

ABSTRACT

Title of Document: THE SAME AND DIFFERENT: A
GROUNDED THEORY OF THE
EXPERIENCES OF COLLEGE STUDENTS
WHO HAVE A SIBLING WITH A
DEVELOPMENTAL DISABILITY

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Research on people who have a sibling with a disability has focused minimally on the experiences of college students who have a sibling with a disability and generally focused on specific aspects and outcomes instead of a more holistic view. Much of the prior research was also conducted during a time when the climate around disabilities was different. This study took a contemporary and broad view of how college students with a sibling with a developmental disability experience college.

This study used a qualitative methodology, constructivist grounded theory, to explore the experiences of college students with a sibling with a developmental disability. There were nine initial participants in the study and seven participants who completed the study. All had at least one sibling with a developmental disability and were either currently enrolled in an undergraduate institution or had graduated within two years. The seven participants who completed the study were each interviewed three times and many

also shared academic papers or admissions essays that related to their sibling or disability issues.

Data from the multiple in-depth interviews and documents were analyzed and the emergent theory was grounded in the data and described the experiences of college students who have a sibling with a disability. This theory contained a core category and five key categories. The core category, which incorporates the essence of participants' experiences, is My Experience in College is the Same and Different. There are five key categories related to the core category: Lessons Learned from Siblings, Having a Sibling Shapes My Personal Traits, Having a Sibling Plays a Role in My College Choices, Having a Sibling Contributes to My Academic Experiences, and Being a Sibling in My Social Interactions.

This research contributes to the literature by providing a holistic and contemporary look at a sub-population of college students that has been understudied. It also offers important recommendations for future sibling research as well as ways for colleges to support siblings. As a qualitative study, it offers an in-depth look at college student siblings and demonstrates the complexity of their experience.

THE SAME AND DIFFERENT: A GROUNDED THEORY OF THE EXPERIENCES
OF COLLEGE STUDENTS WHO HAVE A SIBLING
WITH A DEVELOPMENTAL DISABILITY

by

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DEDICATION

To my family, who, both literally and metaphorically,
helped me get to Maryland and graduate.

To my husband, Gary, who cheered me on and cheered me up more times than I can
count. Your love, patience, and unwavering faith in me kept me going.

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CHAPTER I

INTRODUCTION

The purpose of this study was to examine the experiences of college students who have a sibling with a developmental disability and explore how these students experience college. The data from this study were used to create a conceptual model that illustrated these students' college experiences. In this chapter I will discuss my interest in this topic, briefly review some of the language used in this study, provide an overview of the research problem, elaborate on the purpose of this study, identify important considerations about the self as researcher, and highlight the significance of this study.

Introduction – My Own Experience

My sister's name is Elyssa. She was born on May 27, 1977. She is 2 ½ years old and in the beginning she kept on getting sick. We were scared she was going to die. She has a bad heart. Now she doesn't get sick so much. She also has another problem, she has Down syndrome. This means she is mentally retarded. The doctor told my parents that Elyssa was not like other children. Down syndrome happens to a baby before they are born, they have one extra chromosome. The doctor could tell that my sister had Down syndrome because she looked different. They also did a special test just to make sure. My sister does things slower than other children. She goes to a special school. It is called MARC infant motivation program. They help her to learn things. The teachers teach her to walk and talk. They taught Elyssa to feed herself and drink from a cup. The teachers show her how to play with toys and other children. The teachers show her skills like block building. Like any other sister or brother Elyssa makes a mess, gets in the way and goes in my room when I don't want her to. She cries and breaks things. She hits me and gets me into trouble. My parents make me take care of her when I would rather do something else. Because she is special Mom has to spend time showing her how to do things. This means she can't spend more time with me. It is hard because I would like to be with Mom. There are things I like about having a special sister. She helps with the laundry and cleaning up. Elyssa empties the dishwasher. I like to teach her to do things. I like to teach her new words. Soon she is walking and it is fun to teach her to dance. She entertains my friends and makes them laugh. My friends love her. Elyssa shares her things and we all share in her development. We all feel proud when she does things because it takes her

longer and she has to work harder to learn. Elyssa makes my family closer. I love my sister. (Jennifer Weisman [Age 7], *My Sister Has Down Syndrome*)

My only sibling, Elyssa, is five years younger than me and has a developmental disability. The combination of my personal background and my professional work with college students has led me to wonder what the college experience is like for other students with a sibling with a developmental disability. I believe that my own college experience was affected in countless ways by my role as a sibling. This awareness of the significance of my status as a sibling during college led to an interest in researching this topic. My personal reflections on being a sibling are discussed in more detail later in this chapter.

Notes About Language

There were two important considerations about language used in this study. First, there was the need to use “People First Language;” which literally puts the person first in writing and speech. A standard example is “person with a disability” instead of “disabled person.” This type of language has also been emphasized in disability studies literature. Linton (1998) and Zola (1993) both noted that for groups without social and political power, the act of naming themselves in their preferred language is crucial. Zola argued that for people with disabilities, the labels for their medical conditions are often assumed by others to encompass their entire identity, dehumanize them, and open the door for stereotypes. Important language considerations include the use of active versus passive words, the difference between being something and having something, terms such as “suffering from” or “afflicted with,” and the need to use prepositions instead of nouns and adjectives (Zola). In this study, language that doesn’t follow People First Language

principles was present in original quotations from the literature or excerpts from participants' interviews.

The second consideration was that, in discussions of this research topic, there were at least two siblings being referenced, a sibling with a disability and a sibling without a disability. These multiple references could easily become confusing and often lengthy; the full descriptor of the population was "college students who have a sibling with a disability." In an effort to reduce the wordiness and unclear referents, whenever possible the phrase "college student siblings" was used to refer to the population being studied. In general, the "sibling" descriptor referred to the sibling without a disability; this usage is consistent with the literature.

Overview of the Research Problem

At first glance, the experience of having a sibling with a developmental disability seems rather unique and perhaps not prevalent enough to merit focusing substantive research and services. However, the estimated number of persons in the United States with a sibling with mental retardation is as high as three million (Siegel & Silverstein, 1994). The number only grows larger when other disabilities are considered (Meyer & Vadasy, 1994); the Sibling Support Project (2007a) notes that there are "over six million brothers and sisters of people with special health, mental health, and developmental needs" (§ 1). The President's Committee on Mental Retardation (1997) has estimated that "nearly 30 million, or one in ten families in the United States, are directly affected by a person with mental retardation at some point in their lifetime" (§ 1). There are over 17 million students enrolled in postsecondary institutions (Snyder,

Tan, & Hoffman, 2006) but there is no available estimate of the number of college student siblings.

The U.S. Department of Health and Human Services has defined developmental disabilities as:

Severe, chronic disabilities attributable to mental and/or physical impairment, which manifest before age 22 and are likely to continue indefinitely. They result in substantial limitations in three or more areas: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency, as well as the continuous need for individually planned and coordinated services. (Administration on Developmental Disabilities, 2002, ¶3)

The National Center on Birth Defects and Developmental Disabilities (2002) noted that “mental retardation is the most common developmental disorder” (¶ 6) and is “characterized both by a significantly below-average score on a test of mental ability or intelligence and by limitations in the ability to function in areas of daily life, such as communication, self-care, and getting along in social situations and school activities” (¶ 1). The severity of these conditions can have far-reaching implications for the daily lives and experiences of both the individual with a developmental disability and his or her family members.

Public awareness about the experience of having a sibling with a disability has been increasing. Since 2002 at least six books have been published about the experience of having a sibling with some type of disability (P. Karasik & J. Karasik, 2003; Meyer, 2005; Safer, 2002; Simon, 2002a; Smith, 2002; Strohm, 2002). Two of these books were based on clinical work with siblings, and all six included many personal reflections on having a sibling with a disability. Additionally, articles and essays about this topic have been featured in local and national magazines and newspapers, increasing awareness of

the topic outside of academia and social services (Borchert, 2004; Cowley, 2005; Jensen, 2001; J. Karasik & P. Karasik, 2003; Lindbergh, 2002; McHugh, 2003a; Melia, 2001; Mont, 2002a, 2002b; Simon, 2002b). People with a sibling with a developmental disability have even made it to the world of network television movies (O'Donnell, 2005) and the front page of the *New York Times* (Gross, 2004).

Service agencies have recognized the needs of siblings and offer programs for siblings that focus on providing support and information (Dyson, 1998; Lobato, 1990; Lobato & Kao, 2002; Meyer & Vadasy, 1994; Powell & Gallagher, 1993; The Sibling Support Project, 2007b). One national model of sibling support programs for children, called Sibshops, has been in existence for 25 years (D. J. Meyer, personal communication, December, 28, 2006).

Prior research on siblings of people with a developmental disability has at least five limitations. First, there are only a minimal number of studies on the specific sub-population of college student siblings. Second, the limited amount of research that has examined college student siblings did not study their experiences during college. Third, there is an imbalance in the literature; quantitative studies are more common than qualitative studies. Fourth, there are general inconsistencies in the results. Fifth, the research framework has often assumed that having a sibling with a disability would result in negative outcomes.

One limitation deals with the small amount of research on college student siblings. Although an increasing body of knowledge examines siblings of people with a developmental disability, most of the prior studies have focused on children in grades K-12 or post-college adults. Even the many first-person accounts have had little to say about

the experience of having a sibling with a disability during college; a group interview with four college student siblings did not focus on how their higher education experience was being affected (Klein & Schleifer, 1993). Three research studies have looked at college student siblings (Burton & Parks, 1994; Grossman, 1972; Kibert, 1986) but none has extensively examined how having a sibling with a disability could influence students' experiences during college. Grossman's study was the most extensive and examined college students' adaptation to having a sibling with mental retardation. Despite the valuable information provided by this clinically based research, the contemporary relevance is in question because of the changes that have occurred in the climate for people with disabilities. Since the late 1960s, when the data for Grossman's study were collected, the environment for people with disabilities has changed so much that a more current examination is needed. One example of these changes is legislation that increased educational and vocational opportunities for people with disabilities (U. S. Department of Education, 2001; Young, 1997). It is reasonable to assume that these opportunities could affect the families of these individuals. Thus, a contemporary examination of college student siblings could provide data that reflect the current environment.

The other two studies on college student siblings (Burton & Parks, 1994; Kibert, 1986) are more recent and both utilized quantitative methods to examine specific outcomes. Kibert studied different aspects of college student siblings' perceptions, and Burton and Parks looked at self-esteem, locus of control, and career aspirations. Although both studies were a valuable addition to the literature, they examined discrete aspects of siblings' college experiences instead of an approach that considered their lives as a whole.

A second limitation of the current research is that the existing studies on college student siblings do not provide a holistic look at how siblings experience college. Psychosocial development theory can be used as one of the lenses for viewing college student siblings' experiences. When the literature on siblings is looked at in conjunction with psychosocial development theory and research, several potential intersections emerge. Researchers have found variations in the applicability of psychosocial development theory with different student populations (Evans, Forney, & Guido-DiBrito, 1998). Some of the most well-known research in this area looked at differences related to gender, race, and sexual orientation (e.g., Fassinger, 1998; Pope, 2000; Taub & McEwen, 1992); other studies have looked at how development can be influenced by specific pre-college experiences, such as childhood sexual abuse (White & Strange, 1993) and family background variables such as parents' marital status and family functioning (e.g., Heyer & Nelson, 1993; Johnson & Nelson, 1998). This current project extends the existing research by examining another part of students' family backgrounds, having a sibling with a developmental disability. Several researchers consider the experience of having a sibling with a developmental disability to be distinctive, with specific challenges (e.g., Crnic & Leconte, 1986; Lobato, 1990; Powell & Gallagher, 1993). This study explored how the college experience may be distinctive for siblings.

Additionally, excerpts from first-person and clinical accounts have suggested that siblings may have specific concerns about college, including the college choice process and adjusting to life on campus (Hart, 1989; McHugh, 2003b; Meyers, 1978; Safer, 2002). Safer's discussion of the guilt many siblings feel about their own accomplishments included the story of one woman who felt immense guilt over being

able to do things that her brother with brain damage could not. As a result of those feelings, her desire to attend college created a problem, albeit one she solved:

Sandy has found some ingenious ways around her dilemma: “I chose a women’s college because he couldn’t have gone there even if he could have attended college, so it was my own space.” The campus had the additional advantage of being thousands of miles away, so she could conceal her achievements more successfully. (p. 117)

Robert Meyers’ (1978) memoir of growing up with a brother with mental retardation included the following poignant passage:

College began to loom as something that would break up “the family.” My father, whose pride in me has always been boundless, began debunking it: Your college education is coming at exactly the wrong time. Ninety-five percent of all college teachers don’t know a thing they’re talking about. You can get a good education anywhere. (p. 72)

Unable to resist the family pressure, Meyers moved with his family to Florida to attend a school he had vehemently resisted and where he spent “the worst three years in my life” (p. 73).

Another memoir written by a person with a sibling with a disability touched on the complex issues related to going away to college (Hart, 1989). The following excerpt includes references to the desire to escape from a sibling with a disability, comparisons between siblings, guilt, long-term caretaking worries, and identity development:

As graduation from high school approached I looked for opportunities to leave home. I had no clear plans for my future beyond escape. Almost miraculously, I received a scholarship to Harvard.

When my father proudly wrote the news to his brother, Uncle Scott wept that “Edgar finally had something to be proud of.”

Although my mother hated to see her youngest child move so far away from home, Harvard was a symbol of prestige and achievement that she couldn’t deny me.

She and Daddy helped me prepare for the journey and took me to the airport. It was a strained farewell. I felt guilty and tried to hide my excitement at beginning a new life as they hid their worries about their future alone with Sumner.

They looked so old and defenseless beside their thirty-eight-year-old son. We all shared the same unspoken concern: how long could they care for him without me? In my new college life, I found it very easy to forget about Sumner. For the first time, I had the chance to establish my own identity among people who knew nothing about my family. (Hart, 1989, p. 25)

When Mary McHugh (2003b) went to college, she also found herself forgetting about her brother, who had cerebral palsy and mental retardation. Her experience of leaving home to attend college was transformative:

I fled to Wheaton, a small women's college on a lovely, secluded campus in southeastern Massachusetts. I didn't know at the time that I wanted to get away from my brother. I just knew that I had to escape the tense, angry, atmosphere in that house – my mother's nagging, my father's silence, my brother's mental retardation.

