thought into his sister's future.

*It [the future] does cross my mind quite often, honestly. My mom has had a few health problems in the past few years with her heart... So it is something I definitely need to talk to my mother about. I do feel that if something was to happen to my mother in the near future, I think one of my aunts would more than likely take [my sister] and take care of her, because oftentimes when we go out of town or have to go somewhere that [my sister] just can't go with us or something like that, my aunt, or one of my aunts, will watch her or she'll go spend a week with her in the summer or here and there.*

*And I don't think my mom wants necessarily to put that burden on me. I don't want to say it's a burden, but you know I don't think she wants to kind of... You know, she understands that I'm young and still growing up... And so you know, it's something we'll have to talk about in the near future, but that's not something that we have talked about. I think we've mentioned it once or twice, and it kind of gets blown off to the side. But for the most part, I will say that I will definitely not be alone if something was to happen.*

*...so if I have to take off work one day, I can do that. Which is another reason that I wanted to work for myself. I kind of wanted the freedom of being able to- I won't say take off, because I don't take off very much, because like I said, I'm a work-aholic- but if I had to go do something, I don't have to answer to somebody you know as far as me working at like a Wal-Mart where they'll give me like a strike, you know. You know, it would be kind of hard to hold a job like that. You know, things happen...*

*...I do make a lot of decisions based upon my family and how they will or will not affect my family. I do try to do most everything with them in mind.*

### Influences

Normal to me. Brad expressed how normal his life has felt to him. He said that growing up they went to dinner as a family, did activities as a family, and went on vacation as a family. He said his sister frequently came to his sporting events. He reported that the fact that others in the community all understood their situation and that they were supportive helped him to view his experience as normal. He strongly believed that his family lived like a normal family.

*...when you have anyone in a family with a sibling with a disability, it can only be one of two ways: 1) they're either older or younger than you. In some cases, where they [the sibling] are younger, it might be different than in cases like me where my sister is older. For example what I mean is: for me it's all I've ever known. You know I can't say that my life was going great, and then, you know, I had a sibling born with a disability, and my life has changed. For me it's all I've ever known, so everything that I do has quote unquote come naturally. It's just always been the same no matter what.*

*I mean that's what we say: she's normal just like any of us; she just can't talk.*

*For the most part, like I said, I just kind of consider us a normal family. We do most things like any other family would do.*

Parents. Brad discussed his parents' influence on his experience. He recalled their efforts to manage his sister with minimal help from him. He didn't remember helping much around the house with her growing up; however, in early adulthood he often goes to his mother's house to help keep his sister so that his mother can get things done. He said that his family still has to work very hard, and he sees his parents, now divorced, still working together.

*My parents did struggle for many years with school systems and governments on what they would allow her to do and not do. I will tell you they did not back down as far as giving her every right like any other child to participate in anything that anyone else would.*

*You know, I can go down there and help her [my mother]. That's not a problem. I don't mind at all. Every now and then I think mom will feel a little guilty for asking me to come down there and watch her, and I'm like, "Mom, you know just ask. You know I don't know that you need my help for anything unless you ask me." I don't mind going down there and helping, you know, or anything. It's just, I don't live there, so you know, I don't know that she's going to need help.*

Regan: He is the Cause, and I'm the Effect

The fifth participant was Regan. She is a multiracial female and was 22 years old at the time of the interview. She is younger than her brother, who is her only sibling with a developmental disability. She also has two older half-sisters. She was

raised in the same household as her sibling with a developmental disability for 18 years, or until Regan left for college. Regan participated in taking care of her brother while growing up. Regan earned a bachelor's degree, and at the time of the interview had been hired for a job but not begun work. Regan was single and lived with her sibling with a developmental disability at the time of the interview. Her brother with a developmental disability has been diagnosed with cerebral palsy and intellectual disability. Her brother was impacted in the following life activities listed in the Federal Definition of a Developmental Disability (2000): self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency. Her sibling with a developmental disability lived at home with their parents, and at the time of the interview he was 30 years old. She was in daily contact with her brother. Her sibling with a developmental disability was regularly attending a program geared for persons with disabilities at the time of the interview and had earned a high school diploma.

### Themes

Pragmatism. Regan talked about several of the adjustments in her life that she has made on behalf of her brother that have marked her experience. The most prominent adjustment she reported was the difficulty in coordinating care for her brother. She shared several instances of her brother being an obstacle to schedule activities around. She reported feeling that she and her family were constantly having to ask themselves who will watch her brother and when. Although Regan conveyed a feeling of stress or anxiety about the situation, she did not convey negative feelings towards her brother. She appeared to have a pragmatic approach

to helping care for her brother and adjust her schedule for him. She was willing to do whatever she needed to in order make the accommodations that were necessary for her brother.

*It was always a coordination of who's home. Like, Regan you need to go home. Like today, I'm picking up [my brother] from his day center because my mom works until four, and when I'm here it's a great help because we don't have to pay someone else to pick him up and take him and sometimes she's not available. It's always asking when and who is going to be home and you can't leave without someone knowing, because someone has to be here with [my brother] or you have to take him with you. Then it's: can you take him with you? Everything we do is always a question of like who is going to watch [my brother] or can we take him or how is this going to work? For example, for my graduation: I wanted him there for my high school graduation and we had to take a babysitter just in case he made noise to take him out in the back, and like it was this whole operation just to have my brother at my graduation.*

Realizations. Regan spent much time talking about the realizations that she had in college that she missed out on the experience of family vacations and independence while growing up. This was an accommodation that her family made in order to better meet her brother's needs. She believed that she, her mother, and father were able to venture on a few family vacations, but she believed the majority of vacation opportunities were missed because of her brother's situation. She expressed the difficulty in finding care for her brother while they travel and the fact that when they were able to travel, many times they were unable to relax because her brother still needed to be cared for. She appeared to look back on missing these experiences with regret and possible frustration. Regan said that college was the first time she truly had the entirety of her independence, because prior to college her life was centered on accommodating her brother. She reminisced on her freedoms in college: being able to dictate her own schedule, being able to leave for an activity on a whim or late notice, and being able to choose what she does without

consulting others. Regan said she did not realize her lack of independence until she was among college peers and her newfound college freedom. Regan expressed that now that she is back home after college, she has had to re-adjust to not being able to enjoy the freedom she had in college. She reported that she is now back to putting her brother's care as the priority in her scheduling her time and choosing activities.

*...[My brother] wouldn't always come. I think we did end up going one Christmas. The only time we would really family vacation is to go back to Jamaica during Christmas time, because our help, our old nanny, would be able to take care of [my brother] and that's when it's like it's almost a true vacation. Because my parents won't have to- like no one has to be taking care of him necessarily and we have the help there that we can afford. You know we couldn't just take someone with us and [my brother] to Europe or I don't know... the national parks of America, or like there was just never an option to go on family vacations and that was something that I remember very clearly.*

*So I think I took that for granted because my independence is something I just actually really never had until I went to college, and then I could just do whatever I wanted whenever I wanted with no one asking me. That was really cool for me, and I loved it. I think that was something that was a huge difference that I didn't realize. The responsibility of having another human rely on you is something that I think not very many people, or my peers, completely understood...*

Choosing college. Regan reported that her brother did have an impact on her college decision. She thought that college was a time that she should take for herself to grow and learn before having to commit to being the primary caretaker of her brother. Therefore, she chose a school out of state. In this instance, her decision was not based on her brother's current situation but his future situation. She reported feeling guilty about the choice to go far away for college, because she thought her mother was struggling to care for her brother without her.

*I think college was the time that I could take that I didn't have responsibilities for [my brother] yet... that I would be able to kind of take that leap and go away for a while. Because I knew in my head that I would maybe eventually have to come back.*

*My parents kind of gave me the approval: "You do whatever you want to do, Regan. You go far. You go out of state. We want you to go to the best school you can go to." That was always encouraged. I think the fact that I got my parents to support it, who were the caretakers of [my brother] and myself, was why I felt comfortable doing it. And I think because I knew my parents were healthy and they're doing pretty well, at that time, I didn't feel an urgency to be close to home because they were there for [my brother] and they are his primary caretakers. Um, and I did feel... and sometimes I did feel guilty that my mom was really tired and she doesn't always have the extra help, because my dad does travel a lot.*

*I think they [parents] wanted to make sure that I could have as normal of college experience as possible, and they always made it work for me, which I was very grateful for.*

The future: managing care, living arrangements, & financial responsibility.

Regan was aware of her status as next in line for her brother's primary guardian, and she expressed a sense of responsibility to fulfill that role. She had taken the time to ask herself many questions concerning the future and plans for her brother's care, but thought that she still had time to decide. She stated that she fully intends to take care of her brother and expressed concern at his ever living in a group home or institution of any kind. Regan expressed feeling extensive pressure to figure things out for her brother's care and to have the money to provide for him financially. She shared more than once that she is keeping money at the top of her priority list in job seeking so that she can provide for her brother. Regan was very willing to put her brother's needs before her own needs or desires. Regan expressed that she felt less pressure to choose her college based on her brother and their situation compared to the pressure she feels in choosing where to live and what job to choose after college. She said that she knows this is limiting to her independence, but she did not seem to resent that fact. She reported that her parents were older and that she believed that her taking care of her brother as the



primary caretaker was becoming more of a reality than a far off idea. She had taken the time to contemplate her many options and how each would affect her brother, but she thought she still had some time before she needed to decide with certainty on many things. She had decided on a job in California, because she believed that she still had a few more years of freedom before needing to start taking care of her brother as his primary caretaker. She expressed that in choosing this job she realized that she cannot afford to chase some of her passions at this time or ever because of her feeling responsible for her brother. She expressed her feelings of obligation to earn enough money to provide for her brother, and she said this played a large role in her choosing her new job.

*My mom is the primary guardian right now, but if like she goes or isn't around, after her it's me. I remember going through the paper work with that. And so that was right before college, and so that was something that was kind of a stressor definitely in the middle of college.*

*My priority is feeling comfortable in making the next steps that I can make to support him [brother]. So yeah, I'm going to take a better paying job over maybe a cool unique job traveling around Europe. I'm going to take the higher paying job that's in America, because its closer to my family and its more financially sound, and it can help me almost, if anything, have a higher and higher salary. I feel almost guilty for thinking that way and thinking that you know I want to get a job that pays a lot. I hated that idea. I'm the most "Follow your passions. Do what you love. Like live through your experiences" type of person, but I also realize like what is my passion? And my passion is my brother and making sure that he's okay always.*

*[My brother] is becoming a factor now to be honest with you. It's very present right now in terms of: where am I going to work? What job am I going to take? What schooling am I going to get next? What city am I going to live in? If I ended up in this city permanently and for a really long time, by the time my parents pass away, will [my brother] come here? Will [my brother] stay in Florida? Will I go back to Florida? Like it's all these different factors now, I think, that are playing the bigger role than where I went to college... I always have to think about [my brother] whenever and whatever next step I have to take.*

*I guess I don't have like an open field of options. I have that for a limited amount of time. I think something that is kind of unsettling to me is that I know that*

*eventually I will have to make decisions based off my ability to take care of [my brother]. I think a lot of my decisions now are definitely motivated by: Is this going to help you take care of [your brother]?*

Guilt. Regan expressed how much of an impact her mother has had on her experience by always trying to allow Regan to have opportunities despite her brother's situation. Regan said that her mother tried very hard not to ask Regan to care for her brother so that Regan could leave the house and do activities that were important to her. Regan expressed deep gratitude for her mother's efforts and also guilt at not being able to help her mother more. Regan also expressed anticipating guilt about going away for her new job.

*...but my mom seems to always put my very basic, very ultimate needs or like advantages to make sure it will work- like she always makes it work, if something is very important. Whether that's going to college, or me being able to go babysit and earn money, or go do something to earn money, rather than watch [my brother], she'll always make it work, which I am also very grateful for. I do help out as much as I can when I'm here, which I feel like I should because I am leaving soon and I won't be here to help out as much. So I try to give her a break as much as I can while I'm here. So maybe I won't feel guilty down the road, but I don't know...*

*...and sometimes I did feel guilty that my mom was really tired and she doesn't always have the extra help, because my dad does travel a lot.*

Protective: advocating and concern. Regan defended her brother's intelligence despite knowing that he has a developmental disability. She talked about his ability to remember car routes and distinguish between the correct route home and the incorrect route home from his day center. She expressed humor at his distinguishing between the two routes and his reaction to knowing they were on the incorrect route home. She thought that a sign that his intelligence is greater than others believe is because he is able to understand spoken word and follow instructions to a certain extent. Regan also expressed that she is protective over her

brother in regards to his care, which made her concerned about the possibility of his receiving care in a group home someday.

*He does make eye contact with you. He's not like not present. I really do believe that something is, you know, he knows more than you think. Just because he can't communicate it with you- there's like little things. You know, I'll talk to him and tell him to close the door of the car, and he closes it. He like takes some time, but he'll do it himself. I'll talk to him. He knows the way home. It's really funny on the way home, if you take this right instead of a left to go to like Starbucks or Publix to get something, and he'll scream in the car and freak out. All I have to do is tell him where I'm going and why I'm going there, and it's really funny.*

*I think I'm protective, like possessive of him [brother] as well. And just the idea of me being so far and not having a say over anything in his life made me uncomfortable, and I think that's something that I'm really figuring out right now and deciding having to do day-by-day and also trying to think ahead so that I'll be prepared. That's hard to do, because you just don't really know what's going to happen.*

Lessons learned: a lesson to learn from my sibling & something for others to learn from my experience. Regan expressed a deep gratitude for her brother and their situation helping to influence how her personality has flourished in early adulthood. Regan said she believes that she would not possess the positive qualities that she does if she had not had a sibling with a developmental disability. She gave her brother credit for making her the person she is today. She was very emotional when talking about her experience, and she was very appreciative of how the experience has affected her.

*And I love taking care of people, and that's like how I show love is taking care of people. And that's something I definitely have noticed especially in college is that that's kind of how I can speak love to other people is by taking care of them. I think that's in huge part due to [my brother], of being able to take care of him because I can't tell him that I love him. I can, but I don't know if he knows from words. So I think that translates to my personality of always trying to be as strong as I can be.*

*It's a lot due to [my brother], and I think my confidence level and the drive I have to be successful. I think it's mostly due to him in my life and being able to do a lot*

*of things that I wouldn't have- I just don't know what I would have been like without him.*

*[My brother] is a huge part of who I am, and he is my normal in that he is one of the things that has made me who I am. He's probably one of the biggest, or the biggest that has made me who I am. And I really like who I am right now, and I like, I don't think I would change it. I don't know. If [my brother] was different, then I would be different... We are definitely related. Well at least he is the cause and I'm the effect. So whatever he would have been like, ultimately I think I would have ended up being like. So certain qualities that I really value in myself, like being able to take care of people, being passionate about things, being confident, or being vulnerable, and being sensitive, extra-sensitive to people, and being so aware, socially aware of what's going on around me. All these different qualities that I really value and that make me "me" are directly related to [my brother] and my relationship with him. Being able to be mature at a very young age was something that everyone always pointed out in me, and I know that is something that I know is due to [my brother].*

Regan expressed her appreciation for research on the topic of siblings of individuals with developmental disabilities. She said that she has gained something from her experience and that having a sibling with a developmental disability has certainly affected her development. She implied that others have something to gain from understanding her experience. She reported that she had done some reading on her own on the subject, but wished there were more resources available to her and others in her situation. She said she believed that her experience with her brother affected her development and personality, and she expressed that she is interested in finding more research on that topic.

*I've read a lot about it, like siblings with disabilities, like half-siblings with disabilities, because I was always very curious as to like why I developed the way that I did. I had an interest in that I can remember especially in college, like trying to understand why and how I thought. I remember reading different articles about it as well, so I'm very interested. I would love to hear the rest of your thesis. But that was definitely something that affected my development.*

Misunderstood. Regan expressed that at multiple times in her life, especially in early adulthood, she has been in a situation that her peers did not understand.

Regan felt that she was an outsider in elementary in middle school when her peers were inquisitive about her brother, and she thought that she was the only one who had interactions with a person with a developmental disability. This feeling continued into early adulthood, but it manifested in a different way. Now in her life, she reported that she feels that her peers do not understand her situation of needing to be the caretaker for her brother some day. She believed that she should make financially smart and location savvy decisions now regarding her career in order to best provide for her brother, and she thought that her peers do not understand this obligation because they are not in her situation.

*...my close peers, at least that I can speak on behalf of, they didn't really understand sometimes the responsibility that I carried with knowing that this is someone that I'm going to be taking care of for the rest of my life.*

*I'm still so sensitive about it in terms of just talking about [my brother] and talking about my relationship with him. It's something so personal, and I think its personal because it's affected me so much and it still does. It will always affect me...*

### Influences

Jamaica. Regan's mother founded a school in Jamaica, where Regan was raised until she was 10 years old. Her mother founded the school, because there were minimal resources available in Jamaica for individuals with disabilities. Regan reported a heavy influence on her by being around this school so much as a child. She expressed that her family's involvement in the school aided her feeling that persons with disabilities were normal to her. Other influences from her life in Jamaica included the fact that in Jamaica her family had live-in help for her brother, so that moving to America and losing access to full-time help had an impression on her experience. Also Regan recalled that in Jamaica there were little to no resources

for persons with disabilities, so moving to America was also a significant change in that many more resources and a different attitude regarding persons with disabilities were present.