Going away to college was like leaving the black-and-white part of the Wizard of Oz and going to the color part. I was surprised by "normal" people, smart people, happy people. I loved it there. My roommate, Ann, was the sister I had always longed for. We could talk the night away about boys and parents and life. We could study or not study (usually not). We could go to the basement and smoke; play poker or bridge; talk to other "normal" people; laugh and joke; and obsess about clothes, hair, boys, men's colleges, and food. (p. 129)

McHugh's excitement about being around "normal" people is evident in her reflections about going to college; she was clearly thrilled to be participating in the same activities as her "normal" classmates. The wonder she felt at these everyday events suggests that college student siblings may experience college differently. These daily activities were new and significant for her, yet they probably wouldn't seem remarkable to most college students or even some high school students.

Prior research suggests that some of the developmental tasks often connected to the college experience may be challenging for siblings; siblings may experience isolation

from peers, guilt about leaving home, embarrassment, extra responsibility in the home, or restrictions in social activity (Lobato, 1990; Meyer & Vadasy, 1994). The current study addressed the limited scope of the research on college student siblings by exploring potential intersections between having a sibling with a developmental disability and experiences during college.

A third limitation of the current literature is the lack of balance in methodological approaches, with quantitative research studies outnumbering qualitative studies. It is important to learn about the topic from both qualitative and quantitative research. Gall, Gall, and Borg (2003) discussed the two approaches as complementary, and Glaser and Strauss (1967) supported the idea that theory generation benefits from both types of data. Additionally, the complexity of the college student sibling experience seems to require a body of research that approaches the topic from a variety of view points.

Holistic and comprehensive data on siblings of people with disabilities were missing in many of the prior research studies that used quantitative methods to look at specific outcomes rather than focusing on overall experiences and development (e.g., Abramovitch, Stanhope, Pepler, & Corter, 1987; Bischoff & Tingstrom, 1991; Burton & Parks, 1994; Dyson & Fewell, 1989; Hannah & Midlarsky, 1999; McHale & Gamble, 1989; O'Kane Grissom & Borkowski, 2002). The most typical method in the quantitative studies involved comparing a group of children with a sibling with a disability to a group of children with a "normal" sibling on a variety of measures and then analyzing the results using statistical analyses. These comparison measures included written self-report instruments completed by the siblings, coded behavioral observations completed by researchers, parental rating scales and observations, siblings' self-reports of activities and

behaviors, and behavior checklists completed by parents and teachers. Although parental and teacher reports provided valuable data, an over-reliance on these measures could lead to a lack of emphasis on the siblings themselves.

The results of existing research suggest that there may be a complex combination of effects for siblings of people with disabilities that may not be able to be easily described through quantitative methods alone. Qualitative studies with a more holistic focus on the experiences of people with a sibling with a disability are needed to fill in some of the gaps in the literature and will complement the existing quantitative research. Marshall and Rossman (1999) noted that a qualitative approach is well-suited for complex topics. A balance between qualitative and quantitative approaches is also important because each can contribute to the other – the results of a qualitative study may provide quantitative researchers with new concepts to investigate (Gall et al., 2003). Additionally, contradictory or confusing results from quantitative studies may suggest other relevant areas to be explored in a qualitative study.

A fourth limitation of the prior research is the lack of consistency in the results. Cuskelly (1999) noted, “to anyone reading the literature reporting research studies of the psychological adjustment of the siblings of individuals with a disability, the overwhelming impression is one of contradiction and confusion” (p. 111). Research on the influence of having a sibling with a developmental disability has focused on a wide variety of outcomes. Some researchers have examined psychological variables such as self-concept (e.g., Dyson & Fewell, 1989), self-esteem (e.g., Bischoff & Tingstrom, 1991; Burton & Parks, 1994; Hannah & Midlarsky, 1999; McHale & Gamble, 1989), overall perceived self-efficacy (O’Kane Grissom & Borkowski, 2002), psychological

well-being and adjustment, often including specific outcomes such as anxiety and depression (e.g., Breslau, 1982; Hannah & Midlarsky; McHale & Gamble), and adaptation and coping (e.g., Cox, Marshall, Mandlco, & Olsen, 2003; Nixon & Cummings, 1999). Other research has focused on more social factors: behavior problems (e.g., Dyson, 1989, 1999), interactions and relationships (e.g., Abramovitch et al.; Bischoff & Tingstrom; McHale & Gamble), daily activities and household responsibilities (e.g., McHale & Gamble; Stoneman, Brody, Davis, Crapps, & Malone, 1991), and social skills and peer relationships (e.g., Mandlco, Olsen, Robinson, Marshall, & McNeilly-Choque, 1998). The critical area of family functioning is another topic that has been studied (e.g., Phillips, 1999; Sgandurra & Fish, 2001). One of the previously discussed studies with a sample comprised of college students siblings looked at the variables of locus of control and career aspirations (Burton & Parks).

In examining the literature as a whole, specific results and predictors have often been inconsistent. Studies have reported both negative and positive effects of having a sibling with a disability, as well as many studies in which there was no significant effect (Rossiter & Sharpe, 2001; Summers, White, & Summers, 1994). Hannah and Midlarsky (1985), in their review of the literature, concluded that research suggested that having a sibling with a disability “places one at high risk for psychological distress. However, authors in this research domain range widely in the predictions of the degree to which adverse outcomes may occur and of the nature of the adverse manifestations” (p. 511). Hannah and Midlarsky also noted that although this negative view was prevalent there have been studies that suggest that having a sibling with a disability can also offer advantages.

Another possible reason for the lack of agreement in the research is the complexity inherent in the lives of siblings and the failure of prior research to examine the context for siblings' experiences (Crnic & Leconte, 1986; Skrtic, Summers, Brotherson, & Turnbull, 1984). Crnic and Leconte offered an explanation based on an ecological perspective of siblings:

The conflicting nature of the research on the sibling relationship reflects, in part, the difficulties apparent in research design, as well as the dynamic nature of these relationships. The roles, responses, and feelings of the nonhandicapped sibling toward the handicapped child are not likely to be static, but rather change as the sibling adapts to the handicapped child, and copes with the day-to-day process of interacting with the handicapped sibling in the various ecological contexts of which they are a part. (p. 78)

The fifth limitation is the “pessimistic view” (Hannah & Midlasky, 1985, p. 511) of having a sibling with a disability. Others have noted this use of a deficit perspective in research as well as the assumption that the experience of having a sibling with a disability might create inherently maladaptive behaviors (Boyce & Barnett, 1993; Crnic & Leconte, 1986; Cuskelly, 1999; Meyer & Vadasy, 1994; Simeonsson & McHale, 1981). Meyer and Vadasy elaborated on this idea:

The child with special needs was seen as a burden to the family, and the family itself was assumed to be dysfunctional, experiencing chronic sorrow and pervasive guilt. Positive signs, such as optimism, were frequently interpreted as a sign of denial, not as a sign of strength. (p. 51)

Instead of what they called the pathogenic paradigm, Meyer and Vadasy advocated for a salutogenic approach to families that recognizes the positive opportunities that can result from having a sibling with a disability. These benefits can include increased maturity, self-concept and social competence, insight, tolerance, pride, vocational opportunities, advocacy, and loyalty (Meyer & Vadasy). Using this paradigm, researchers would not

make the assumption that having a brother or sister with a disability would uniformly damage siblings and could recognize that positive outcomes are also possible.

Purpose of the Study

The purpose of this study was to examine how college students who have a sibling with a developmental disability experience college. The data from this study were used to create a conceptual model that illustrated how these students experienced college. Previous research has shown that students' experiences of college can vary based on factors such as race, gender, sexual orientation, pre-college experiences, and family background (e.g., Fassinger, 1998; Heyer & Nelson, 1993; Pope, 2000; Taub & McEwen, 1992; White & Strange, 1993). Additionally, the literature on people with a sibling with a developmental disability has acknowledged the uniqueness of the sibling experience; at each phase of siblings' lives they have specific needs and concerns (e.g., Crnic & Leconte, 1986; Lobato, 1990; Powell & Gallagher, 1993). Having a sibling with a developmental disability is a substantial part of a student's family background and could influence the way college student siblings understand their undergraduate experience; this study examined this previously unexplored intersection.

A qualitative methodology was selected in order to provide a holistic look at the experiences of these students and overcome limitations of many prior research studies. Denzin and Lincoln (2000) argued that qualitative researchers "seek answers to questions that stress *how* social experience is created and given meaning" (p. 8), and this was the type of question being addressed in this study. By conducting research on college student siblings and focusing on how they experience college, this study attended to the first and second limitations, the lack of research on this population and the absence of information

about their experiences and development during college. The third limitation, the imbalance in the literature that favors quantitative approaches, was overcome by the choice of a qualitative method. Creswell's (1998) definition of qualitative research describes the benefits of this framework:

Qualitative research is an inquiry process of understanding based on distinct methodological traditions of inquiry that explore a social or human problem. The researcher builds a complex, holistic picture, analyzes words, reports detailed views of informants, and conducts the study in a natural setting. (p. 15)

The presentation of the participants' views and a holistic representation of their lives as college students were important in examining a complicated topic such as experiences during college. A qualitative approach was also useful in tackling the fourth limitation, the inconsistencies in prior research. Although one study cannot remove an inconsistency in a large body of research, the results of this study have the potential to fill in some gaps. Patton (2002) emphasized that "the advantages of qualitative portrayals of holistic settings and impacts are that greater attention can be given to nuance, setting, interdependencies, complexities, idiosyncrasies, and context" (p. 60). The lack of agreement in the literature on siblings suggests that the experience is intricate and dependent on various contextual influences (Crnic & Leconte, 1986; Skrtic et al., 1984); a qualitative approach is an appropriate way to examine such an experience. Skrtic et al. specifically suggested a qualitative perspective in their call for future research. The fifth limitation, the use of the deficit perspective, was avoided by making the explicit assumption that having a sibling with a developmental disability could involve both positive and negative experiences and outcomes.

The specific type of qualitative methodology used for this research was constructivist grounded theory; like most qualitative methodologies, grounded theory

differs from quantitative approaches because of its inductive approach (Patton, 2002). In grounded theory, “the researcher begins with an area of study and allows the theory to emerge from the data. . . grounded theories, because they are drawn from the data, are likely to offer insight, enhance understanding, and provide a meaningful guide to action” (Strauss & Corbin, 1998, p. 12). A theory with these likely properties was consistent with the practical implications of the research discussed later in this chapter. Constructivist grounded theory, as described by Charmaz (2000), shifts away from the positivist assumption of an “external reality” (p. 513) found in earlier approaches to grounded theory:

A constructivist approach to grounded theory reaffirms studying people in their natural settings and redirects qualitative research away from positivism. My argument is threefold: (a) Grounded theory strategies need not be rigid or prescriptive; (b) a focus on meaning while using grounded theory *further*s, rather than limits, interpretive understanding; and (c) we can adopt grounded theory strategies without embracing the positivist leanings of earlier proponents of grounded theory. (p. 510)

This study used constructivist grounded theory methodology to explore the following primary research question: how do college students with a sibling with a developmental disability experience college? Individual, in-depth interviews with traditionally aged college students with a sibling with a developmental disability, along with written materials shared by some participants, provided the data for inductive analysis and served as the basis for the conceptual model.

Self as Researcher

A tenet of qualitative research is that “the researcher is the instrument” (Patton, 2002, p. 14). When the role of the researcher is defined in this way, one’s personal background and experiences become relevant. As noted at the beginning of the chapter,

my interest in this topic stems from my own identity as a person with a sibling with a developmental disability. I believe that my experience as a sibling has sensitized me to issues that college student siblings may face. However, my personal connection to the research topic also required caution; it was important to make sure that my beliefs weren't projected onto the data. In addition to maintaining a careful awareness of this possibility, several measures were taken to ensure the credibility of the research. These included peer debriefing, an inquiry audit, and member checks. A more detailed discussion of these processes is included in Chapter III.

Being a sibling is a central part of my identity and has affected every aspect of my life. Because I was the only child without a disability in my family, I felt pressure to be a high achiever – although this pressure was never expressed directly, I felt I was the “one shot” for the “normal” things parents expect. I have strong perfectionist tendencies that I connect to this pressure. In college I often felt more mature than many of my classmates since I had so much more responsibility at home and spent more time by myself. I was often at a loss to understand how casually some of my classmates took their academics, and the culture of drinking and random sexual encounters was foreign to me. Although class and religious differences between many of the students on campus and me also increased this isolation, I still connect some of this loneliness with having a sibling with a developmental disability. Another issue was always feeling different. I was different from the majority of the students because of my socioeconomic status, my religion, my political orientation, and lack of membership in a sorority. The fact that my sister looked and acted different from other students' siblings only added my feeling of being different. For example, because my sister had a disability, my job options during the summers were

limited since I needed to be available to pick her up from camp. Trying to explain this, and other facts about my family life, was often awkward and added to the isolation. The following description by a person with a brother with a disability has always rung true to me:

Later on, when asked the simple question, “What grade is your brother in?” I either had to lie or divulge something about myself that I was unprepared to reveal. At a time when blending in was the most important thing in my life, I stood out. (Siegel & Silverstein, 1994, p. 7)

Despite all of the wonderful services available to my sister and the love and attention my parents provided for me, we weren't aware of any formal support services for children with siblings with disabilities. Although I went to many events with my sister over the years, such as Special Olympics and school functions, I didn't meet many other siblings like myself. Prior to the start of this research project I had met other siblings only through random encounters. When I met other siblings the sense of connection was usually instantaneous. The mix of both positive and negative emotions about the sibling experience sometimes makes it difficult for me to have truly honest discussions with peers whose siblings do not have disabilities. Casual conversations about families often evoke feelings of sadness about my lack of a “normal” sibling relationship, and I sometimes find I am jealous of friends who can talk to siblings about adult topics and concerns. My own conversations with my sister can only go so far because of her limited cognitive capacities, and I often struggle for things we can discuss. At times it seems surreal, this sense that literally and figuratively she is still in a place that I left a long time ago.

As both my sister and I grow older, different issues arise. The process of planning my wedding, with such a focus on families, again brought into sharp focus the contrast

between my family and families without a child with a disability. Elyssa was thrilled to be asked to be the maid of honor of my wedding but some aspects of that role had to be dispersed to other members of the bridal party, leading to occasionally awkward situations. At times I longed to have a more “traditional” wedding, without having to explain once again why part of my life didn’t fit the norm. I realize, of course, that the perfect family is a myth, but it didn’t stop me from feeling very different from other brides. Additionally, as we went through the process of talking about our marriage and future together, my fiancé and I discussed the fact that my parents have designated me to be my sister’s legal guardian if anything happens to them. This is a sobering conversation to have, and most significant others are not asked to accept such a heavy level of future responsibility so early in a relationship.