*And because [my brother] is 8 years older than me, I grew up going to the school. And it was founded the same year that my mom was pregnant with me, so I was kind of raised at this school with people that have disabilities from severe, like [my brother] is definitely more on the severe spectrum, to people with just minor intellectual disabilities, or just more common syndromes such as Down syndrome. So that was the kind of priming of my development. The first people I interacted with were people with disabilities, were children with disabilities.*

Influence of adolescent years. Regan said that her early adulthood experience has been affected by the fact that she spent a portion of her adolescence embarrassed of her brother. She recalled that the embarrassment began when she and her family moved from Jamaica to the United States. She thought that more people noticed that her brother was different because their family went to public places more frequently with him due to their eventual lack of full-time care for him. She believed that this embarrassment was caused by her peers' lack of knowledge of and exposure to persons with disabilities. Regan shared two very important experiences as having helped her progress through her embarrassment of her brother: joining the Best Buddies organization and a certain speech she gave in school. Regan thought that these two experiences were what helped her to achieve the mentality she has in early adulthood regarding her brother and their situation. Regan joined the Best Buddies organization in middle school. Best Buddies is a club that volunteers with individuals with disabilities. Her involvement led to her eventual leadership in the organization. She shared that this increased her confidence so that she could also participate in and lead other organizations. In

middle school she was tasked with writing a persuasive essay, and she chose to write against the inappropriate use of the “r-word”, retard/retarded. She was ultimately encouraged to read her essay aloud in an assembly at her school. She recalled that this was the first time she voiced aloud her support of her brother and all persons with disabilities. She said that this initial standing up for her brother in her speech and the support that she received were what have allowed her to have the confidence to continue advocating for him now in early adulthood. These two experiences greatly impacted her relationship with her brother for the better.

*I think that was one of the first times that I was very overwhelmed, and I didn't know how to comfortably and confidently explain what was going on. And my peers were younger and hadn't really experienced or interacted with people with disabilities before. So during that period I remember just being very embarrassed and not really talking about it and it being something kind of very personal to me that I lived with but no one really knew about.*

*...I joined Best Buddies and that was a really big turning point for me in terms of viewing [my brother] as a very positive person in my life versus a negative. So it was cool for me to be able to see that other people wanted to interact with people with disabilities and wanted to understand them and wanted to care for them. It wasn't just a negative. Because I think that until that point, I had always seen it as a negative from other people not a positive. And so when I joined Best Buddies, I realized that this is something that I can do to help other people.*

Normal to me. Regan expressed that her experience was normal in her eyes. She stated that her life with her brother is all that she has ever known. Regan shared more than once that she thought that her experience was very normal. She believed that interactions with persons with disabilities were very normal for her. Her reluctance to open up about having a brother with a developmental disability and her feelings that her brother was her version of normal, led to her never having contemplated her experience compared to others' experiences until college. Regan described her college experience as very eye opening in regards to how different her

life had been compared to that of others. She expressed neither happiness nor sadness at this difference.

*I knew that he had- that he was different, but it was also very confusing, I think to me, because he was my brother and I recognized that it was normal to my family, but then I also started recognizing that it was different to others.*

*I think just in general in regards to like the experience of having someone with a disability is that I didn't really think about it until I went to college and people would start talking about it and I just didn't necessarily realize how different my life was from my peers until people would ask me about it just while having those interesting conversations throughout my college experience.*

*Like what is normal? That's another question I ask myself. My normal is [my brother], and I'm happy for that.*

*There's a story I remember where I realized like... I remember calling my mom to help me with homework when I was little one time, and [my brother] after I called her, called her or like went out to get her, and she went to him first. And I remember being like, "Why do you always go to [him] first? Like why? I called you first. It's not fair. I don't understand." I think I was around 7 at the time, 7 or 8, and she was like, "Regan." I remember she didn't really know what to say to me and how to explain it to me. It was weird because she didn't have a response for me necessarily that stuck with me. It was just kind of just like that's the way it is. There was no justification. There was no reasoning that I could understand as a child. That was like- it was just kind of like that's the way it is. That kind of relates to her like saying that: that it is just the way it is. That's just how my life was, and I don't like thinking about the other option.*

Parents. Regan discussed the influence of her parents on her experience numerous times. Her mother was a big contributor to her experience; however, she also mentioned her father. Regan discussed her mother starting a school for persons with disabilities in Jamaica and how that affected the people she associated with for many of her childhood years. She said she was surrounded predominantly by persons with disabilities until she was 10 years old because of her mother's endeavors in the school. She also said her mother encouraged her to do Best Buddies in adolescence, a club that she said completely altered her relationship with her brother. She said her mother was the prominent caretaker for her brother,



which caused Regan to feel guilty whenever she wasn't around to help her mother care for him. She also said her mother had been influential in Regan's contemplating her brother's future, because her mother stated that he would move into a group home when Regan's parents aren't around anymore and Regan doesn't agree with that possibility. Regan discussed how her father had stepped up and helped her mother care for her brother more since Regan left for college.

*It was my mom who mentioned it to me. She was like, "Regan, there's this club! You should do it when you're in middle school." And I was like, "Yeah that would be good." I think my confidence was starting to build a lot more in terms of me feeling comfortable and confident during puberty, etc... But I joined Best Buddies and that was a really big turning point for me in terms of viewing [my brother] as a very positive person in my life versus a negative.*

*But it was cool to see that my dad definitely stepped up in terms of being a caretaker for [my brother], which he never... I never saw him in that role before I went to college. He never really... I didn't see him you know pick [my brother] up from school, or bathe him, or get him dressed, or like- he has diapers- change his diaper. Like my dad is very masculine, traditional, kind of conservative idea of the male role. Doing all of these as a caretaker is actually something that I was very surprised by, because it had always been my mom, the babysitter, and then I would help out too... it just became like an equal role between my mom and him almost when I went to college.*

#### Brandon: A Goal of Independence

The sixth participant was Brandon. He is a White male and was 22 years old at the time of the interview. He is younger than his brother, who is his only sibling with a developmental disability. He had no other siblings. He was raised in the same household as his sibling with a developmental disability for 18 years, or until Brandon left for college. Brandon earned a bachelor's degree and had a job at the time of the interview. Brandon was single and lived approximately four hours away from his sibling with a developmental disability at the time of the interview. His brother with a developmental disability has been diagnosed with autism. His

brother was impacted in the following life activities listed in the Federal Definition of a Developmental Disability (2000): learning, self-direction, and capacity for independent living. His sibling with a developmental disability lived at home with their parents, and at the time of the interview he was 27 years old. His brother had his own cell phone, which he used for daily contact. They also saw each other frequently. His brother earned a high school diploma as well as an associate's degree and had a job at the time of the interview.

### Themes

Guilt. Brandon reported feeling guilty in his teenage years for being able to do things that he knew that his brother could not do. He said that this caused him to feel guilty when he succeeded at his endeavors as well. He appeared to feel guilty for having the abilities that he did, because his brother did not have these abilities.

*I guess not until like my later teenager years, I started... some of the stuff that I would do, I would feel guilty, because I knew that he couldn't do it... I guess sometimes I would think about it and I don't know I guess I felt sorry for him. Where I didn't want to succeed too much, because I knew that he couldn't.*

Protective: advocating & concern. Brandon discussed past instances of bullying and trying to stand up for his brother. He said that these instances affected him then and continue to affect him now. He recalled wanting to be able to talk about these things with his brother, but his brother did not want to talk about the bullying. Brandon expressed concern for his brother in wanting to know how his brother felt and wanting to make sure he was okay. Brandon also discussed his current concerns for his brother's well being. Brandon said that he has concern for his brother living at home alone with his parents and without friends while Brandon is living somewhere else. Brandon also expressed that he wishes to be able to help

his brother put his life together so that his brother isn't upset by his living situation anymore. Brandon's concern for his brother appeared to stem from a sense of responsibility to help his brother.

*I mean I realized that at a young age that older kids were picking on him, like on the football team. That really, that hurt my mom a lot. I can remember some incidents that happened that were kind of big deals in our little community, I guess. That really hurt. I can remember walking to my mom's classroom from the elementary school one day, and I was little, and I remember seeing some kid pick on him. You know, I was probably 7 or 8 years old, but I ran over there like I was 22 and I was about to... I don't know beat the crap out of this kid, and I obviously wasn't. He was like a senior in high school. I started crying, and all this stuff. The kid got suspended for three days. So I mean that stuff hurt pretty bad I guess when he was in high school.*

*It's hard, because I see him- suffering is a harsh word- but suffering down here with no friends, still living with mom and dad, and here I am trying to put my life together. At the same time I want to help him put his life together too. I feel like he counts on me for things that are out of my control.*

*He doesn't understand that the rest of the world would eat him alive.*

Intimate with sibling. Brandon and his brother clearly shared a close relationship. Brandon reported that the two talk every single day and see each other frequently when he goes home or his brother comes to stay with him. Brandon said he is always the first person that his brother goes to for advice or questions.

*He texts me more than he texts anyone else by far, I guarantee you. Really in the last year and a half, I bet he texts me 15-20 times a day.*

Frustration. Brandon expressed clear frustration over his experience as well. Brandon claimed that his brother had more capabilities than he was using and expressed frustration that his brother was not maximizing his potential. Brandon wanted his brother to work on overcoming difficulties but thought that his brother was being complacent regarding his disability.

*He's happy, but the thing that drives me nuts the most and for the longest- this has always been a big deal- is him asking questions. He will ask a question, I mean, he will point at this wall right here and be like, "Brandon, is that wall purple?" I mean obviously it's purple. It's like he just wanted to hear me say it for some reason. I feel like now that has affected him in the way that he can't make a decision for himself. He cannot make a decision for himself. He can- let me rephrase that- he definitely can, but he just won't because he just needs a second opinion or something.*

*He uses it. He knows he has a problem, and he uses it to get away with stuff. When I get mad at him or he's getting on my nerves and I'm trying to make my point that he is wrong, he'll just throw his hands up and say, "Well, I can't help it." Yes, he can. That's the frustrating thing about it. When it comes to be too much, he'll just shy away from it and say, "Well I can't help it. That's just a part of me having a problem." No, it's not. It's not. It's simple things that he can overcome, but he just won't because he knows that he has a problem. So he uses it like a crutch.*

*You know I've been making- the decisions that he's texting me about, or asking my mom about- I've been making them since I was 15 or 14 years old. You know, and I feel like that's back to the thing I said earlier... The fact that his mind is under-developed. You know he's 27, but he has the mind of a 14 or 15 year old. So, I don't know. That worries me.*

The future: managing care, living arrangements, & financial responsibility.

Brandon expressed that he had thought significantly about the future regarding his brother and his care. Brandon believed that it was possible for his brother to live independently some day, and he did not desire to co-reside with his brother.

Brandon reported that he intends to live in close proximity to his brother so that he will be able to help his brother if he needs anything. Brandon reported that he had talked with his parents about his brother's future, and he said his parents told him that his brother was financially taken care of. Brandon still felt worried about the future and responsible for helping financially assist his brother. Despite his concerns and frustrations, Brandon expressed a hopeful disposition towards the future. He said that he and his family were making efforts to increase his brother's independence and capabilities and that he felt positively regarding those efforts.

*It's in the back of my mind that if I had to, I still need to be able to provide for him if I had to, or help him. You know it may get to the point where his truck is messing up really bad and he can't afford a new one right now. He has a little money or something, and I feel like I should be able to... what word am I looking for... responsible for helping him. As long as my parents are here, they will. But once my parents are gone, I have to step into that role I feel like. Because obviously he's not going to call them anymore, and instead he's going to call me if something is wrong. I feel like I have to be prepared for that a little bit, but that doesn't mean I have to necessarily pick a particular career. I can do whatever I want to do. I just kind of have to keep that in the back of my mind that I'm going to have to be responsible for him at some point in his life.*

*I mean I would like to not put him in a group home just because nobody wants to be put in a group home. He's going to hate me if I try to put him in a group home. I'd like to get him to the point where he can live in an apartment or something by himself with me being in the same city or making sure that there are other people around than just me. Not to say I want to push them off on [my brother]- no I mean, push [my brother] off on them. But there need to be other people that he can call like a couple of my friends or 2-3 friends of his own, if he can make them. I think he'll live by himself in the next 10 years... I think in the next 10 years- sometime in the next 10 years, at least five- we'll start making bigger moves towards getting him out of the house and being more independent.*

*...because in a bad situation, you know, he can't handle it. Like I feel like I'm always going to have to take care of his money. You know, and that's probably just going to be easier with us living in- I mean it doesn't have to be the same town. He could live here, and I could live in Little Rock. You know, two hours. If I needed to be here quick, I could be*

*I mean it gives me hope that, okay, maybe by the time he's like 40, he'll be independent enough. I mean obviously he's still living with my parents, and he's 27. He just got to the point where he's starting to pay them rent. He doesn't pay much rent, but he pays mom and dad rent now. So I feel like that's a step, and he really wants, he really wants to move out on his own.*

Pragmatism. Brandon believed that the accommodations that he and his family made for his brother and his disabilities were unhelpful for his brother. He thought that realistically his brother was capable of more than they encouraged him to do. He expressed a practical attitude. He said that he simply thought that by not pushing his brother to work on attaining other skills and abilities was a disservice to his brother. Brandon clearly believed that his brother was capable of more than

they hold him accountable for doing. Brandon said that he and his parents were all at fault of doing this at certain times, but he wished that they were all able to take the time to help his brother gain more skills and work on the disabilities with which he struggles.

*He's been living with my mom and dad for 27 years, so I feel like at some point- I guess more in the latter years- mom started giving in to him just because on a long day after work, he would come home barking about something, or complaining about something, asking questions. Mom would just be like, "Okay. Fine. Whatever. Get out of my ear." She'll just do whatever he's barking about. I don't know. Sometimes it's crippling. I'm guilty of it too.*

*I guess when you have a kid, or a brother, with a disability you really want to treat them the same as if they didn't have it you know, like there was no disability, especially with [my brother]. For [my brother] when you're trying to get to the point where he can be independent and live by himself, you have to treat him like a normal person without a disability. Every time you treat him like he has a disability, it cripples him.*

Embarrassed. Brandon expressed that embarrassment, or the fear of embarrassment, are feelings he experiences in early adulthood. He stated clearly that he is not embarrassed of his brother, his brother's diagnosis, or the developmental disability that his brother has. Brandon stated that it is the actions of his brother, which are caused by the developmental disability, that embarrass him. Brandon explained that his brother struggles to correctly perceive social contexts and then appropriately act in those social situations. Brandon said these inappropriate actions are what embarrass him.

*Actually, it is embarrassing sometimes. I know that he doesn't try to be. Not embarrassing, but I guess I'm just scared of what he's going to do or what he's going to say. It's embarrassing, because especially like when he come to Fayetteville and we're on Dickson Street or wherever seeing everybody. I'll see one of my girl friends, and I'll introduce him and then the conversation is over or whatever. The next time I see them [girl friends], they'll say, "Well, your brother added me on Instagram or somehow found me on Snapchat." I'm just like, "Dear Lord. I'm sorry. I don't know. He's his own person..." You know that's embarrassing.*

*I'm not embarrassed to say that he has a disability. That's just how it is. I'm not scared to say that he's autistic. But you never know what he's going to say or do. Especially in situations where he feels very comfortable with the people he's around, more comfortable than he should, and he's excited. He'll just have no filter.*

### Influences

Normal to me. Brandon said that he thought that his childhood was normal and that his brother was normal to him. He did not think that his brother's developmental disability affected the activities they did together at a young age. He reflected positively on the normalcy of their growing up. The idea that Brandon considered their relationship to be normal continued throughout all of his discussion.

*I guess in the beginning for me it was just a normal brother. I don't really know. I mean I knew at a young age that something was wrong with him, but I didn't pay attention to it, you know, because at that age, we did everything together you know... We would do everything that normal brothers would do.*

*I never had to get him dressed or anything like that. We would get up in the morning before school, and mom would cook us breakfast. We would eat breakfast just like a normal family I guess. I mean we would go outside and play basketball before school, if we got up early enough. Then we would both ride to school with mom, because she has always taught at the same place where we went to school at. We would come home after school and we would have like an after-school snack and sit there and watch cartoons or sports, whatever we were doing at the time, or we'd go outside and play, or somebody would come over. I mean it was normal.*

Parents. Brandon described his parents, mainly his mother, as being a source of help in being a sibling to his brother. He remembered his mother trying to help him understand his brother's disability when he was younger. He also described his mother as a sort of facilitator in the conversations between Brandon and his brother regarding his brother's desire to have a girlfriend some day. Brandon said that when his brother wants to talk to someone about his wanting a girlfriend, his

mother suggests that Brandon discuss it with him. He also recalled that his parents have included him in previous conversations about the future care of his brother, which implied a relationship that is open and comfortable for future discussions on the topic.

*Like I'd be walking through the hallways, and he'd be in the classroom with just the teacher. And that's when I kind of figured it out, and I asked my mom. And she said, "Nothing is wrong with him. He's just... underdeveloped. His brain is underdeveloped. You know, he's older than you, but... he's 12 years old, but he may have the mind capability of a 6 year old or 7 year old."*

*Sometimes he doesn't understand why he can't get a girlfriend. I feel like that's my department. If [my brother] starts to talk to mom about it, mom won't talk to him about it but she'll say, "Brandon, you need to talk to [your brother] about this."*

*I mean I worry about it, even though they [parents] tell me not to. Which I mean I... They told me before college that [my brother] was taken care of. I'm going to have to obviously be there for him and watch over it and you know make a couple big decisions for him, or something like that. But that he's already taken care of.*

### Summary

In summary, this research study was designed to describe the early adulthood experience of having a sibling with a developmental disability. Through the interviews, influences presented themselves in each of the participant's interviews. The themes and influences of each participant's description of the experience were explored through analysis of each interview. In the following chapter, the essential themes and influences, which were identified from the analysis, will be described.