Many of my peers have been tremendously empathic about my experiences with my sister. However, they cannot truly understand how different my sibling relationship really is, and I have struggled with my efforts to express what it is really like. Writing those few sentences about my struggles with my sister’s role in my wedding felt almost like a betrayal and I immediately wanted to erase them, so nobody would see what a terrible sister I was. There is some comfort in knowing that this feeling may be common; Meyer and Vadasy (1994) observed that siblings may feel guilty about “harboring less-than-charitable feelings about their siblings” (p. 13).

This guilt can sometimes be exacerbated because people who are unfamiliar with individuals with a developmental disability often harbor idealized notions about them. The description of them as “angels” or “blessings” is one of my least favorite. This doesn’t mean that I believe that people with disabilities don’t have a large number of

positive characteristics, just that these simplistic comments fail to acknowledge that people with a developmental disability are just like everyone else, they have good traits and bad traits. Having a disability does not place one above worldly emotions and actions. Strangers and even close friends don't always understand that fact, and sometimes my sister's negative traits and behaviors are viewed as cute or funny. Both strangers and friends don't realize that her stubbornness is not "feisty" or amusing when dealt with on a regular basis. Martha Beck (1999), whose son Adam has Down syndrome, described this phenomenon better than I ever could. In this passage, she describes talking with a psychic who tells her that Adam is an angel:

I cleared my throat. "Adam has Down syndrome," I said.

The psychic didn't seem surprised at all. She just shrugged.

"That," she said, "has nothing to do with it."

This was what clinched my belief in her psychic gifts. If she had said "Oh, yes, that makes it perfectly clear; *all* our little retarded brothers and sisters are angels," I would have looked upon her with a more jaundiced eye. I've heard that line many, many times, from people so sanctimoniously sweet that just standing near them will rot your teeth. These are the same people who always tell me that God would never give *them* such a child, because they are too weak to be deserving. They are the people who look at Adam and then tell me, in a stage whisper, "Mongoloids are always so content, aren't they?" I wish these "contented-mongoloid" theorists had to deal with Adam when he's sleep deprived or his dad is out of town or his sisters are picking on him. It's true he doesn't indulge in the sort of morose weeping to which I am prone. Mostly he dismantles the furniture. But there are definitely times when he is not content. (pp. 261 - 262)

People with siblings with disabilities often learn that the "normal" rules of sibling behaviors and relationships don't always apply. In "normal" families there is generally not a stigma for expressing negative thoughts about a sibling, and fights and disagreements are often commonplace and accepted as a fact of life (Meyer & Vadasy, 1994). However, when a child with a sibling with a disability expresses negativity about

their sibling's embarrassing, frustrating, or even violent behavior, their parents may chastise them and tell them that "your brother can't help how he acts" or "you need to be more patient." These differences between "normal" families and families with a child with a disability can remain into adulthood. For example, there is generally no real stigma for an adult who doesn't have frequent contact with a sibling, but an adult with a sibling with a disability is often expected to maintain high levels of contact and responsibility.

Safer (2002) offered a clinical perspective on this double-standard:

Nobody simply grows apart from a damaged brother or sister, as do people with functioning siblings whose lives diverge; obligation, guilt, or the need to repudiate are too great. Whether they rebel or comply, their parents' admonition to take care of the troubled one makes them maintain at least minimal contact; an involuntary bond binds them together. (p. 80)

Having a sibling with a developmental disability has changed and influenced my life in more ways than I will ever really realize, and this influence will continue throughout my lifetime. These influences are often positive and often challenging. There is no simple way to summarize what it's like to have a sibling with a developmental disability and there is no clichéd happy ending to the story.

My own history has provided me with a valuable perspective about the experiences of college student siblings but it was important to approach this research with the assumption that each participant in the study would have their own set of thoughts, feelings, insights, and experiences. My experiences as a college student sibling were important, and my goal was to explore the meaning of these experiences for other siblings and help other siblings through the application of the study's results.

Significance of the Study

Although the literature on siblings has expanded, “research on siblings of individuals with disabilities remains underdeveloped” (Hodapp, Glidden, & Kaiser, 2005, p. 334). The importance of a developmental perspective in sibling research has also been emphasized: “Are there particular times during development – transition points for either the sibling or for the brother or sister with disabilities – that are more difficult?” (Hodapp et al., p. 336). This study provides an in-depth look at the understudied population of college student siblings and offers valuable knowledge about a specific period in siblings’ lives. Findings of this study also can provide a more contemporary and holistic view that complements the previous research on college student siblings.

This study can bridge the gap between the existing research on college student siblings and what is already known about students’ experiences during college. The study can extend the current understanding about college student siblings and provide important information for professionals. Limitations of prior research are addressed by using a qualitative framework that enables the voices of the siblings to be heard and allows a more inclusive picture of their lives as college students to emerge. The idea that growing up with a sibling with a disability can be damaging has been prevalent in prior research (e.g., Boyce & Barnett, 1993; Crnic & Leconte, 1986; Meyer & Vadasy, 1994), and the current study can provide current perspectives of the experiences of college student siblings. This research study uses constructivist grounded theory methodology to explore the experiences of college student siblings and create a conceptual model based on those experiences.

The results of this study can have important implications for student affairs professionals and researchers by contributing to the limited amount of knowledge about college student siblings, beginning the process of theory development based on this population, and providing results that can be used in professional practice. The importance of theory is important in both student affairs practice (Evans et al., 1998; McEwen, 2003) and sibling research and services (Cox et al., 2003). An extension of student development theory that addresses college student siblings' experiences can help student affairs professionals to meet the needs of this population and be aware of specific developmental issues.

The use of a constructivist grounded theory approach results in a theory that provides important information about how college student siblings experience college. This theory has the potential to reveal the complexity of the college experience for siblings and explore the multiple ways that their time in college may be influenced by having a sibling with a developmental disability. The positives and negatives of college student siblings' lives are explored, with the resulting theory highlighting the depth and breadth of their experiences in college. The results of this study can extend existing knowledge and theory about students' experiences, further understanding of college student siblings, and provide a foundation for student affairs professionals' work with this population.

Summary

This chapter provided an introduction to the research question addressed in this study: how do college students with a sibling with a developmental disability experience college? Chapter II reviews relevant research on people with a sibling with a disability.

Chapter III outlines the research design for this study, including the specific procedures for data collection, data analysis, and profiles of the participants. Chapter IV provides the results of inductive data analysis and proposes a conceptual model of the experiences of college student siblings. Chapter V discusses the results within the context of prior research on siblings, reviews the strengths and weaknesses of the study, and addresses the implications of the study for future college student sibling research and professional practice.

CHAPTER II

LITERATURE REVIEW

This chapter begins with a brief overview of important concepts from the general literature about siblings. Before examining the research on people with a sibling with a disability, it is important to consider what the research has to say about sibling relationships and the influence of this relationship on individuals. This information provides a foundation for the research that focuses specifically on siblings and disability. The examination of the literature on people with a sibling with a disability includes a history and overview of relevant research, a general discussion of outcomes studied, and the mediating factors that have been shown to influence those outcomes, followed by a detailed review of the research on college student siblings.

General Sibling Research

The sibling relationship was not an early focus of family research (Cicirelli, 1995), but researchers and clinicians now recognize the potential importance of having a sibling:

The sibling relationship is life's longest lasting relationship, longer, for the most of us by a quarter of a century, than our ties to our parents. It lasts longer than our relationship with our children, certainly longer than with a spouse, and, with the exception of a few lucky men and women, longer than with a best friend. (Bank & Kahn, 1997, p. xv)

Research in this area has been expanding and covers a broad range of issues (Dunn, 1992). Bank and Kahn's extensive clinical work on siblings resulted in the concept of sibling bonds, which they describe as follows:

After many years of observation we believe that the sibling bond

- Remains an island of stability and familiarity in a world where very little remains as it once was: it is a storehouse of memory.

- Is lifelong, marking the earliest memories we hold, and with us at life's end, defining and configuring our mortality. When a brother or sister falls ill or dies, we truly understand our own mortality and vulnerability.
- Is, for many people, a relationship which defines one's life journey. Siblings are, for better or for worse, each other's ultimate fellow travelers.
- Becomes a repository of secrets, some shame-filled, some nostalgic, some primitive, some painful, of times in our childhood when no parents were present to observe, deter, or punish.
- Satisfied for some the childhood need for attachment and solace.
- Sadly, for some, is permanently damaging or can be inconsequential. (Bank & Kahn, 1997, p. xviii)

Experimental research complements Bank and Kahn's (1997) clinical observations about the importance of the sibling relationship and provides more specific information about the actual relationship and how it can influence individual outcomes (Dunn, 1992). The sibling relationship has three important influences: the development of emotional experience and expression, social experiences and skills, personality, and language and motor skills; relationships with others; and learning about peers, dating, and modern culture (Lobato, 1990). Some specific outcomes that have been shown to be affected by having a sibling include aggressive behavior, self-esteem, internalization and externalization of problems, competitiveness, prosocial and cooperative behavior, altruism, nurturance, conflict management, and general social skills (Dunn; Powell & Gallagher, 1993; Siegel & Silverstein, 1994). Regardless of the presence of a disability in a family, siblings are influential in many meaningful ways. The next section will review research that examines how the additional factor of disability can increase the complexity of the sibling relationship.

Research on Individuals with a Sibling with a Disability

This chapter reviews information about siblings from clinical sources and empirical research, an approach that provides a broad range of knowledge about siblings.

Knowledge about siblings is often available from these two different sources and each has its advantages and disadvantages. Limitations of clinical research include the following: specific information about how clinicians came to their conclusions is not always provided; their observations may be based on small samples that may differ from the population due to research participants' presence in treatment; and their interpretations could be influenced by their biases and backgrounds. Although there can be issues of bias in experimental research, the risk of this seems greater in a clinical setting because of the more interpersonal nature of the interactions. Despite these drawbacks, clinically based research can provide rich and detailed information that goes beyond scores on instruments. Methodological critiques of experimental research on siblings have included: examining too wide an age range in one study, aggregating participants with siblings with different types of disabilities, lack of appropriate instrumentation, including more than one sibling from each family in studies, using data from parents and not the siblings themselves, using inappropriate control groups, ignoring larger contextual influences on siblings, making the assumption that siblings will demonstrate negative outcomes, and the lack of racial diversity in samples (Cuskelly, 1999; Rowitz, 1993; Simeonsson & McHale, 1981; Skrtic et al., 1984; Stoneman & Brody, 1984). Although there are some limitations to experimental research on siblings, these types of studies are an extensive and valuable source of information on how people are influenced by having a sibling with a disability. Well-designed empirical studies offer data, as opposed to clinical interpretations, and can be analyzed in a more systematic way.

Overview of General Findings

The majority of the studies on siblings have focused on children, not adults (Rossiter & Sharpe, 2001). These children have had siblings with a variety of disabilities: mental retardation, Down syndrome, autism, speech disorders, visual impairments, hearing impairments, and physical disabilities, as well the general category of developmental disabilities and multiple disabilities (e.g., Dyson, Edgar, & Crnic, 1989; Hannah & Midlarsky, 1999; Kaminsky & Dewey, 2001; Mandlco et al., 1998; O'Kane Grissom & Borkowski, 2002). Outcomes that have been investigated can be divided into three categories: psychosocial variables; family functioning variables; and behavioral and relational outcomes.

Some of the initial research on siblings of persons with a developmental disability focused on the effect of a child with Down syndrome on other children within the family (Gath & McCarthy, 1996). Prior to the 1950s, children with Down syndrome were often institutionalized from birth, sometimes out of concern for other children in the family (Gath & McCarthy). As this practice became less common and more children with Down syndrome began to be raised in the family home, parents had questions about how their children without disabilities might be affected by keeping their child with Down syndrome at home (Gath & McCarthy). Other questions about siblings of people with a developmental disability arose from clinicians' concerns about difficulties encountered by siblings undergoing clinical treatment (Boyce & Barnett, 1993; Cuskelly, 1999). Throughout the 1960s, 1970s, and 1980s, most of the literature reflected the view that siblings were at greater risk for negative outcomes and could be expected to demonstrate

poor adjustment (Cuskelly, 1999; Senapati & Hayes, 1988; Simeonsson & McHale, 1981; Summers et al., 1994).

One exception to this pessimistic view was a 1962 study of 21 adolescents (aged 13-18) who had a sibling with mental retardation (Graliker, Fishler, & Koch, 1962). Through interviews with the adolescents Graliker et al. conducted a general assessment of each sibling, their family relationships, and their attitudes toward their sibling with mental retardation and institutional care of their sibling. Based on these interviews, they found no negative effects on the adolescents in terms of their daily life and family relationships and accepting attitudes about their siblings and any current or future plans for institutional care (Graliker et al.). The positive results of this study are promising, especially during a time when a deficit perspective seemed to be so prevalent. However, the conclusions are lessened by some methodological weaknesses. The sample was small and representative only of an urban area. Additionally, the teenagers' families were participating in a longitudinal study that appeared to involve services from a multi-disciplinary team and thus may not have been representative of most families during that time period. The source of some of the data was not always explicit; the authors described several Likert-style scales for different aspects of the teenagers' lives but it was unclear if the resulting ratings were self-ratings from participants or were based on the interviewer's assessment of the participants' answers. In addition to the difficulties related to the source of the data, there were additional problems with the measures used in the study. The authors did not provide any information about validity and reliability of the measures and the approach seemed too simplistic for an involved topic such as relationships in families. For example, family life was measured in the following way:

“Two points were given for those who found family life happy; one, for those who described it as average, neither too happy not too unhappy; and zero, where there was an awareness of tension” (Graliker et al., p. 840).

The positive outcomes reported in Graliker et al.’s (1962) early study were not representative of the prevailing view in the literature. Psychiatric accounts of negative outcomes for siblings remained the dominant view in the literature:

Although these early reports lacked any empirical bases, they were uncritically accepted by many writers and researchers and surprisingly still have some currency today. Interest in the fate of siblings with individuals with a disability grew during the 1970s but because of the acceptance of the fact that they were more likely to have problems than were those from families in which all the children were developing normally, few studies were conducted which included comparison groups. Rather, the focus of research was on trying to pinpoint just who was the most vulnerable. (Cuskelly, 1999, p. 111)

The negative view of families with children with a developmental disability began to diminish in the 1970s but did not entirely disappear (Helff & Glidden, 1998). An analysis of researchers’ views of these families over the next 20 years showed a decline in negative views but no corresponding increase in positive views; despite this decrease negative views toward the families remained prevalent (Helff & Glidden).