## CHAPTER 5

### FINDINGS

The purpose of this study was to describe the early adulthood experience of having a sibling with a developmental disability. In this chapter, the essential themes and influences on the participants' experiences are described. The findings are presented in terms of themes and will be illustrated by quotes written in italics. Five essential themes and eight variations were identified (Table 2). The variations display how the themes presented differently among the participants. Two influences on the early adult experience of having a sibling with a developmental disability are also discussed.

Table 2. Essential Themes of the Experience and Their Variations

THEMES	VARIATIONS
1. Lessons learned	a. A lesson to learn from my sibling b. Something for others to learn from my experience
2. Protective	a. Advocating b. Concern
3. The Future	a. Children b. Financial responsibility c. Living Arrangements d. Managing care
4. Intimate with Sibling	
5. Pragmatism	

## Essential Themes with Variations

### 1. Lessons learned.

Each participant expressed that their experience offered lessons to learn. The two variations on this theme were: that there was a lesson to be learned from their sibling and that others had something to learn from their experience. Participants spoke of their siblings with gratitude for the lessons that their experience has afforded them. Some participants expressed that there is something for them to continuously learn from their sibling. One participant thought that her sibling was able to teach her a lesson through her sibling's perspective on life and even believed that her sibling served as a role model in her life.

*Because she is in a way my role model for life with the way she is into her things, her perspective on life, and the purity of her heart kind of thing.*

Some participants expressed that they are the person they are because of their sibling. Some participants thought that their sibling had taught them a specifically valuable life lesson. They shared that their own personalities and perspectives had been altered by their experience with a sibling with a developmental disability.

*I know for a fact that if she was not my sister that I'm pretty sure I would be a lot more selfish. I guess I would take a lot of stuff for granted honestly. I know I would. I mean I'm not proud of that at all. I just don't feel like- it's been a lot easier as a teaching lesson for her to be my sister to learn: don't take stuff for granted.*

*So I definitely had to learn a lot of patience, kind of adaptability to that situation. You know, I didn't know anybody that had a sibling with Down syndrome. I didn't know anybody with Down syndrome, except him... So it was kind of a learning curve, adapting to that situation, and kind of having to understand that most things aren't going to come easy. It's going to take a lot more time and patience and a lot more work for him to accomplish the things that somebody his age normally would. That's pretty much how it always was. It was just kind of having to learn to slow down. The patience was the biggest virtue, or attribute, that I had to learn.*

*[My brother] is a huge part of who I am, and he is my normal in that he is one of the things that has made me who I am. He's probably one of the biggest, or the biggest that has made me who I am. And I really like who I am right now... I don't think I would change it. I don't know. If [my brother] was different, then I would be different... We are definitely related. Well at least he is the cause and I'm the effect. So whatever he would have been like, ultimately I think I would have ended up being like. So certain qualities that I really value in myself, like being able to take care of people, being passionate about things, being confident, or being vulnerable, and being sensitive, extra-sensitive to people, and being so aware, socially aware of what's going on around me. All these different qualities that I really value and that make me "me" are directly related to [my brother] and my relationship with him. Being able to be mature at a very young age was something that everyone always pointed out in me, and I know that is something that I know is due to [my brother].*

Some participants expressed that others have something to learn from their experience. Participants thought that if other individuals without siblings with a developmental disability were exposed to their experiences, other individuals would also learn valuable life lessons.

*I do think we all could learn something by living a day or two with somebody with a disability and seeing how life is with that and really just kind of seeing for the most part, like yourself, that might not have a sibling with a disability to understand and see just how life- you don't know how that life is until you're put into a position to where you know somebody else is dependent on you no matter what. And I'm not saying it's a bad thing. It's not, but it's just more- I consider it knowledge. You know, its more knowledge for somebody to have to understand what it's like to have to go through life like that.*

## 2. Protective.

Each participant displayed protectiveness over his or her sibling.

Participants demonstrated their protectiveness in two different ways: by expressing concern and by advocating for their sibling. Participants expressed concern regarding their sibling's safety and well being. One participant expressed concern regarding her sibling's safety as she and her family encouraged more independence. Another participant expressed concern about his/her sibling being able to handle

being in the real world without his/her help. Another participant similarly expressed concern about his/her sibling living in a group home or anywhere where they were not able to care for his/her sibling.

*The goal is for her independence to grow, but at the same time one of the biggest fears is her being taken advantage of. Obviously it happens to females, but can happen to males. I worked in adult programs, and I've heard horrific stories, just horrific stories.*

*I think I'm protective, like possessive of him [brother] as well. And just the idea of me being so far and not having a say over anything in his life made me uncomfortable, and I think that's something that I'm really figuring out right now and deciding having to do day-by-day and also trying to think ahead so that I'll be prepared. That's hard to do, because you just don't really know what's going to happen.*

*It's hard, because I see him- suffering is a harsh word- but suffering down here with no friends, still living with mom and dad, and here I am trying to put my life together. At the same time I want to help him put his life together too. I feel like he counts on me for things that are out of my control.*

Participants advocated on behalf of their sibling, which was interpreted as a variation of protectiveness. Participants expressed that their sibling should not be messed with and by expressing that their sibling should not be underestimated. Some participants expressed that their sibling should not be messed with by standing up for them in some capacity. One participant demonstrated this variation of protectiveness as he tried to stop a bully from picking on his sibling. Some participants felt that other peoples' use of the "r-word" was offensive to them and their sibling, so they stood up for their sibling by promoting the disuse of the word.

*So on Friday night football games my sister would come, and there would be some people, not all... I use the term "ignorance", not in a negative way, just they truly did not know, because they weren't around it. So that kind of was something that I struggled with, and I was very vocal, even later in college, you know if people used the "r-word" even just for joking. If they said "Oh that's so retarded." I would immediately say, "Please don't use that word around me." I would be very quick, and you know people would always feel bad. But that's a precedence I set early on.*

Participants expressed that their siblings should not be underestimated. One participant advocated for his sibling as he tried to facilitate social situations in which his sibling was involved. He sat down and talked with his friends and also his sibling before his sibling came to stay with him in college. He wanted everyone involved in the social situation to be prepared for the encounter in order to protect his sibling. Participants thought that others underestimated the intelligence and the abilities of their siblings. They defended the intelligence of their siblings despite the fact that they were aware that their sibling had a developmental disability. They also believed that underestimating their siblings was not helping them reach their full potential and full range of capabilities.

*She has a lot more cognitive ability than a lot of teachers thought that she had, and my mom knew that and she was mad that they weren't trying. They were teaching her how to wash dishes, stuff like that, and it's like okay she knows how to memorize some Spanish. She knows Spanish pretty darn well, which is crazy. She can do simple math, but she has a hard time writing. Anything you try to teach her with complex ideas or discussion, she doesn't follow. She knows very basic stuff, like in the math area or Spanish- different areas that you wouldn't think they get or understand she does really well in.*

*I don't let a lot of my friends kind of baby her, or be easy with her, because I know they're not here 24/7. I know that she can do this stuff.*

*He does make eye contact with you. He's not like not present. I really do believe that something is, you know, he knows more than you think. Just because he can't communicate it with you- there's like little things. You know, I'll talk to him and tell him to close the door of the car, and he closes it. He like takes some time, but he'll do it himself. I'll talk to him. He knows the way home. It's really funny on the way home, if you take this right instead of a left to go to like Starbucks or Publix to get something, and he'll scream in the car and freak out. All I have to do is tell him where I'm going and why I'm going there, and it's really funny.*

### 3. The Future

Each of the participants discussed their contemplations on the future. There were four variations regarding thoughts on the future: financial responsibility for their sibling; future living arrangements for their sibling; managing the future care of their sibling; having children. Participants said that they intended to become financially responsible for their siblings in the future and had already made some efforts towards that goal.

*So if something were to happen to my parents, let's say there are three of us siblings so technically a family would divide things three ways in their will. Well if anything is left under her [sister with developmental disability] name, then she will not qualify for services, and she will be kicked out of services. There is something going through legislation now called the Able Act that has been passed and looks to help in that area. I am the executor of the special needs will and trust, so it is basically money allocated to her but not under her name. I am also the guardian or conservatorship, if something were to happen to my parents.*

Participants discussed the possible future living arrangements for their siblings. Some participants intended for their sibling to co-reside with them. Some participants intended for their siblings to live in their own space but very close by. One participant thought that his sibling would live with one of his aunts in the future.