Boyce and Barnett (1993), in their review of research on siblings of people with mental retardation from the 1960s through the 1980s, identified some important shifts within the field of sibling research. First, research design began to be informed by different theories, such as ecological systems theory, as well as advances in statistical analysis (Boyce & Barnett). Second, changes within society were reflected in the research findings; these changes included smaller families, more single-parent families, increased lifespans for people with disabilities, decreased instances of institutionalization, improved educational opportunities for children with disabilities, and changing attitudes

about disability (Boyce & Barnett). These substantial societal shifts may limit the applicability of earlier research on siblings and should be taken into account (Powell & Gallagher, 1993).

Meyer and Vadasy (1994) provided a useful overview of common issues faced by persons with a sibling with a disability and highlighted what they called unusual concerns and unusual opportunities. These themes reflect the complexity of siblings' lives and were developed from the literature as well as the authors' extensive experiences working with siblings. Meyer and Vadasy identified unusual concerns of siblings such as overidentification; embarrassment; guilt; isolation, loneliness, and loss; resentment; increased responsibilities; and pressure to achieve. The unusual opportunities for siblings were maturity, self-concept and social competence, insight, tolerance, pride, vocational opportunities, advocacy, and loyalty (Meyer & Vadasy). Meyer and Vadasy's valuable overview of these concerns and opportunities is comprehensive and balanced. They identified possible challenges for siblings but didn't automatically assume that siblings would have negative outcomes. They also highlighted potential positive outcomes from being a sibling while acknowledging that the challenges still existed: "Many of the insights and opportunities, while invaluable, are hard-earned" (Meyer & Vadasy, p. 53). Lobato's (1990) summary of potential issues for siblings, compiled from interviews and essays with teenagers and adults, corresponds to many of the themes identified by Meyer and Vadasy. Lobato identified the following potential positive effects: maturity, responsibility, altruism, tolerance, humanitarian concerns and careers, sense of closeness in the family, and self-confidence and independence. Potential negative effects included feelings of parental neglect; feeling of resentment; perceived parental demands and

expectations for achievement; embarrassment; guilt about health; extra responsibility in the home; restrictions in social activity; and sense of distance in the family.

Some similar conclusions were present in a phenomenological study of nine adolescents (aged 13-18) with a sibling with Down syndrome (Wilkerson, 2001). This particular study was of interest because of the age group of the participants; it was helpful to learn about experiences from the developmental stage just prior to college. Based on interviews with the adolescent participants, Wilkerson characterized “the experience of having a sibling with Down syndrome” (p. 126) as having eight “essential themes” (p. 125):

The experience of having a sibling with Down syndrome

- Was all they have ever known.
- Included thoughts of the future which always incorporated the sibling and an awareness that they would always be intimately involved in the life of the sibling.
- Involved an increased workload and level of responsibility.
- Involved the development of pragmatism.
- Included being a role model to the sibling.
- Included having an intense love for the sibling.
- Included feelings of embarrassment because of the sibling’s behaviors.
- Taught patience, tolerance, understanding of others’ differences, altruism, compassion, and empathy. (p. 126)

One limitation of Wilkerson’s study is that it is more representative of the experiences of adolescents who have younger siblings with Down syndrome, as eight of the nine participants in the study were older than their sibling with Down syndrome. The effects of birth order are discussed in more detail later, but there is some evidence to suggest that birth order can have an effect on sibling outcomes (Lobato, 1990).

Additionally, like many other sibling studies (Lobato, Kao, & Plante, 2005), there was limited racial diversity; eight of the nine participants in Wilkerson’s sample were White.

Several meta-analyses of empirical sibling research from 1972 – 1999 examined whether the existing research actually supported the commonly held view that siblings were likely to have negative developmental outcomes (Rossiter & Sharpe, 2001; Summers et al., 1994). The first meta-analysis, by Summers et al., identified more negative findings than positive. In addition to this general analysis, Summers et al. also examined the quality of the research to determine if there was a relationship between the validity of the study and a finding of positive or negative outcomes for siblings. They found that sibling outcomes were slightly different when only the higher quality studies were examined; in over 75% of the higher quality studies the children with siblings with disabilities were not significantly different from children with siblings without disabilities. They concluded that “in spite of the prevailing claim of previous reviewers that siblings of children with disabilities behave more negatively, the evidence is not completely convincing” (Summers et al., p. 178). Summers et al. argued that the quality of the previous research was an important factor to consider when drawing conclusions from the literature and offered the following summary of the specific findings of their review:

It appears that generally, the siblings of children with disabilities display a tendency toward greater anxiety, withdrawal, aggression, agonism, and perhaps dominance. They demonstrate an equally strong tendency to higher levels of prosocial behavior. The magnitude of this impact as reported in the literature is influenced by both the quality of the study as well as the specific outcome variables that are measured. (p. 180)

Rossiter and Sharpe (2001), whose meta-analysis was designed to continue Summers et al.’s (1994) examination of the empirical literature, “found a statistically significant but small negative effect for having a sibling with mental retardation on the functioning of the typically developing sibling” (p. 76). In addition to looking at overall

effect, Rossiter and Sharpe's exploration of different methods of data collection and types of dependent measures used yielded other findings. They found that self-reported data by siblings "produced the smallest negative effect size" (Rossiter & Sharpe, p. 77) in comparison to parent survey and direct observation. One of the dependent measures, psychological functioning, was divided in five sub-categories: social functioning, depression, anxiety, internalizing behaviors, and externalizing behaviors. Of these five sub-categories, social functioning was the only one not consistently problematic for siblings (Rossiter & Sharpe). The results of these two meta-analyses provide a context for the discussion of specific outcomes in the next sections.

Outcomes

In this section, the variables examined in prior research have been organized into three categories: psychosocial variables, family functioning, and behavioral and relational outcomes.

Psychosocial Variables

Beginning with a more global measure, Hannah and Midlarsky (1999) studied general well-being or happiness in a matched sample of 100 children (aged 6–17); 50 of the children had a sibling with mental retardation, and 50 of the children had siblings without mental retardation. All of the children completed a self-report measure, the General Positive Affect scale; Hannah and Midlarsky found no significant differences between the two groups on this measure of well-being. The similarity between the two groups on this global outcome is positive, but an important limitation of the study is the wide age range of the participants; this wide age range meant that the entire sample spanned several developmental stages, which could have masked differences. The study

would have been strengthened by disaggregating the results by age group or choosing an initial sample with a smaller age range; the authors acknowledged that age is an important variable to examine (Hannah & Midlarsky).

Many of the studies within the sibling literature have focused on how siblings view themselves; researchers have examined self-esteem, self-efficacy, self-concept, and self-worth. Using a variety of self-report measures for these different variables, researchers frequently found no significant difference between children with a sibling with a disability and a control group (Bischoff & Tingstrom, 1991; Dyson, 1989; Dyson & Fewell, 1989; Eisenberg, Baker, & Blacher, 1998; Hannah & Midlarsky, 1999; Sgandurra & Fish, 2001). The lack of differences between the groups may not be limited to younger children. Dyson (1999) conducted a follow-up study of her 1989 research on self-concept. The original sample consisted of 110 children (aged 7 ½-15); 71 participants (aged 11-18) from the original sample participated in the follow-up study conducted four years later. In both the original study and the follow-up study the Piers-Harris Children's Self-Concept Scale was used to measure self-concept. Dyson found that there continued to be no difference in self-concept between the participants with a sibling with a disability and those with a sibling without a disability. O'Kane Grisson and Borkowski (2002), using the Perceived Self-Efficacy Scale, found similar results with an older sample of 27 adolescents (aged 13-18). In O'Kane Grisson and Borkowski's study of perceived self-efficacy in adolescent siblings there was no significant difference from the scores of the control group of 27 adolescents with siblings without disabilities.

There have been some exceptions to the finding that siblings' views of themselves do not differ from the views of people without a sibling with a disability. Sgandurra and

Fish (2001) used the Piers-Harris Children's Self-Concept Scale as their measure of self-concept. This measure was also used in several other studies of self-concept (Dyson, 1989; Dyson & Fewell, 1989; Eisenberg et al., 1998). Sgandurra and Fish's comparison of the groups based on an ANOVA was consistent with other studies and also showed no significant differences. However, in a regression analysis, the family group (child with a disability or child without a disability) and family problem solving communication were significant predictors of siblings' self-concept (Sgandurra & Fish). Additionally, with family problem solving communication held constant, the siblings' self-concept was lower in the families with a child with a disability, Sgandurra and Fish suggested a possible explanation for this finding: "perhaps due to the fact that siblings of children with special needs are frustrated by inevitable family challenges and their involvement in family conflicts" (p. 9).

In a study on self-esteem, McHale and Gamble (1989) found that children with a sibling with a disability had significantly lower scores than children with a sibling without a disability on the Harter's Perceived Competence Scale. There was also a gender difference, with girls with a sibling with a disability showing significantly lower scores on the self-esteem measure than the other groups (McHale & Gamble). Nastasi (1997) and Bischoff and Tingstrom (1991) both used the same self-esteem measure, the Domains of Self-Perception Profile for Children, on samples that were somewhat similar in number and age, 48 children (aged 8–12) and 32 children (aged 6–13) respectively. In Bischoff and Tingstrom's study, the global self-esteem score and scores on the five subscales were not significantly different between the 16 children with a sibling with a disability and a control group of 16 children without a sibling with a disability. In

contrast, Nastasi found significant differences between the groups on the global self-esteem score, as well as on the subscales for athletic competence, social acceptance, and physical appearance; in all cases the children without a sibling with a disability scored higher than the children with a disability. In addition to having the children complete the self-esteem instrument, Nastasi used the same instrument to collect data from parents and teachers about the children. The children's teachers reported no significant differences on the global measure or subscales but there was a significant difference between the two groups of parents on the social acceptance subscale; the children without a sibling with a disability were seen by parents as having more friends than the children with a sibling with a disability (Nastasi).

Mandelco et al. (1998) and Nastasi (1997) both studied children's social skills using the Social Skills Domain of the Social Skills Rating System (SSRS), with subscales measuring cooperation, assertion, responsibility, empathy, and self-control. In both studies children's teachers completed the Social Skills Domain of the SSRS. Mandelco et al. found that the 39 children with a sibling with a disability were rated significantly higher than the control group of 39 gender and age matched children on the cooperation and self-control subscales. Nastasi found that children with a sibling with a disability were rated lower than the control group on the overall social skills measure. In addition to having the children's teachers complete the Social Skills Domain of the SSRS, Nastasi also had the children and their parents complete the same measure. On these two administrations of the Social Skills Domain of the SSRS there was no significant difference between the children with a sibling with a disability and the control group. Finally, Nastasi looked at an additional domain of the SSRS, the Academic Behaviors

domain. The children's teachers completed Academic Behaviors domain of the SSRS and Nastasi found no significant difference between the children with a sibling with a disability and the control group.

Based on a variety of measures from different studies completed by both parents and teachers, several studies have shown that children with a sibling with a disability generally did not have more problem behaviors than their peer comparison group (Bischoff & Tingstrom, 1991; Dyson, 1989; Mandlco et al., 1998; Nastasi, 1997). One longitudinal study suggested that these results were stable over time (Dyson, 1999). Of all of the different measures for general problem behaviors, school problems (attention or learning problems), atypicality, withdrawal, adaptability, leadership, social skills, study skills, and social competence, the only significant difference was that teachers perceived children with siblings with disabilities to be more likely to withdraw from others (Nastasi).

Compared to the teacher and parent reports, self-report measures completed by the children revealed a somewhat different picture of siblings' views of themselves and their behaviors (Nastasi, 1997). Based on the scores on the scales for school maladjustment, clinical maladjustment, person adjustment, and emotional symptoms, the children who had siblings with a disability "perceived themselves to have more negative emotions and more problem behaviors than siblings in the control group" (Nastasi, p. 43).

Competence is another important outcome that has been frequently studied in the sibling literature (Bischoff & Tingstrom, 1991; Dyson, 1989; Hannah & Midlarsky, 1999; Nixon & Cummings, 1999; O'Kane Grissom & Borkowski, 2002). On measures of overall social competence completed by parents and teachers in four different studies,

only one study showed a difference between siblings and the control group (Bischoff & Tingstrom; Dyson; Hannah & Midlarsky; Nixon & Cummings). Nixon and Cummings, in their study of 60 children (aged 7-15), found that children with a sibling with a disability were rated lower in overall social competence by their parents. When specific aspects of social competence were examined, there were significant differences in two of the subscales of social competence. As assessed by both mothers and teachers, boys (aged 6-17) with a sibling with a disability were considered to be lower than the control group on the school functioning measure (Hannah & Midlarsky). In another study, parents of children with a sibling with a disability reported that their children (aged 7 ½ -15) were less active in sports and non sports activities (Dyson). The lack of differences in social competence was not only present in children; similar results were found in a sample of adolescents (aged 13-18) (O'Kane Grissom & Borkowski). On the emotional support and negative assertion subscales of the Adolescent Interpersonal Competence Questionnaire, there were no significant differences between the 27 adolescents with a sibling with a disability and the 27 adolescents with a sibling with no disability (O'Kane Grissom & Borkowski).

Depression and anxiety have generally been examined as part of the larger categories of externalizing and internalizing behaviors reviewed below, but in some cases these outcomes were studied separately. McHale and Gamble (1989) studied 62 children (aged 8–14) and used self-report instruments to examine both depression and anxiety, the Childhood Depression Inventory (CDI) and the Revised Children's Manifest Anxiety Scale (R-CMAS). The results on these measures indicated that children with a sibling with a disability experienced more depression and anxiety than the control group.

However, it is important to note that although there were significant differences, the sibling group's scores on the depression and anxiety measures were still within normal ranges (McHale & Gamble). Sgandurra and Fish (2001) also used the R-CMAS to measure anxiety in their sample of 56 children (aged 8–14) and found no significant differences in anxiety between the sibling group and the control group. Regression analysis in Sgandurra and Fish's study showed that, for both groups, better family problem solving communication was related to lower levels of anxiety.

Many researchers have examined externalization and internalization in children and adolescents who have a sibling with a disability (Bischoff & Tingstrom, 1991; Eisenberg et al., 1998; Hannah & Midlarsky, 1999; Nastasi, 1997; Nixon & Cummings, 1999). Internalization is defined as anxious, depressed or inhibited behaviors and externalization is aggressive or uncontrolled behaviors (Hannah & Midlarsky). Based on the Child Behavior Checklist completed by parents about their children, four separate studies found no difference in internalizing behaviors between children and adolescents with a sibling with a disability and a control group (Bischoff & Tingstrom; Eisenberg et al.; Hannah & Midlarsky; Nixon & Cummings). The same measure completed by the children themselves and the Behavior Assessment System for Children (BASC) completed by parents also showed no significant differences in either internalizing or externalizing behaviors (Eisenberg et al.; Nastasi). Nastasi, using the BASC completed by teachers about children, found that children with a sibling with a disability had higher levels of internalizing behaviors than the control group but no difference between the groups on externalizing behaviors. Results from the Child Behavior Checklist completed by parents showed some variation in levels of externalizing behavior; two studies found

no differences between the groups of children (Biscoff & Tingstrom; Eisenberg et al.), and in Nixon and Cummings's sample the children with a sibling with a disability were reported as having significantly more externalizing behaviors than the control group.

Family Functioning Variables

Given that siblings are part of the family system, many studies have examined how the family environment may be different when there is a child with a disability. Some of the research reviewed in this section focused on the family system as a whole and not specifically on siblings, but it does provide a strong foundation for understanding how their life within the family may be affected.

Several studies of broad aspects of family functioning have found either no differences or minimal differences between families with a child with a disability and families with no children with disabilities (Mahoney & O'Sullivan, 1992b; Mandleco et al., 1998; Sgandurra & Fish, 2001). In comparison to a normative sample, families with a child with a disability differed on only one subscale of the Family Environment Scale; they scored significantly higher on the Moral-Religious subscale (Mahoney & O'Sullivan). In another study, parents' perception of family functioning did not differ between families with and without a child with a disability (Mandleco et al.). In Sgandurra and Fish's study, families with a child with a disability did not differ from the control group on measures of family adaptability or family cohesion.

Some studies have also examined more specific aspects of family functioning in families with children with disabilities, such as problem solving, coping skills, marital conflict, and parental depression (Costigan, Floyd, Harter, & McClintock, 1997; Mandleco et al., 1998; Sgandurra & Fish, 2001). Two studies have examined specific

aspects of family problem solving. Sgandurra and Fish looked at how families communicate during problem solving using the Family Problem-Solving Communication scale; their results indicated no significant difference on this measure between families with a child with a disability and families with a child without a disability. Costigan et al. looked at the actual problem solving process in 165 families with a child with mental retardation and 52 families without a child with mental retardation; they videotaped families as they discussed a specific problem and attempted to reach a resolution. In the analysis of those observations, Costigan et al. found some significant differences in how the two groups of families solved problems. The differences between the family groups included: parents of children with mental retardation had higher levels of directive behavior; single mothers of children with mental retardation had lower levels of supportive problem solving behavior than single mothers without children with mental retardation; and children of both genders (aged 6-12) with a sibling with mental retardation had decreased amounts of active problem solving compared to a control group of girls in the same age range (Costigan et al.). However, Costigan et al. found that, overall, the family roles between the two groups were similar and the families with a child with mental retardation demonstrated resilience to disruptions.

Sgandurra and Fish (2001) found that on a measure of family coping skills, families with a child with a disability used two coping strategies, acquiring social support and mobilizing family support, at significantly higher levels than the comparison group. Sgandurra and Fish noted that these families “more regularly face overwhelming family problems (e.g., childcare, financial stress, emotional support)” (p. 3) and utilize support-

based coping strategies “in order to function similarly to families not coping with disabilities” (p. 3).

Mandelco et al. (1998) studied marital conflict in families with a child with a disability, based on the idea that this variable can have an effect on children. Using a self-report measure from both parents, there was no difference in reported marital conflict in front of children between the families with a child with a disability and the control group (Mandelco et al.). However, some correlations showed differences in how children responded to marital conflict. For both groups of children, higher levels of marital conflict were significantly correlated with less positive social skills (Mandelco et al.). However, the specific types of less positive social skills differed between the children with a sibling with a disability and the control group (Mandelco et al.). For the children with a sibling without a disability, as marital conflict increased, there was a decrease in cooperative behavior; for the children with a sibling with a disability, as marital conflict increased there was an increase in internalizing and externalizing behavior and a decrease in self-control (Mandelco et al.).

In two studies of families with a child with a disability, the mothers or fathers have shown higher levels of depression than the comparison group of families without a child with a disability (Mandleco et al., 1998; Nixon & Cummings, 1999). Nixon and Cummings reported differences in maternal depression, although it is important to note that the levels of depression in both family groups were within the normal clinical range. Mandelco et al. found that levels of depression in the families with a child with a disability were higher for both mothers and fathers; there was not enough information available to determine if those rates were outside normal clinical range. These findings

are particularly important because of research showing that “depression may be directly and indirectly related to children’s social skills” (Mandleco et al., p. 113). Negative effects could include social withdrawal, adjustment problems, and internalizing and externalizing behaviors (Mandleco et al.). In their sample of 52 children, Mandelco et al. found that for the children with a sibling with a disability, maternal depression was correlated with internalizing behavior.

Behavioral and Relational Outcomes

Just as children’s family functioning may vary when they have a sibling with a disability, their relationship with their sibling and their daily life may also be different. Research studies in the sibling literature have examined the sibling relationship, sibling roles, attitudes toward siblings, daily activities, and responses to conflict and other stressors (Bischoff & Tingstrom, 1991; Brody, Stoneman, Davis, & Crapps, 1991; Cox et al., 2003; Johnsey, 2000; McHale & Harris, 1992; Mobley, 1984; Nixon & Cummings, 1999; Stoneman, Brody, Davis, & Crapps, 1988; Stoneman, Brody, Davis, Crapps, & Malone, 1991).

Some research has suggested that sibling relationships can differ when one of the children has a disability. A review of two studies that used the Sibling Relationship Questionnaire (SRQ) suggests that these differences may not affect all aspects of the relationship and do not always reflect negative relationships when a child has a disability (Bischoff & Tingstrom, 1991; Johnsey, 2000). Both studies compared families with a child with a disability to a control group of families. Bischoff and Tingstrom looked at siblings aged 6-13 and Johnsey looked at siblings aged 6-17. The SRQ produces four factor scores measuring distinct aspects of the sibling relationship: Warmth/Closeness,

Power/Status, Conflict, and Rivalry. Additionally, the Rivalry factor contains two subscales, Maternal and Paternal Partiality. There are specific versions of the measure for parents and children. Discussions of the results of these studies are presented by factor scores.

On the Warmth/Closeness factor, no significant differences were found between the groups on both the child and parent measure (Bischoff & Tingstrom, 1991; Johnsey, 2000). Results of the Power/Status factor scores varied between studies. Johnsey found no significant differences between the groups on both the child and parent measure of Power/Status levels but in the Bischoff and Tingstrom study, compared to the control group, the parents with a child with a disability “perceive[d] a greater difference between their child [without a disability] and his/her younger siblings [with a disability]” (¶25). Given that children with disabilities often need a great deal of caretaking, it is not unusual that their parents would perceive them as having less Power/Status than their siblings (Bischoff & Tingstrom). In that same study, based on the child version of the SRQ, children did not perceive any differences in Power/Status (Bischoff & Tingstrom). There were varied results for the Conflict factor scores; in the Johnsey study higher levels of Conflict were reported by both parents and children in families without a child with a disability but no differences were found in the parent and child measures in the Bischoff and Tingstrom study. There were no differences for parents and children on the general Rivalry factor score in either study (Bischoff & Tingstrom; Johnsey). However, in one of the studies there was a disparity on one of the subscales of the Rivalry factor, Maternal Partiality: “siblings of children with disabilities perceive their siblings as receiving more

attention and being more favoured by the mothers than did siblings of children without disabilities” (Bischoff & Tingstrom, ¶24).

Crnic and Leconte (1986) highlighted some of the difficulties in capturing definitive results about sibling relationships:

The conflicting nature of the research on the sibling relationship reflects, in part, the difficulties apparent in research design, as well as the dynamic nature of these relationships. The roles, responses, and feelings of the nonhandicapped sibling toward the handicapped child are not likely to be static, but rather change as the sibling adapts to the handicapped child, and copes with the day-to-day process of interacting with the handicapped siblings in the various ecological contexts of which they are a part. (p. 78)

In addition to potential variations in the sibling relationship, children who have a sibling with a disability may have different attitudes towards their sibling. One study of 60 children (aged 5-11) found that children with a sibling with a disability had more positive attitudes toward their siblings than children with a sibling without a disability (Mobley, 1984).

Daily activities of children with a sibling with a disability have been a consistent focus in both the research and clinical literature (e.g., Boyce & Barnett, 1993; Lobato, 1990; McHale & Harris, 1992; Meyer & Vadasy, 1994; Simeonsson & McHale, 1981). Based on a series of telephone interviews with 62 children (aged 8-14), McHale and Harris found a difference in the activities of children with a sibling with a disability and children with a sibling without a disability. The children with a sibling with a disability spent significantly more time in caretaking activities with their sibling, and the children with a sibling without a disability spent significantly more time doing chores with their sibling. There were no differences between the two groups for leisure and recreational activities (McHale & Harris). For all of the children in the study, there was a significant

positive correlation between the duration of caretaking activities and symptoms of anxiety. An analysis of depression symptoms disaggregated by gender and sibling group found that only the girls had a significant correlation between caretaking activities and depression. Specifically, girls with a sibling with a disability had a significant positive correlation between caretaking and depression, and girls with a sibling without a disability demonstrated a negative correlation. McHale and Harris were careful about emphasizing these correlations: “our findings did not lead us to conclude that any one set of experiences will necessarily put children with disabled siblings at risk for adjustment or relationship problems” (p. 97).

Variations in caretaking activities, household responsibilities and peer contacts were explored for both older and younger siblings of children with mental retardation (Stoneman et al., 1988; Stoneman et al., 1991). In the study of older siblings (aged 6–12), older sisters of girls with mental retardation had significantly more childcare responsibilities than other groups (Stoneman et al., 1988). The results of the data from younger siblings (aged 4-10) of children with mental retardation were the same as those found by McHale and Harris (1992): younger siblings of children with mental retardation had more childcare responsibilities than the control group, and the control group had more household responsibilities than the younger siblings of children with mental retardation (Stoneman et al., 1991). Based on these same studies of younger and older siblings, having a sibling with mental retardation was not related to contact with their peers (Stoneman et al., 1988; Stoneman et al., 1991). Research on daily activities of younger siblings of children with mental retardation highlighted a unique result of the increased caretaking responsibilities. In addition to higher levels of childcare tasks, the

context of those tasks was considered “atypical of the role relationships of siblings in the general population” (Stoneman et al., 1991, p. 547). This distinction resulted from the role reversal that occurred with children with a sibling with a disability, they were taking on childcare tasks for their older siblings, something that would be unfamiliar for most children (Stoneman et al., 1991). A review of research from a 30-year period comes to a similar conclusion about sibling roles and relationships:

In many ways, including frequency of interactions and positive exchange, the relationship between a child with a disability and his or her sibling is much like the relationships between nondisabled siblings, but atypical relationships seem to be qualitatively different in that they are characterized by a greater frequency of caregiving, teaching, and dominating behaviors by the nondisabled siblings. (Boyce & Barnett, 1993, p. 178)

In two different studies researchers examined how children responded to family conflict and daily life stressors (Cox et al., 2003; Nixon & Cummings, 1999). In research by Nixon and Cummings, 60 children (aged 7-15) listened to pre-recorded family conflicts, answered questions about the conflicts, and responded to an open-ended question about how they would respond if the conflict occurred in their family. When compared to the control group, the children with a sibling with a disability demonstrated more negative emotional reactions, reported more negative or burdensome cognitions, used more involved coping strategies and fewer avoidance strategies, and responded to low-intensity conflicts more quickly. Cox et al.’s examination of siblings’ coping responses seems to be consistent with Nixon and Cummings’ conclusions on coping strategies. In the Cox et al. study, 46 children (aged 6–18), all with a sibling with a disability, gave open-ended responses to sentences about different stressful situations. Content analysis of their responses showed that 65% of the responses were proactive, 19% were interactive, 13% were internally reactive, and 3% were nonactive (Cox et al.).

There was, however, an important difference between these two studies. The siblings in Cox et al.'s sample were completing open-ended sentences about their self-reported response to a verbal descriptor. In Nixon and Cummings' study the children were listening to audio taped family conflicts and then answering questions. Although the children in Nixon and Cummings' study were not listening to a recording of their own family arguing, the experience may have been more realistic than the sentence completion exercise. As with many of the other studies on siblings, the wide age range of the participants weakens the validity of the findings.

Mediating Influences

Specific outcomes are not the only important part of the sibling literature; a comprehensive discussion would be incomplete if the role of mediating influences was not included. Clinical and empirical research have shown that there are numerous factors that can mediate the influence of having a sibling with a disability (e.g., Boyce & Barnett, 1993; Lobato, 1990; Powell & Gallagher, 1993; Rossiter & Sharpe, 2001). The framework used for the discussion of mediating influences was based on Lobato's review of individual differences between siblings. Mediating influences were classified as characteristics of the child with a disability, characteristics of the sibling, and characteristics of the family.

Characteristics of the Child with a Disability

Type and severity of the disability. In general, the specific type of disability does not appear to be an important influence on siblings (Lobato, 1990; Powell & Gallagher, 1993; Simeonsson & Bailey, 1986). The severity of the disability has been shown to influence siblings' adjustment in some research (Grossman, 1972; Siegel & Silverstein,

1994) but this effect is not consistent and often interacts with other mediating influences (Lobato; Powell & Gallagher). Simeonsson and Bailey suggested that this variation in results may relate more to child-specific variables than the type of disability: “The reaction of siblings is likely to be mediated by individual differences of the handicapped child in the form of traits, temperament, and functional behavior as much as it is by the nature of the handicapping condition itself” (p. 75).

Place of residence. Some research has tried to determine if the child with a disability’s place of residence has any influence on their sibling’s adjustment, but much of this research is of questionable relevance because of societal shifts and changes in residential options (Blacher, 1993; Lobato, 1990). The research that is available offers conflicting results on how siblings’ adjustment differs when their sibling with a disability lives outside of the home (Blacher; Lobato). Blacher highlighted the need for more current research that focuses not only on how siblings are influenced by these out-of-home placements but if there are differences based on when the placement occurs in the family lifespan.

Age. Some research has suggested that as the person with the disability ages, his or her sibling experiences more negative outcomes (Boyce & Barnett, 1993; Lobato, 1990). Possible explanations for this finding include intensified caretaking needs for the person with a disability and increasingly obvious disparities in development (Boyce & Barnett; Lobato).