*I've mentioned it to my brother, and he's said she is welcome to stay there or it depends on the situation, if she stayed with us for a year or two and then went over there for a year or two. He seemed okay with it, so if something ever happened she was with one of us. That's the most extent that we've talked about it, but I guess when that bridge comes we'll have to make a decision.*

*Yeah, I mean my plan, and it has been for a while, is to hopefully, eventually by the time I'm 30 or so to be in a position, you know financially stable enough and things like that, to be his primary caretaker. The goal is to buy a house with like an apartment over the garage, or maybe buy two houses one a lot smaller, just so he can have his own place and take care of himself and live as independently as he possibly can, while I can still be nearby as a support system.*

*And I don't think my mom wants necessarily to put that burden on me. I don't want to say it's a burden, but you know I don't think she wants to kind of... You know, she understands that I'm young and still growing... And so you know, it's something we'll have to talk about in the near future, but that's not something that we have talked about. I think we've mentioned it once or twice, and it kind of gets blown off to the side. But for the most part, I will say that I will definitely not be alone if something was to happen.*

One participant discussed the intention to have children. She reported that she had already sought the advice of a doctor on whether or not she was at a higher risk for having a child with a developmental disability because of her sibling.

*When I want kids, not any time soon, but when I do that will be in the back of my mind. Nothing is genetic. I've talked to the doctor about it, because I wasn't really sure... I was wanting to know if complications of pregnancy were genetic or if I was having any risk factor of having it, but he said no.*

Participants discussed the intention to manage care for their sibling. Each intended to participate in the caring for their sibling in some capacity. Some participants reported that their sibling and their care needs influenced their job choice.

*My priority is feeling comfortable in making the next steps that I can make to support him [brother]. So yeah, I'm going to take a better paying job over maybe a cool unique job traveling around Europe. I'm going to take the higher paying job that's in America, because it's closer to my family and it's more financially sound, and it can help me almost, if anything, have a higher and higher salary. I feel almost guilty for thinking that way and thinking that you know I want to get a job that pays a lot. I hated that idea. I'm the most "Follow your passions. Do what you love. Like live through your experiences" type of person, but I also realize like what is my passion? And my passion is my brother and making sure that he's okay always.*

*I guess I don't have like an open field of options. I have that for a limited amount of time. I think something that is kind of unsettling to me is that I know that eventually I will have to make decisions based off my ability to take care of [my brother]. I think a lot of my decisions now are definitely motivated by: Is this going to help you take care of [your brother]?*

*It's in the back of my mind that if I had to, I still need to be able to provide for him if I had to, or help him. You know it may get to the point where his truck is messing up really bad and he can't afford a new one right now. He has a little money or*

*something, and I feel like I should be able to... what word am I looking for... responsible for helping him. As long as my parents are here, they will. But once my parents are gone, I have to step into that role I feel like. Because obviously he's not going to call them anymore, and instead he's going to call me if something is wrong. I feel like I have to be prepared for that a little bit, but that doesn't mean I have to necessarily pick a particular career. I can do whatever I want to do. I just kind of have to keep that in the back of my mind that I'm going to have to be responsible for him at some point in his life.*

#### 4. Intimate with sibling

Each of the participants reported an intimate relationship with their sibling. The participants spoke of their sibling fondly and with affection. The participants also talked to their sibling frequently and reported a close bond with their sibling, despite varying physical distances between them. One participant lived in the same household as her sibling and was in contact with her sibling daily. Some participants lived in the same city as their siblings and saw their siblings more than once a week. Some participants lived in separated cities (4 hours or less away) from their siblings but saw them frequently. One participant lived in a separate city (9 hours away) from his sibling and saw his sibling occasionally. The siblings of four participants had cell phones and frequently used them to contact the participants. Two participants illustrated their close relationship with their sibling by describing their continuing communication after they moved away for college or work.

*It was tough at first. He called me a lot. He has a cell phone, which by the way he can operate masterfully. He called me a lot, like every single day. It took him a while to really kind of grasp what I was doing there, why I left, why I wasn't coming home every day. Then it just became that he wanted to do it too. He's always looked up to me and always kind of wanted to do what I'm doing. Then he got it in his mind like, "Well I want to move out and go to college too." The hardest part was him understanding what I was doing and why I was there.*

*He texts me more than he texts anyone else by far, I guarantee you. Really in the last year and a half, I bet he texts me 15-20 times a day.*



The participants described having relationships with their siblings that were intimate and strong enough to overcome obstacles that they faced. They elaborated on the difficulties of maintaining a close sibling bond while also knowing they are in a caretaking position for their sibling as well. They discussed the effort required to preserve their close relationship even through physical separation as early adulthood has brought them out of their natal home. The participants seemed eager and willing to make the efforts necessary to help their sibling feel loved and befriended, and the participants also seemed to genuinely have a friend in their sibling.

*She gets a little headstrong. I think we both do, because it is hard because in a way first and foremost we are sisters but at the same time I'm caretaker-ish. I'm very momma-bear, even though she already has a momma-bear.*

*But it's another thing having to explain why I'm so far away and why I don't get to see him as much. The thing is now he's 20 years old, so he tends to understand real world concepts a lot better. So he understands that I'm out here working and the reasons, but it's definitely even harder than when I went to college just because, like I said, I'm his primary person that if he has something he wants to tell somebody, he wants to tell it to me. We're both kind of having to adjust to being able to do that on the phone a little bit better.*

## 5. Pragmatism

Pragmatism was a characteristic of participants in this study. The participants realized the good and the bad in life were unavoidable, and they made their best efforts to accept the events of life as they came. They were accepting of their situation and the differences their situation had from those of others. One way that pragmatism manifested was in accommodations made by participants in order to fit their siblings' needs. They described these accommodations as a necessity more than a choice.

*But there are just certain things we couldn't do or had to do in a different way. You know, going out to dinner, we would go early. We would always be the early birds, with the people who were older for the early bird special, because putting your name in and having to wait, and those kinds of things. Going to stores, having to be in line, we would tag team and have someone walk around the store with her while someone else waited in line.*

*It was always a coordination of who's home. Like, Regan you need to go home. Like today, I'm picking up [my brother] from his day center because my mom works until four, and when I'm here it's a great help because we don't have to pay someone else to pick him up and take him and sometimes she's not available. It's always asking when and who is going to be home and you can't leave without someone knowing, because someone has to be here with [my brother] or you have to take him with you. Then it's: can you take him with you? Everything we do is always a question of like who is going to watch [my brother] or can we take him or how is this going to work? For example, for my graduation: I wanted him there for my high school graduation and we had to take a babysitter just in case he made noise to take him out in the back, and like it was this whole operation just to have my brother at my graduation.*

*I already know in my mind if the same situation- some people might see her as- I can't think of the word! I guess like an obstacle, makes life harder. And I'm not saying that she doesn't make life harder. I mean you have to set a little more time to make two people like more, make sure that she's fine. You can't always get up and go to the grocery store, if you're the only one at the house. You know to stay there. Burden! Some people think she's a burden. That's the word! I feel like what's the difference in just having a younger child? Anybody can view them as a burden interrupting conversations or anything. It's just like taking care of a younger child, but forever.*

One participant expressed pragmatism by discussing the fact that his situation could actually be worse. He explained his sibling's disability and symptoms and then explained that other persons with the same disability have more severe symptoms than his sibling.

*I will say for her personally, there are a lot of Angels [persons with Angelman syndrome] that we know about and are confined to a wheel chair. And she is not, so we feel very fortunate that she can walk on her own, because having someone in a wheelchair on top of not being able to talk and not being able to kind of explain yourself is you know, it just makes things harder. There's really no nice way of putting it, but it's just not great for anybody. We are definitely fortunate that she can walk on her own and get around on her own.*

Another participant expressed pragmatism by discussing how their family's accommodations were actually not helping his sibling. He expressed that realistically his sibling could achieve more if the family pushed the sibling to do more things instead of catering to the things that the sibling cannot do. The participant was not oblivious to the manifestations of the sibling's disability, but simply felt that accommodating was keeping the sibling from reaching their full potential.

*I guess when you have a kid, or a brother, with a disability you really want to treat them the same as if they didn't have it you know, like there was no disability, especially with [my brother]. For [my brother] when you're trying to get to the point where he can be independent and live by himself, you have to treat him like a normal person without a disability. Every time you treat him like he has a disability, it cripples him.*

### Influences on the Experience

The participants described two influences on their early adulthood experience of having a sibling with a developmental disability: their parents and their perception that their experience was normal. These influences emerged from the participant interviews when asked to describe the experiences of having a sibling with a developmental disability. A discussion of these influences follows. Influences are illustrated by quotes written in italics.