Gender. Studies on the influence of gender on siblings have primarily focused on the gender of the sibling without a disability. There is minimal research on the influence of the gender of the person with a disability, and what is available offers no consistent

conclusions (Lobato, 1990). A more detailed discussion of gender influences is provided in the next section, focusing on characteristics of the sibling.

Characteristics of the Sibling

Age. Lobato's (1990) review of research on differences in adjustment between siblings in different age groups suggests that children with a sibling with a disability may experience more negative outcomes when they are younger. Lobato suggested that this difference could be attributed to three different factors. First, younger children may have difficulty comprehending their sibling's disability (Lobato). Second, their sibling's diagnosis may have been more recent and "their parent's reports of more behavioral problems may reflect this period of greater emotional instability" (Lobato, p. 56). Finally, younger children "may have fewer opportunities for establishing associations and friendships outside the family. Their happiness and satisfaction may be more exclusively dependent on family matters; whereas older, school-age children usually begin to develop interests and close relationships outside the family" (Lobato, p. 56).

Birth order and age spacing. Lobato (1990) has observed the importance of birth order and age spacing as influences: "Of all the fixed, unchangeable factors that may mediate sibling functioning, sibling constellation variables such as age-spacing and birth order appear to play the strongest role in sibling adjustment" (p. 56). It is important to note that birth order by itself is not as important as the interaction between birth order and gender (Lobato; Siegel & Silverstein, 1994). A more detailed discussion of research on the associations between gender and sibling outcomes is provided in the next section on gender.

Research on age spacing has suggested that a wider age gap, generally three years or more, between siblings is related to more positive outcomes (Dyson, 1989; Lobato, 1990; Siegel & Silverstein, 1994; Simeonsson & Bailey, 1986). Siegel and Silverstein offered some explanations for this finding:

The close-in-age sibling, especially if younger, tends to be particularly deprived of parental time and may be cared for by a variety of older siblings, relatives, and others who are helping out. A more psychological barrier that exists between close-in-age non-handicapped siblings and their parents is that their developmental level is a concrete reminder of the degree and reality of their developmentally disabled sibling's shortcomings. . . . Some parents deny or minimize the accomplishments of the close-in-age non handicapped sibling, so that the contrast to the developmentally disabled child seems not to be so marked. (p. 30)

Research on the influence of birth order and gender on siblings' adjustment has found that there tend to be more adjustment problems among older sisters and younger brothers (Lobato, 1990; Siegel & Silverstein, 1994). Consistent with earlier discussions about atypical roles when the sibling is younger than the child with the disability, younger siblings may be more likely to experience adjustment difficulties (Simeonsson & Bailey, 1986). Lobato (1983) also pointed out that the lack of control groups for many of the studies on birth order and gender requires caution when interpreting the results: "Thus, at the time, there is no way of concluding whether the greater psychological impairment found for younger brothers and older sisters is attributable to the presence of a disabled child or to that general status position within the family" (p. 355).

Gender. Researchers have also observed gender differences in outcomes related to having a sibling with a disability (Boyce & Barnett, 1993; Grossman, 1972; Hannah & Midlarsky, 1985, 1999; McHale & Gamble, 1989; Meyer & Vadasy, 1994; Powell & Gallagher, 1993; Siegel & Silverstein, 1994). Boyce and Barnett, in their review of 30

years of research on siblings, noted that of the different mediating variables “gender was most frequently investigated, and the findings indicate that gender differences, which are probably due to gender role expectations, exist” (p. 173). These gender differences often included higher amounts of caretaking responsibilities for sisters (Grossman; Meyer & Vadasy; Powell & Gallagher; Siegel & Silverstein). Gender differences have also been found in some psychosocial outcomes (McHale & Gamble; Nixon & Cummings, 1999). McHale and Gamble reported that “girls with disabled siblings experienced lower global self-esteem than did children in another other group” (p. 425). Nixon and Cummings found that, compared to girls with siblings with disabilities, boys had more externalizing behaviors.

However, these differences are not universal. One sample of 33 children (aged 5-17) with a sibling with autism found no gender differences on self-concept, academic achievement, home adjustment, and school adjustment (Mates, 1990). Additionally, Dyson’s (1989) study of 110 children (aged 7 ½ -15) did not reveal any gender differences in self-concept, behavior problems, and social competence.

Characteristics of the Family

Family size. Grossman’s (1972) study of college students with a sibling with mental retardation found that for the female community college students there was a significant correlation between more children in the family and higher levels of adaptation. Other research has also suggested that siblings from larger families tend to have better outcomes on measures of adjustment than siblings from smaller families (Dyson, 1989; Lobato, 1990; Powell & Gallagher, 1993). There are several ways that being part of a larger family can benefit siblings without disabilities: caretaking

responsibilities can be spread out among more people; reduced parental attention can be supplemented by interactions with other siblings; and siblings may not feel isolated because of their unique family situation (Lobato; Siegel & Silverstein, 1994). In addition, being a member of a large family could help alleviate siblings' anxieties about future caretaking responsibilities; if there are more children in the family it provides more opportunities to share the guardianship later on and siblings know that they will not likely bear sole responsibility for future care. As with most mediating factors, these results are not universal. Mates (1990) did not find any significant difference in adjustment and performance of children with a sibling with autism based on family size.

Parental attitudes and family environment. Several reviews of the sibling literature have highlighted the importance of parental attitudes and adjustment as well as the family environment (Boyce & Barnett, 1993; Lobato, 1990; Powell & Gallagher, 1993). For example, O’Kane Grissom and Borkowski (2002) reported that having a mother who emphasized and modeled prosocial and empathic behavior influenced adolescents’ levels of self-efficacy. Another study found that family psychological factors such as parental stress, social support, relationship, personal growth, and system maintenance can influence children’s self-concept, behavior problems, and social competence (Dyson et al., 1989). These influences were present for both children with a sibling with a disability and children without a sibling with a disability, although different psychological factors were significant for each group (Dyson et al.).

Socioeconomic status. Some information about the potential influences related to socioeconomic status (SES) can be gained from Grossman’s (1972) study of 83 college students with a sibling with mental retardation. The sample included students from an Ivy

League college, a private women's college, and two community colleges. After examining the quantitative results of measures of adjustment and psychological health, Grossman determined that there were two different "family styles" – one for students from private universities and one for students from community colleges. These were also further differentiated by gender. Grossman concluded that the differences between the students from private schools and community colleges could be attributed primarily to sociocultural status; the families with students at private schools had more "economic and social resources" (p. 68) and the access to these resources made daily life easier. As a result, "this freedom from major deprivation and disruption, in the context of intense family ties, enabled more subtle aspects of the family members' reactions to the retarded child and his or her handicap to assume greater importance" (Grossman, p. 68).

Grossman (1972) noted that the financial circumstances of the community college students created a different type of family environment; fewer resources meant that "emphasizing the growth and development of each child to his or her maximum potential" (p. 69) wasn't a high priority. Additionally, there were increased expectations for children in the family; once they reached a certain age it was assumed that they would help the family financially or take on responsibilities within the household. Grossman concluded that this had a specific effect on the community college families: "The energy consumed by this effort left little available for intense interpersonal involvement among family members, and generally these families appeared loosely knit and relatively uninvolved with each other" (p. 69).

Although Grossman's (1972) study was limited by a small, non-racially diverse sample, it offers information about initial efforts to look at the influence of SES. In their

clinically based work, Siegel and Silverstein (1994) noted that the impact of socioeconomic status has not been studied extensively and suggested that for families with a higher socioeconomic status, having a child with a disability may have two contrasting effects. First, families with higher levels of education and income may be able to “understand the child’s problem more readily and buy helpful services more easily” (Siegel & Silverstein, p. 32). Second, expectations may decrease parents’ acceptance of a child with a disability, who “may be seen as more markedly deficient and therefore may bring more shame to educated or wealthier parents” (Siegel & Silverstein, p. 32).

One national research study explored family environment variables and found some empirical relationships between SES and various aspects of the family environment, as measured by the Family Environment Scale (FES) (Mahoney & O’Sullivan, 1992a). A full scale regression analysis using the scores on the FES as the dependent variable revealed only one significant relationship between SES and the family environment: there was a positive relationship between SES and “participation in recreational and intellectual/cultural activities” (Mahoney & O’Sullivan, p. 22). The researchers also discovered a significant difference in family environment between the families with a child with a disability and the normative sample, with families from the normative sampling having higher levels of participation in recreational activities. This finding seems particularly relevant for sibling issues – greater participation in recreational activities could be beneficial for siblings and may suggest advantages for siblings from higher SES families. This study also looked at the variation within the sample of families with a child with a disability; 17.5% ($n=88$) of the families were

classified as “High Problem,” meaning that their overall FES scores were lower than the national normative sample (Mahoney & O’Sullivan). Using logistic regression, the authors determined that SES was a significant contributor to families’ classification as “High Problem.” There are several limitations to this study, including the inclusion of only mothers and the dominance of White, two-parent households. Additionally, Mahoney and Sullivan acknowledged the absence of “the more extreme socioeconomic conditions” (p. 30) in their sample. In contrast to other research on this mediating factor, Dyson’s (1989) research on sibling adjustment included SES as a possible influence. Dyson’s results showed that SES was not related to siblings’ self-concept, behavior problems, or social competence.

It is difficult to make generalizations about the socioeconomic status of families with a child with a disability. Some information can be gleaned from the analysis of the participants’ demographic information from individual studies. Several studies have found significant differences between families with a child with a disability and families with a child without a disability, with the former at a lower socioeconomic status (Hannah & Midlarsky, 1999; Nixon & Cummings, 1999). Hannah and Midlarsky attributed the difference in their study to fewer dual income families among families with a child with a disability. Nixon and Cummings observed that, despite the statistical differences in SES between the two groups of families, both groups were considered to be middle class. In contrast, Mandelco et al. (1998) reported higher levels of family income in the families with a child with a disability. Other studies, however, have found no differences between the family groups in socioeconomic status (Costigan et al., 1997; Dyson et al., 1989).

Race and ethnicity. In most explorations of mediating factors on children with a sibling with a disability, race and ethnicity have not been included. Research on sibling adjustment has primarily used European American families (Lobato et al., 2005). Although it hasn't often been explored in the literature, there are many ways that race and ethnicity can influence siblings.

One clinical perspective from the general literature on siblings offers the important observation that race and ethnicity have an effect on the sibling relationship: "Four major ethnic determinants which affect sibling relationships seem to be birth order, gender, separation/individuation, and emotional expressiveness" (Welts, 1988, p. 70). Sibling relationships can be affected by birth order and gender if there is a cultural tradition of favoring older children or male children (Welts). Relationships between siblings may also be different based on levels of separation/individuation (Welts). Welts also noted one possible result in ethnic groups with minimal displays of emotion: "Emotional distance of the parents promotes a closer sibling bond" (p. 76).

The relationship between culture, families, and siblings becomes more complex when disability is added as a factor. Culture may also be intertwined with views of disability, and it is important to recognize that many attitudes about disability are influenced by the dominance of a Western perspective (Harry, 1992). Beliefs about the origins of disability can have far-reaching implications and can influence a family's use of interventions or support services (Barnwell & Day, 1996; Hanson, 1992). Hanson offers a more detailed look at the relationship between these beliefs and involvement in services:

Certainly the views held by families about causation and disability will influence their need or willingness to seek help or intervention. Further, these views will

affect the degree to which the family elects to participate and the type of participation. (p. 10)

This relationship between beliefs about causation of disabilities and subsequent involvement in interventions can affect siblings. If parents' beliefs about the cause of their child's disability make them less likely to utilize support services, there could be an increased burden on siblings. Additionally, cultural differences can exist in the role of siblings within the family (Boyce & Barnett, 1993; Cicirelli, 1995). Boyce and Barnett offer a useful overview of the importance of studying the influence of culture on siblings: "Cultural expectations for sibling interaction, roles, and responsibilities, as well as for coping with the presence of a disability in a family member, may differ markedly among different ethnic groups" (p. 180).

It is important to note that there are many other factors in addition to race and ethnicity that influence people's beliefs and behaviors and there is often a great deal of variation within racial and cultural groups (Cho, Singer, & Brenner, 2000; Hanson, 1992; Harry, 1992; McCubbin, Thompson, Thompson, McCubbin, & Kaston, 1993; Rogers-Dulan & Blacher, 1995; Zhang & Bennett, 2001). For example, there may be within-group differences based on residency (immigrant or aboriginal population) and generational status (McCubbin et al.; Zhang & Bennett). There may be specific concerns for first generation siblings or siblings who immigrated to the United States at a young age. In addition to the different stresses often associated with having a sibling with a disability, these siblings may face the additional role of serving as their parents' "bridge" to schools, service providers, and the medical community by acting as a literal translator or a translator of unfamiliar medical, educational, and psychological terminology. Some research has found that language barriers can sometimes be a significant impediment to

parents' understanding and utilizing treatment and services (Cho et al.; Choi & Wynne, 2000). Parents may rely on their children without disabilities to help them navigate the often confusing worlds of medical treatment, special education, and social services.

Several empirical studies have attempted to examine families with a child with a disability from different racial and ethnic groups. Some studies looked at a single racial/ethnic group while others compared groups. Several researchers have noted that a Eurocentric perspective dominates the literature and have emphasized the need to study a wide variety of families (Boyce & Barnett, 1993; Lobato et al., 2005; Mary, 1990; Rogers-Dulan & Blacher, 1995). Boyce and Barnett specifically advocate for more sibling research with diverse samples. This section will briefly review the empirical and clinical research on families of color with a child with a disability; the discussion of these studies is organized by racial/ethnic group. It is important to note that, except for one study (Lobato et al., 2005), the literature reviewed was based on studies of families, not specifically siblings, because of the lack of information available about the influence of race/ethnicity on siblings. However, these studies are still valuable because of their ability to provide a context for examining and understanding siblings from diverse backgrounds.

Based on their clinical experiences, Siegel and Silverstein (1994) noted a high incidence of shame and denial in Asian American families with a child with a disability. They also found that "Asian parents also tend to lack an interest in joining support groups" (Siegel & Silverstein, p. 77). This clinical observation about underutilization of services is reinforced by other research (Choi & Wynne, 2000). A culture of shame around disability and a reluctance to use support services may also make Asian American

siblings less likely to seek out help for their own concerns. Additionally, a culture of shame related to disabilities could result in more silence around plans for the future, which could cause more anxiety for the sibling.

Ryan and Smith (1989) used an experience survey to conduct descriptive research with Chinese American parents who had a child with a developmental disability and received services related to the disability. In their sample of 59 families, Ryan and Smith found that for the majority of families, their child's disability was not diagnosed until the child was at least one year old. This delay in diagnosis affected treatment and awareness. Additionally, if families and medical staff did not share the same language, there was a risk that the families may not have had an accurate understanding of their child's diagnosis (Ryan & Smith). Ryan and Smith also discussed an important cultural belief about caretaking responsibilities that has possible implications for siblings: "Morally and legally, Chinese people still feel obligated to take care of their elderly, their children and the disabled. If they neglect their duty in taking care of the disabled, they can be criticized" (p. 295). The results of Ryan and Smith's study suggest that Chinese American siblings could have more caretaking responsibilities than other siblings as a result of a cultural emphasis on caretaking and a potential need to assist first-generation parents with any existing language barriers.

Latino families are underrepresented in the literature on disability issues (Skinner, Correa, Skinner, & Bailey, 2001) but there is some research available to provide information about the experiences of these families. In one study specific to siblings, Lobato, Kao, and Plante (2005) focused on psychological adjustment and knowledge of disability in children (aged 8–14) and compared a group of 20 Latino children with a

sibling with a disability to a matched control group of non-Latino children with a sibling with a disability. Scoring of qualitative interviews showed a significant difference between the Latino and non-Latino children on knowledge of disability, with Latino children showing “lower levels of accuracy for naming and for explaining the child’s disability” (Lobato et al., p. 629). Psychological functioning was assessed using parents’ responses to the Child Behavior Checklist (CBCL). Based on mothers’ responses, Latino children scored higher on internalizing problems and 75% of Latino children were considered above normal clinical ranges (Lobato et al.). There were other significant group differences based on a qualitative measure, the Three Wishes Interview, in which children made three wishes for themselves and parents made three wishes for their child without a disability (Lobato et al.). Compared to the non-Latino children, “Latino siblings reported more wishes about their relationship with their parents and family” (Lobato et al., p. 629). Finally, there was no significant difference between the groups on externalizing behaviors based on the CBCL or adjustment to disability as measured by the Sibling Perception Questionnaire (SPQ) (Lobato et al.).

Siegel and Silverstein’s (1994) clinical work with Latino families led them to make the observation that Latino families “tend to have more children, who make the family environment more normal, and who lessen the parental sense of failure over having produced a child with a disability” (p. 80). Skinner et al., in their empirical study, noted that religion often plays an important role in the lives of Latino parents with a child with a disability. In another study by Mary (1990), data from interviews with mothers of children with disabilities were analyzed to make comparisons between racial/ethnic groups. Based on interviews with 20 White mothers, 20 Black mothers, and 20 Latino

mothers, there were only two between-group findings and both were relevant for Latino families:

This self-sacrifice on the part of Hispanic mothers and reported denial on the part of Hispanic fathers suggests that Hispanic mothers may shoulder more of the emotional burden of the child's retardation than do White or Black or married mothers of children with retardation. (Mary, 1990, p. 3)

African American families have been viewed as typically providing a positive family environment for children with disabilities due to the presence of extended family, shared authority for caretaking among family members (including siblings), and "the more accepting attitude of African-American children" (Siegel & Silverstein, 1994, p. 82). Another factor that could contribute to siblings' levels of responsibilities is a reported tendency for African American families to be reluctant to utilize formal support services (Rogers-Dulan & Blacher, 1995). Harry (1992) has also noted that the historical legacy of misdiagnosis and overrepresentation of African American children in special education classes may foster a sense of mistrust toward schools. It is not known how this skepticism could affect siblings, but it is possible that delays in treatment or appropriate educational placement could have a negative effect on the entire family. In the study by Mary (1990), none of the African American mothers reported a sense of self-sacrifice or any denial on the part of their husbands. Finally, the prominent role of religion in the lives of African Americans and the relationship between religion and adjustment to having a child with a disability (Rogers-Dulan, 1998) is an important issue and will be discussed more fully in the section covering religion.

Finally, Barnwell and Day (1996) provide another discussion of racial/ethnic differences among families with a child with a disability. Their observation that "there is evidence that many minority families do not become involved in service delivery systems

and treatment programs” (Barnwell & Day, p. 49) could have important implications for siblings. If families utilize fewer services, then an even greater amount of responsibility for caretaking could fall onto siblings.

Religion. When examining the influence of religion on people with a sibling with a disability there are three important points to consider. First, the majority of studies on the topic of religion and disability focus on families in general, with minimal or no mention of siblings (e.g., Mahoney & O'Sullivan, 1992b; Marshall et al., 2003; Tarakeshwar & Pargament, 2001; Weisner, Beizer, & Stolze, 1991) This is clearly a large limitation but these studies have been included because they provide the best source of information about the possible relationship between religious background and siblings. Second, in many cases it is difficult to separate the influence of religion from the influence of race, culture, and ethnicity (Glidden, Rogers-Dulan, & Hill, 1999; Weisner et al.). Finally, the research in this area has primarily looked at Christian families. Although some studies have included families from other religions, generally the representation of non-Christian families in the samples has been minimal or absent (e.g., Tarakeshwar & Pargament; Weisner et al.). In the next section I will discuss research on the general relationship between religion and families with a child with a disability and then examine studies which focused on specific religions and racial/ethnic groups.

Siegel and Silverstein (1994), in their clinical work, and Grossman (1972) in her research concluded that, for many families, religious beliefs can offer a great amount of comfort and support when dealing with the challenges associated with having a child with a disability. Although Grossman was able to make anecdotal summaries about the influence of religion in her study, there were few consistent religious differences and no

definite connection between religion and the sibling experience. Several empirical studies have found a relationship between families' religious involvement and beliefs and their adjustment to having a family member with a disability (Mahoney & O'Sullivan, 1992b; McHale & Gamble, 1987; Tarakeshwar & Pargament, 2001; Weisner et al., 1991). McHale and Gamble, the only researchers to identify a relationship between religion and sibling outcomes, found that mothers with higher levels of religious activity "had and used more coping strategies for dealing with the stressors involved with disabled children's care" (p. 151). Additionally, there was a relationship between mothers' levels of religious activity and children's levels of self-esteem, depression, and anxiety that suggested more positive outcomes for the children of mothers with higher levels of religious activity (McHale & Gamble).

It is important to note that there is not always a universally positive relationship between religious belief and observance. Several studies showed that families could experience both positive and negative outcomes related to their religiosity (Rogers-Dulan, 1998; Tarakeshwar & Pargament).

Some studies have examined families of specific religions who have a child with a disability (Leyser & Dekel, 1991; Marshall et al., 2003). These results can offer valuable information for people working with siblings from different religious groups. One drawback of the research on religion and families with a child with a disability is that studies in the United States seemed to focus primarily on Christian families. For example, the only study that looked explicitly at Jewish families with a child with a disability has limited generalizability because it examined Orthodox Jewish families from an insulated area of Jerusalem (Leyser & Dekel). One study found that Roman Catholic

families may have a more accepting attitude toward a child with a disability when compared to Jewish or Protestant families (Zuk, Miller, Bartram, & Kling, 1961).

However, Zuk et al.'s study must be considered with caution, as it was published over 40 years ago.

Clinical work with Mormon (also known Latter-Day Saints or LDS) families in Utah suggested that religious beliefs and larger family size can be helpful for both the child with a disability and the other siblings: "There are enough siblings so that the burden of extra care and supervision that the disabled child requires does not fall on only one or two" (Siegel & Silverstein, 1994, p. 84). In a qualitative study of 32 LDS families in Utah, researchers found that religion was a major positive influence on these families (Marshall et al., 2003). Within a context of strong religious beliefs the experience of raising a child with a disability was seen as intensely spiritual and something that provided the entire family with a unique and important perspective on life (Marshall et al.).

The importance of religion in particular racial and ethnic groups has also been researched; studies have found high levels of religious belief and observance in Latino families (Skinner et al., 2001) and Korean American families (Cho et al., 2000). The importance of religion in the African American community and its role in facilitating a positive adjustment of a family member with a disability has also been noted in the literature (Alston & Turner, 1994; Glidden et al., 1999; King, 1998; Rogers-Dulan, 1998).

Within the sibling literature, very few studies have examined the influence of familial religiosity on siblings of children with a disability. However, some of the

research on families and religion offer some possible implications for siblings. For example, one example of religion as a source of stress was the difficulties associated with taking a child with autism to church: “It appears that the insensitivity of the church toward the challenges of raising an autistic child caused a strain on being able to function as a family” (Tarakeshwar & Pargament, 2001, p. 256). This negative influence on family functioning could have implications for siblings who may be deprived of the spiritual and community benefits of attending religious services. Additionally, it can serve as another reminder of how the sibling’s family is different. It is clearly positive when families’ religious beliefs can assist with the adaptation to the birth of a child with a disability. Several studies have found families who view these children as a challenge, test from God, or a blessing (Marshall et al., 2003; Skinner et al., 2001; Tarakeshwar & Pargament). These familial views may potentially influence siblings. It is normal for a child with a sibling with a disability to have negative feelings about their sibling. However, if their parents express the belief that the child with a disability is a blessing, siblings may understandably be fearful or reluctant to vocalize these normal feelings.

Themes from Research on Having a Sibling with a Disability

The previous review of sibling outcomes and mediating variables demonstrates that the literature on siblings is full of conflicting results that make it difficult to fully understand how individuals may be affected by having a sibling with a disability. Two conclusions emerge from this review: first, there is little agreement within the clinical and empirical literature on sibling outcomes and second, a wide variety of mediating factors influence those outcomes, often in combination with each other. In addition to these intersecting mediating factors, theories about the outcomes for siblings are difficult to

make due to two other reasons. First, methodological weaknesses in many of the studies hinder efforts to make comparisons and develop conclusions (Crnic & Leconte, 1986; Cuskelly, 1999). Complicating this problem is the fact that the literature includes research spanning several decades; within that time period there have been substantial changes in how society has viewed disability and how families with a child with a disability have changed (Boyce & Barnett, 1993; Powell & Gallagher, 1993). Second, the mixed results may be representative of the fact that being a sibling is a mixed experience that can rarely be characterized with simple descriptors: “These research difficulties (particularly the lack of control groups), as well as the fluid and complex nature of sibling relationships, limit the generalizations which can be made from the studies to date” (Crnic & Leconte, p. 77).

Cuskelly (1999) provided an extensive discussion of methodological weaknesses in the literature that could account for some of the conflicting results:

1. Variations in children’s ages across studies: Wide age range of participants in individual studies (i.e., sample is children aged 6-17), variations in age spacing of siblings, changes in the amount of self-disclosure as children age.
2. Measurement instruments: Differences in the sensitivity of measures among different populations, instruments producing results that are statistically significant but not clinically significant.
3. Use of multidagnostic samples: Variations in the sample related to different disabilities, including diagnosis, timeline of diagnosis, onset, etiology, stability, prognosis, visibility, and functional implications.

4. Multiple siblings: Differences in results when two children without disabilities from the same family are included in the sample.
5. Data collection: Over reliance on maternal reports, absence of data from fathers, lack of consistency in source of data across studies.
6. Failure to examine the effect of marital status on outcomes.
7. Control groups: Poorly chosen control groups, inadequate description of control groups, selecting control groups that do not match the experimental group on demographic variables.

The source of the data used in many of the studies on siblings is also of particular concern; some of the quantitative research was based on data from instruments completed by parents and/or teachers and used as either the sole basis for an outcome measure or in combination with instruments completed by the children (e.g., Bischoff & Tingstrom, 1991; Breslau, 1982; Dyson, 1999; Dyson et al., 1989; Dyson & Fewell, 1989; Hannah & Midlarsky, 1999; Mandleco et al., 1998; McHale & Gamble, 1989; McHale, Sloan, & Simeonsson, 1986). It is important to question how accurate these instruments are in assessing the experience of people with a sibling with a disability – many parents may not be aware of the extent of the experience or may have a vested interest in minimizing additional problems in an already overburdened family system.

It is also difficult to make definitive conclusions about effects on siblings when research studies from different time periods are compared. As noted earlier in the chapter, some of the research available was conducted on a specific definition of a family that doesn't represent the full range of family types; being part of a single-parent family or a smaller family may alter the context (Boyce & Barnett, 1993). Additionally, attitudes

toward people with disabilities have shifted, and there have been tremendous improvements in vocational and educational opportunities (Boyce & Barnett).

Although methodological challenges and historical changes have contributed to the lack of cohesion in the sibling literature, there may be a more fundamental reason why it is difficult to clearly map the influence of having a sibling with a disability: it is an experience that is inherently contradictory. Not only do different siblings report varying effects, but each individual sibling can experience a combination of positive and negative effects:

Being the sibling of a handicapped child evokes a range of emotional responses, from pride and enjoyment to irritation and resentment. At times, it's just plain confusing. While these emotions may seem little different from those characterizing all sibling relationships, the potential for more extreme responses exists, given the ongoing stress related to the presence of a handicapped child. (Crnic & Leconte, 1986, p. 76)

Powell and Gallagher (1993) offered more specific examples about the combination of emotional responses that siblings may experience, in language that reflects the reality of the outcomes studied by researchers:

On the positive side, some siblings report satisfaction in learning to live and cope with the demands of a child with a disability. They experience genuine joy and pleasure at the smallest accomplishments of the child, and feel a warmth and compassion for all people as individuals with unique needs and abilities.

It is a situation ripe for mixed emotions, however, and siblings also report negative effects. These negative effects include feelings of bitterness and resentment because of the extra attention given the child with the disability. Some siblings explain that they feel fearful and anxious about how to interact with the child, or even feel guilty because of their own good health. (p. 42)

Powell and Gallagher suggested that the influence of having a sibling with a disability be examined as a continuum from very positive outcomes to very negative outcomes, with the different mediating factors influencing where individual siblings would be on the

continuum. This model is useful because it avoids assuming negative outcomes and acknowledges the importance of the many different mediating factors that shape siblings' lives.

This notion of a continuum influenced the current study, along with the perspective that there are positive and negative aspects of being a sibling. Many of the studies discussed in this section viewed the sibling experience as something that could be easily quantified. The underlying assumption of many studies seemed to be that having a sibling with a developmental disability would result in negative outcomes. As a result, the goal of most of the research reviewed in this chapter was to figure out what problems the siblings had and who was most vulnerable based on their mediating influences. This approach resulted in useful information, but without a coherent framework for understanding it. Complicating the issue further was the mix of research in the field; studies from a variety of decades and with critical methodological weaknesses were combined together in the general pool of knowledge about siblings.