#### 1. Parents

The participants described how influential their parents were on their experience. They identified how their parents facilitated their relationship with their sibling, helped explain to them their sibling's disability, and modeled the accommodations in their daily life in order to help the sibling with a developmental disability. Participants discussed the lessons that they have learned from their

parents through the experience. The parents' approaches to the situation influenced the participants. Participants evidenced that even in situations where parents are not still married and co-residing, the parents had influence on their experience.

*Like I'd be walking through the hallways, and he'd be in the classroom with just the teacher. And that's when I kind of figured it out, and I asked my mom. And she said, "Nothing is wrong with him. He's just... underdeveloped. His brain is underdeveloped. You know, he's older than you, but... he's 12 years old, but he may have the mind capability of a 6 year old or 7 year old."*

*I think my parents have done an amazing job always being advocates for her, and that's what has gotten me into the field. I think the reason she has progressed as much as she has is because we do know her rights. My parents have always killed with kindness... They were always well educated and worked together. I do see an impact that it had on my parents' marriage. I do think that that's something just like with any children. But their faith was a firm foundation, which taught me a lot of things now that I'm married, you know, how to approach relationships. I generalize what they went through and how they dealt with things, and I think it's a testimony to their faith.*

*Like my mom, you're not always going to have the best outcome. Don't expect or assume everything is going to be okay. Always be prepared for the worst, even if it comes out the best. Always be prepared for the worst.*

*Our parents got divorced when we were younger, so that definitely drew us a lot closer. We've split time between our parents, like one week with mom and one week with dad, back and forth like that, but since me and him were always doing it together, I think that's what kind of established our bond so strongly because we were kind of in that together.*

## 2. Normal to me

Participants related that their perception that their life and their sibling were normal had influenced their early adulthood experience of having a sibling with a developmental disability. They had always known their sibling with a developmental disability and would never know their sibling without their developmental disability. They acknowledged that over time they realized other families were different than their families. While some participants discussed coming to an understanding, they did not remember ever being unaware of their

situation. They described the perception of their sibling and their situation being their version of normal. The majority of descriptions were of situations in childhood or adolescence; however, it appeared that this greatly influenced the participants' early adulthood experiences.

*... I never looked down upon her. It was just- I don't know how to explain it- like I guess I just felt like it was normal, you know. I didn't think that- I mean, I know that other kids didn't have siblings that had cognitive disabilities, but for us it was normal. So I didn't think anything was abnormal about it.*

*...when you have anyone in a family with a sibling with a disability, it can only be one of two ways: 1) they're either older or younger than you. In some cases, where they [the sibling] are younger, it might be different than in cases like me where my sister is older. For example what I mean is: for me it's all I've ever known. You know I can't say that my life was going great, and then, you know, I had a sibling born with a disability, and my life has changed. For me it's all I've ever known, so everything that I do has quote unquote come naturally. It's just always been the same no matter what.*

*I knew that he had- that he was different, but it was also very confusing, I think to me, because he was my brother and I recognized that it was normal to my family, but then I also started recognizing that it was different to others.*

*I guess in the beginning for me it was just a normal brother. I don't really know. I mean I knew at a young age that something was wrong with him, but I didn't pay attention to it, you know, because at that age, we did everything together you know... We would do everything that normal brothers would do.*

## Summary

In summary, five essential themes emerged through the analysis of the experiential descriptions of the participants. There were eight variations related to the five essential themes. Two influences on the early adult experience of having a sibling with a developmental disability emerged. In the following chapter, the findings of the study are discussed. Additionally, the implications for practice, education, and research are explored.

## **CHAPTER 6**

### **DISCUSSION OF FINDINGS**

The purpose of this study was to describe the early adulthood experience of having a sibling with a developmental disability. Five essential themes and two influences were identified through the analysis of the experiential descriptions of the participants. The themes and influences were depicted in detail in Chapter 5. In this chapter, implications for practice, education, and research are also discussed.

#### **Limitations to Transferability**

This study elicited descriptions and analyzed early adults' experiences of having a sibling with a developmental disability. The purpose of this study was not to empirically generalize the findings. The purpose of this study was to attain a better understanding of the early adulthood experience of having a sibling with a developmental disability. The researcher cannot specify the transferability of the findings. Snowball sampling, announcements in psychology classes of the researcher, and announcements in the Sally McDonnell Barksdale Honors College e-mail newsletter were used to recruit participants. This sampling may have resulted in participants with similar situational contexts in this study. Therefore, the experiences of the early adults in this study might not reflect the experiences of all early adults who have a sibling with a developmental disability.

## Implications

The findings of this study represent new knowledge discovered through descriptions of the participants' accounts of their experiences. The essential themes and influences that were identified add to the existing knowledge, not only to assist with understanding the experience, but also to clarify issues that have been discovered by previous research and that have been described in the literature review. In this section, implications related to practice, education, and research will be explored.

### Practice

Early adults who have siblings with a developmental disability are capable and willing to describe the experiences. The purpose of the current study was to investigate the experience of having a sibling with a developmental disability from the perspective of persons in early adulthood. The development of interventions was not the focus of the current study; however, practice implications may arise from the better understanding of the experience. The current study may add to professionals' understanding of early adults who have siblings with a developmental disability by offering an alternative perspective to previously published research findings.

Five themes and two influences on the early adulthood experience of having a sibling with a developmental disability were identified as common among participants. Some of these themes and influences pose relevant possibilities for interventions in practice. Firstly, participants believed that there were lessons to be learned from their sibling and their experience with their sibling. Participants

expressed that they had learned something worth sharing with others and that others had something to gain from knowledge about their experience. One participant expressed that he felt that his experiences was something that “is overlooked in a lot of people’s minds”. In practice, early adults may feel more supported and more understood by other individuals, including those without siblings with a developmental disability, if other individuals were more knowledgeable about the experience.

Secondly, participants expressed protectiveness over their sibling.

Participants expressed concern for their sibling and also advocated on behalf of their sibling. Some participants expressed concern for the mental and emotional health of their sibling when participants left for college or work and left their sibling in an empty nest. It could be beneficial for early adults to have access to information on how to best prepare their siblings for the transition as well and information on how to best make the actual transition. The majority of participants advocated on behalf of their sibling in situations where they felt someone was messing with their sibling or underestimating their sibling’s abilities. Participants advocated for their sibling in social situations with persons without disabilities, when others around them used the “r-word”, and when others were bullying their sibling. In practice, if more people had knowledge of the practices that offend or upset siblings of individuals with disabilities, less stress would be placed on the siblings to stand up for their brother or sister with a developmental disability. Also, it could be beneficial for professionals who interact with early adults to understand the protectiveness they feel towards their sibling so that they could help them advocate for their



sibling. Professionals could better advise them on how to best advocate for their sibling.

Thirdly, participants heavily discussed their thoughts about the future of their siblings. Participants discussed their plans to be financially responsible for their siblings, plans to manage the care of their siblings, plans on living arrangements for their siblings, and plans to have children based on the fact that their sibling has a developmental disability. It was reiterated by all participants that they had not been able to create an exhaustive plan for the future and discuss it with their parents. One participant admitted to being scared to initiate the conversation about the future with her parents for fear that she would upset her parents. In practice, it could be beneficial for the parents of the early adults to initiate the conversation regarding the future. Participants expressed that not all parts of the plan could be developed because they just did not know what would happen in life before they needed to take over caring for their sibling, but it was common among all participants that they had thought about some aspects of their plan for the future. Several participants did not express knowledge of what their parents planned or desired for the future. For one participant, her plan actually was contrary to the plan her parents desired. In practice, it could be beneficial in easing the stress of the early adult sibling for parents to discuss with them their plans and desires for the future care of the sibling with a developmental disability and to ask for the early adult's input in the plan. It would certainly be beneficial for parents of early adults who have a sibling with a developmental disability to be aware that some early adults

who have a sibling with a developmental disability have uncertainty about the future and would like to create a plan for the future of their sibling.

Two influences on the early adulthood experience of having a sibling with a developmental disability emerged as common to all participants. Participants acknowledged the influence of their parents on their experience. The reported influence that parents had on participants pose relevant opportunities for interventions in practice. The influences may add to the knowledge that professionals possess and also their understanding of the early adults experience of having a sibling with a developmental disability. Participants thought that their parents had helped to facilitate their relationship with their sibling, helped them to understand their sibling's disability, and modeled the accommodations that their family made for their sibling. One participant expressed that her parents were the biggest influence on her experience. It is possible that parents were such a strong influence in their lives, because in a sibling relationship in which one sibling has a developmental disability, parents are needed to provide a bridge between the siblings. Parents may be needed in order for the non-disabled sibling to navigate his/her relationship with the sibling with a disability. In practice, it could be beneficial for parents to be cognizant of their role as a mediator between the siblings so that they may best facilitate the relationship. Parents need to be aware that their approaches to situations and their support influence the early adult's experience of having a sibling with a developmental disability.

## Education

The essential themes and influences identified in the current study contribute to the existing knowledge available to professionals who interact with early adults who have siblings with a developmental disability not only by aiding in the better understanding of the experience, but also by clarifying previous research findings described in the literature review. No other studies have been conducted to investigate the subjective early adulthood experience of having a sibling with a developmental disability. While remaining aware that each early adult's experience is unique, these findings can provide a base for conversations with early adults regarding their experiences. Those who interact with early adults who have a sibling with a developmental disability could benefit from knowing that by asking the early adult what the experience is like and listening to their account of their experience, they can learn much about the sibling, their experience, and interventions that could help them. It could be helpful for both the early adult who has a sibling with a developmental disability and their family, if parents and other family members were educated on the essential themes and influences on the experience identified in this study. Knowledge of the findings of this study could assist parents in better understanding more about the experience of their own early adult who has a sibling with a developmental disability. Education of the parents could also assist them in initiating conversations with the early adult regarding his/her experience and how the parents can help them in the experience.

## Research

Replication of this study with samples in setting other than the southern region of the United States with a wider range of ethnic and socioeconomic groups would serve to broaden the existing understanding of the early adults' experience. Longitudinal studies of individuals who have siblings with a developmental disability may provide useful information about differences and similarities of the experience of having a sibling with a developmental disability throughout various developmental stages and, therefore, potentially further increase the knowledge related to the experience of having a sibling with a developmental disability. Additionally, a replication of the study with equivalent or greater heterogeneity in diagnoses of the sibling with the developmental disability and increased participants with siblings with a developmental disability in each homogeneous category of diagnosis would be beneficial in gaining knowledge on differences in the early adulthood experience. This would help elucidate the similarities and differences of early adults' experience across various siblings' developmental disability diagnoses and would provide useful information regarding the experience of early adults with siblings with one diagnosis compared to the experience of early adults with siblings with another diagnosis.

## Summary

The purpose of the current study was to explore the early adulthood experience of having a sibling with a developmental disability. Influences on the experience were also identified. The early adults who participated in the current study were capable and willing to share their experiences of having a sibling with a

developmental disability. Using the participants' own words, themes and influences of the experience of having a sibling with a developmental disability were identified. The siblings were pragmatic, generally appreciative of their experiences, and grateful for the lessons their experiences had afforded them. They were thoughtful and insightful in their plans for their futures and those of their siblings.

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## APPENDICES

APPENDIX A

**The Early Adulthood Experience of Having a Sibling with a Developmental  
Disability  
Research Study  
Demographic Information Sheet**

**Participant #:** \_\_\_\_\_

**Pseudonym:** \_\_\_\_\_

**(1) Age in Years:** \_\_\_\_\_

**(2) Gender: Male** \_\_\_\_\_ **Female** \_\_\_\_\_

**(3) Ethnicity:** \_\_\_\_\_

**(4) Diagnosis of Sibling with Developmental Disability:**

\_\_\_\_\_

**(5) List three of the criteria listed by the Federal Developmental**

**Disabilities Act that apply to your sibling:**

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**(6) City of Permanent Residence:**

---

**(7) Education:**

---

---

**(8) Total Number of Siblings without a Developmental Disability:**

---

**(9) Total Number of Siblings with a Developmental Disability:**

---

**(10) Were you raised in the same household as your sibling with a developmental disability? If so, for how many years?**

---

**(11) Are you 21 or older? \_\_\_\_\_**

APPENDIX B

**DEVELOPMENTAL DISABILITY DEFINITION**

(A) IN GENERAL

The term “developmental disability” means a severe, chronic disability of an individual that—

(i) is attributable to a mental or physical impairment or combination of mental and physical impairments;

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(ii) is manifested before the individual attains age 22;

(iii) is likely to continue indefinitely;

(iv) results in substantial functional limitations in 3 or more of the following areas of major life activity:

(I) Self-care.

(II) Receptive and expressive language.

(III) Learning.

(IV) Mobility.

(V) Self-direction.

(VI) Capacity for independent living.

(VII) Economic self-sufficiency; and

(v) reflects the individual’s need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.



## APPENDIX C

### **The Early Adulthood Experience of Having a Sibling with a Developmental Disability**

#### **Information Sheet**

##### **Investigator**

Fran Jennings  
Sally McDonnell Barksdale Honors  
College  
(870) 344-1656  
[cfjennin@go.olemiss.edu](mailto:cfjennin@go.olemiss.edu)

##### **Advisor**

Robin Wilkerson, PhD, RN  
University of Mississippi School of  
Nursing  
(662) 915-1681  
[rwilkerson@umc.edu](mailto:rwilkerson@umc.edu)

*INCLUDE THE FOLLOWING ONLY IF YOU ARE COLLECTING DATA EXCLUSIVELY FROM ADULTS*

*By checking this box I certify that I am 18 years of age or older.*

##### **Description**

The purpose of this research project is to learn more about the experience of an early adult with a sibling with a developmental disability. Examples of developmental disabilities include: Down syndrome, autism spectrum disorders, fragile X syndrome, Williams syndrome, and Prader-Willi syndrome. Other developmental disabilities have not been listed here, but will be included in the study. Contact the researchers if you have questions regarding the inclusion of specific developmental disabilities. You will be asked to give some basic information including your age and your sibling's diagnosis and to then participate in an interview.

##### **Cost and Payments**

The interview will be held on the phone or in a location that you choose. The interview will last no longer than one hour. There will be no compensation.

##### **Risks and Benefits**

The interview question is: "What is your experience of having a sibling with a developmental disability?" You may feel uncomfortable with your feelings while talking about your experience in the interview. You will choose how much information you share during the interview. We do not think that there are any other risks.

##### **Confidentiality**

Your phone number will be collected in order to contact you later if clarification of data is needed. You may also be contacted at the end of all research and analysis to confirm that the writing accurately portrays your experiences. Your interview will only be identified with a code and pseudonym. This data will be kept separately from your phone number. The results of the research may be published, but your name will not be used. You may learn about the research findings either by attending a presentation (the researcher's thesis defense) and/or by requesting a copy of the results.

**Right to Withdraw** Being in the research study is voluntary. If you participate in the interview, you are saying that you want to be in the study. You may stop participation at any time. If you start the study and decide that you do not want to finish, all you have to do is to tell the researchers in person, by letter, or by telephone (contact information listed above). You may skip any questions you prefer not to answer.

**IRB Approval**

This study has been reviewed by The University of Mississippi's Institutional Review Board (IRB). If you have any questions, concerns, or reports regarding your rights as a participant of research, please contact the IRB at (662) 915-7482 or [irb@olemiss.edu](mailto:irb@olemiss.edu).

**Statement of Consent**

I have read and understand the above information. By completing the survey/interview I consent to participate in the study.

APPENDIX D

**THE UNIVERSITY OF MISSISSIPPI**

**RELEASE**

For valuable consideration, I do hereby authorize The University of Mississippi, its assignees, agents, employees, designees, and those acting pursuant to its authority ("UM") to:

- a. Record my participation and appearance on video tape, audio tape, film, photograph or any other medium ("Recordings").
- b. Use my name, likeness, voice and biographical material in connection with these recordings.
- c. Exhibit, copy, reproduce, perform, display or distribute such Recordings (and to create derivative works from them) in whole or in part without restrictions or limitation in any format or medium for any purpose which The University of Mississippi, and those acting pursuant to its authority, deem appropriate.
- d. I release UM from any and all claims and demands arising out of or in connection with the use of such Recordings including any claims for defamation, invasion of privacy, rights of publicity, or copyright.

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Phone No.: \_\_\_\_\_

Signature: \_\_\_\_\_

Parent/Guardian Signature (if under 18): \_\_\_\_\_

## APPENDIX E



Carole Jennings <cfjennin@go.olemiss.edu>

---

### IRB Exempt Approval of 15x-234

---

irb@olemiss.edu <irb@olemiss.edu>  
To: Carole Jennings <cfjennin@go.olemiss.edu>  
Cc: "rwilkerson@umc.edu" <rwilkerson@umc.edu>

Tue, May 5, 2015 at 3:26 PM

Ms. Jennings:

This is to inform you that your application to conduct research with human participants, "The Early Adulthood Experience of Having a Sibling with a Developmental Disability" (Protocol #15x-234), has been approved as Exempt under 45 CFR 46.101(b)(#2).

Please remember that all of The University of Mississippi's human participant research activities, regardless of whether the research is subject to federal regulations, must be guided by the ethical principles in The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research.

It is especially important for you to keep these points in mind:

- You must protect the rights and welfare of human research participants.
- Any changes to your approved protocol must be reviewed and approved before initiating those changes.
- You must report promptly to the IRB any injuries or other unanticipated problems involving risks to participants or others.

If you have any questions, please feel free to contact the IRB at [irb@olemiss.edu](mailto:irb@olemiss.edu).

### Jennifer Caldwell, PhD

#### Senior Research Compliance Specialist, Research Integrity and Compliance

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