Previous research on outcomes and influences are important and can provide some clues about possible concerns or factors for college student siblings. However, the fact that the results often conflict with each other suggests that additional approaches are needed to help synthesize the knowledge about siblings. The research on siblings of people with a developmental disability included extensive results and discussion sections dealing with self-esteem scores, competency ratings, and quantified descriptions of the sibling relationship, but offered little sense of what it is really like to have a sibling with a developmental disability. Although some studies have taken a multifaceted approach to this topic, they are far outweighed by the research that focused on discrete aspects of

siblings' lives. There is a need for additional research that is more contemporary and reflective of the complexity of the sibling experience.

Research on College Students with a Sibling with a Disability

Only a small number of studies have examined the sub-population of college students with a sibling with a developmental disability (Burton & Parks, 1994; Grossman, 1972; Kibert, 1986). Although all three studies used college students in their samples, none of them explored the intersection between being a sibling and experiences during college. Additionally, Burton and Parks and Kibert did not provide a rationale for their choice of sample and the selection of college students in the studies seemed to be based more on convenience rather than a specific research emphasis on the experiences of college student siblings. The outcomes investigated in the studies on college student siblings were psychological health and adaptiveness (Grossman, 1972), perceptions of self and family life (Kibert, 1986), and self-esteem, locus of control, and career aspirations (Burton & Parks, 1994).

Grossman (1972) chose college students in order to learn more about the experiences of siblings of all age groups; she believed that this particular population would provide more accurate information than younger children and that the retrospective memories could offer insights on how younger children are affected. This decision was based on several assumptions: college students were likely to be more communicative than younger children, college students were more likely to be independent from their families and thus less defensive, and enrollment in college reflected a certain level of adjustment. Grossman's study included 83 college students with a sibling with mental retardation and 66 college students with a sibling without

mental retardation; the total sample was comprised of 72 women and 77 men. The study had a quantitative foundation but also included excerpts from interviews conducted that gave a richer glimpse at siblings' experiences. The method for this study included semi-structured interviews that were later given numerical rating scores, an intelligence test, a written measure of knowledge about mental retardation, and a test anxiety measure. Although Grossman looked at students from different socioeconomic levels (participants were from an Ivy League College, a competitive private women's college, and two community colleges), the sample was limited because every student except one was White. Of the entire sample of college students with a sibling with mental retardation and college students without a sibling with mental retardation, 54 students (31 women and 23 men) were enrolled at a community college and 95 students (41 women and 54 men) were enrolled at one of the private institutions (Grossman).

The outcomes under investigation were adaptation and psychological health (Grossman, 1972). Adaptation encompassed seven different measures. The first three were more relevant for students with a sibling with mental retardation and the last four were more general: coping-effectiveness; being embarrassed by being seen with their sibling; talking to friends about their sibling; academic functioning in college; overall functioning in college; IQ; and anxiety (Grossman). The psychological factors studied that related to family functioning were mother's acceptance of the child with mental retardation, father's acceptance of the child with mental retardation, family's acceptance of the child with mental retardation, the student's feelings toward his or her sibling with mental retardation, and marital integration (Grossman). All of these psychological variables were determined based on the researcher's clinical judgment (Grossman).

Statistical analyses, primarily partial correlations and analysis of variance, were conducted to compare results between students with a sibling with mental retardation and the students with a sibling without mental retardation. The study also analyzed differences between different subgroups of college student siblings, such as type of school (private university or community college) and a variety of demographic factors (Grossman).

Grossman (1972) found that, when compared to students without a sibling with mental retardation, the college student siblings did not differ on measures of adaptation. There were several significant differences within the group of college student siblings: students from private universities scored higher on academic functioning and IQ than community college students; community college students scored higher than private university students on the measure of talking to friends about their sibling; male students scored higher than female students on IQ; female students scored higher than male students on the measure of talking to friends about their sibling; and male students scored higher than female students on the measure of being embarrassed when seen with their sibling (Grossman). Other significant differences related to familial and sociocultural influences were discussed in previous sections of this chapter.

There were also significant differences in the psychological factors measures. An ANOVA revealed that mothers of male students had higher mean ratings of acceptance of the child with mental retardation than mothers of female students, community college students had higher mean levels of liking their sibling, and private university students had higher mean levels of family acceptance of their sibling.

Of the sample of 83 students, 45% were judged “to have benefited (as reflected by high scores on coping effectiveness) rather than being harmed by the experience of growing up with a retarded brother or sister” (Grossman, 1972, p. 92). Another 45% were judged to have been harmed and 10% were neither harmed nor benefited (Grossman). Grossman’s judgment of “harm” was based on scores on the coping effectiveness measure; this measure appeared to consist of one item that was scored based on the “clinical judgment of interviewer” (p. 210). The use of a single item, scored by a clinician, seems insufficient to assess such a broad concept as ‘harm.’

In addition to the lack of racial diversity of the sample in Grossman’s (1972) study, the major limitation in the relevance of this study is the societal changes that have occurred since this study was conducted. The results of this research were published in 1972 and based on a five-year study, meaning that the data were collected earlier than 1972. The environment for people with disabilities has changed substantially since this study was completed. As discussed in Chapter I, there have been several pieces of legislation passed since 1972 that have had a substantial impact on the lives of people with disabilities and their families (U. S. Department of Education, 2001; Young, 1997). Grossman’s study is part of the foundation of sibling research and was the first to present the experiences of college students. This research is a valuable contribution to the field but needs to be supplemented with more recent data.

In the second study of college student siblings, Kibert (1986) analyzed students’ perceptions of life within the family unit, life outside the family unit, and self-perceptions. Kibert also looked at the influence of a specific mediating factor on how college student siblings perceived life with their sibling. The mediating factor examined

was the severity of their sibling's mental retardation. The sample consisted of 33 college students (aged 18-26) who all had a younger sibling with a primary diagnosis of mental retardation; none of these younger siblings was institutionalized. A demographic questionnaire, personal interview, and 63-item Sibling Survey created by the researcher were used to examine the research questions. For each item on the Sibling Survey students indicated their level of agreement, using a 4-point Likert scale, with statements dealing with perceptions of life in their family, perceptions of life outside of their family, and perceptions of themselves. Examples of statements on the Sibling Survey included "having a mentally retarded brother/sister has not interfered with my social life," "I have coped well with my brother's/sister's mental retardation," and "there is enough time and attention for all of the children in my family" (Kibert, pp. 191-193).

For the research questions dealing with perceptions, data were based on students' answers to the 63 statements in the Sibling Survey (Kibert, 1986). There were four potential responses to the individual items on the Sibling Survey: Strongly Agree; Agree; Disagree; and Strongly Disagree. For each individual item, Kibert provided the frequency and percent of students who selected each response and the mean level of agreement with the corresponding standard deviation. .

For the research question investigating the relationship between students' perceptions and severity of their sibling's disability, Kibert (1986) selected 20 statements from the Sibling Survey that were considered to be particularly relevant to severity of disability. The responses to these 20 statements were collapsed from Strongly Agree, Agree, Disagree, and Strongly Disagree to either agree or disagree and analyzed using chi-square tests. Degree of severity of mental retardation was taken from the

demographic questionnaire, in which students were asked about their perception of their sibling's mental retardation. The categories of Moderate and Mild retardation remained the same and Severely and Profoundly retarded were collapsed into the category of Severe/Profound retardation. None of the chi-square tests for these 20 statements was statistically significant. Kibert concluded,

In general, normal siblings do not view having a mentally retarded brother or sister as having been harmful. Although negative consequences such as lack of parental attention, child care responsibilities, and interference with social relationships were noted, an overall positive atmosphere prevailed. (p. 170)

There are several methodological limitations that decreased the usefulness of Kibert's (1986) study. First, there was no discussion of why college age siblings were chosen for this sample and no rationale for the chosen methodology. Second, the results section lacked a comprehensive description of how data from the personal interviews were analyzed. Data from the personal interviews were presented in two ways: as excerpts to complement the data from the sibling survey results and in percentage form. It was unclear exactly how the responses to the five open ended questions in the personal interview were coded into numerical form. This lack of specificity is problematic, especially if later researchers wish to replicate the study. Third, the design of the sibling survey only allowed responses that were positive (agree or strongly agree) or negative (disagree or strongly disagree). There was no response that allowed the siblings to report any mixed perceptions, reflecting the assumption that siblings' perceptions will be rigidly dichotomous. Although this type of survey requires fixed responses, at least one additional response could be included to allow a combination of positive and negative perceptions. The results reported in the study may not be an accurate reflection of siblings' perceptions because it forces respondents to choose between absolutes. Finally,

in the chi-square analysis of differences in perceptions based on severity of mental retardation, the cell sizes were low. In 16 of the 20 chi-square tests at least half of the cells had less than 5 observations, making the use of chi-square as a statistical analysis in this study questionable.

In the most recently published study on college students with a sibling with a disability, Burton and Parks (1994) conducted a “quasi-experimental field study” (abstract, ¶1) to examine self-esteem, locus of control, and career aspirations. In addition to comparing the results of students who had a sibling with a disability with students who had a sibling without a disability, Burton and Parks also looked at possible influences on these outcomes. Their sample consisted of 60 college students (aged 18-23) from rural state universities in the Pacific Northwest, 30 of whom had a sibling with a disability and 30 of whom had a sibling without a disability. The measures used in this study were the Rosenberg Self-Esteem Scale, Rotter’s Internal-External Locus of Control Scale, and two questionnaires designed specifically for the study – a Sibling Demographic and Background Questionnaire and a Sibling Evaluation Scale (SEQ) to measure siblings’ “perceptions of the advantages and disadvantages of growing up with a brother or sister with a disability” (Burton & Parks, ¶24).

Only one demographic difference was reported between the two groups. Students with a sibling with a disability “came from larger families of lower socioeconomic status” (Burton & Parks, ¶38). MANOVAs with follow-up univariate ANOVAs revealed that students with a sibling with a disability scored significantly higher on the measure of internal locus of control. The researchers also found no significant differences between groups of students on measures of self-esteem or career aspirations. There were several

significant correlations between items on the SEQ and outcome measures. The researchers concluded that “the higher the self-esteem the lower the feelings of guilt and concern about the future. Moreover, self-esteem seemed to be higher the more visible the disability” (Burton & Parks, ¶29). Correlational analysis also revealed other significant relationships between locus of control and SEQ items. Higher internal locus of control was positively correlated with higher ratings on the variables measuring “focused on positive aspects,” “enhanced flexibility,” “expanded my options,” and total adaptation scores; higher internal locus of control was negatively correlated with higher ratings on the “felt embarrassed” item.

Burton and Parks (1994) also looked at several potential mediating factors on the outcomes. The gender of the sibling with a disability had no significant influence on self-esteem or locus of control but the researchers found that more students with brothers with a disability entered helping professions than students with sisters with a disability. Results on the influence of gender similarity were also significant. For students with a sibling with a disability, the levels of internal locus of control were significantly higher when students had a sibling of the same gender; a similar pattern was found for levels of self-esteem but the differences were not significant. The type of the sibling’s disability had mixed results; for students with a sibling with a disability, visible disabilities were associated with higher levels of self-esteem than invisible disabilities but there were no differences in locus of control or career aspirations. No significant differences in any of the three outcomes were found based on family socioeconomic status and students’ birth order position. Burton and Park’s overall conclusion from their research highlighted the idea that the sibling experience is complex:

On the positive side, sibling-Ds [students with a sibling with a disability] felt that living with a disabled brother or sister helped them be more responsible, be more tolerant, better see the good in others, develop a better sense of humor, and be more flexible. However, sibling-Ds also reported such negative feelings as embarrassment, guilt, isolation, and concern about the future of their disabled siblings. (Burton & Parks, ¶28)

The use of a sample from rural state universities in the Pacific Northwest limits the generalizability of the study. Additionally, the SEQ, which was created by Burton and Parks (1994), was not validated prior to using it in their study. Despite these limitations, Burton and Parks' study adds valuable information to the body of knowledge on college student siblings. The variables they examined, self-esteem, locus of control, and career aspirations, are relevant to the population and provide some insight into college student siblings' experiences and development.

As this discussion shows, there is a paucity of research on college student siblings. Of the few studies on this population, the most current study is over 10 years old and the most comprehensive examination of this population is over 30 years old. Most college student siblings today would have a hard time recognizing or relating to the environment that existed at the time of Grossman's (1972) study. These studies provide a foundation for knowledge about college student siblings, but as a whole the literature on college student siblings is incomplete. There is a need for more research that both reflects contemporary life and goes beyond descriptive information and discrete outcomes. Additionally, the wealth of information about students' development during college (e.g., Evans et al., 1998; Pascarella & Terenzini, 1991) needs to be brought into the research on siblings. All college students have multiple identities related to dimensions such as gender and race; the role of a sibling is another facet in college students' identities and

deserves to be closely examined in order to illuminate students' experiences and increase knowledge of their development.

Summary

This review of the sibling literature highlighted the historical view of negative sibling adjustment, reviewed relevant outcomes and mediating factors, and discussed the existing research on the specific population of college student siblings. Methodological flaws in much of the research on siblings make comparisons between studies difficult and contribute to the contradictory findings about siblings. The complex nature of the sibling experience also makes it challenging to draw definitive conclusions about how individuals are affected by having a sibling with a developmental disability. It is even more difficult to determine how college student siblings experience college because there is minimal research on this specific population and the existing studies are outdated and not representative of the current climate for people with disabilities. These gaps in the sibling literature highlight the need for research on college student siblings that is able to reflect their often contradictory lives and illustrate the relationship between having a sibling with a developmental disability and experiences and development during college. The current study used constructivist grounded theory to obtain such an in-depth look at how college student siblings experience college and understand their dual roles as student and sibling. This qualitative approach to the research question helped further knowledge about college student siblings, addressed many of the weaknesses of previous research, and provided a current, fresh, and holistic look at an overlooked population.

CHAPTER III

RESEARCH DESIGN AND METHODOLOGY

This chapter provides an overview of the methodology and research design used in this study. The specific procedures for participant selection, data collection, and data analysis are described. The choice of methodology, role of the researcher, ethical considerations, and goodness of the study are reviewed.

Purpose of the Study and Research Questions

The purpose of this study was to examine the experiences of college students who have a sibling with a developmental disability. This study used constructivist grounded theory methodology to explore the population of traditionally aged college students who have a sibling with a developmental disability and to develop a conceptual model. The primary research question under investigation was: How do college students with a sibling with a developmental disability experience college? The data generated by this research question were used to build the emergent theory and conceptual model.

Rationale for Research Design

Qualitative methods are particularly well suited to the examination of complex topics (Marshall & Rossman, 1999; Strauss & Corbin, 1998). The topic of people with a sibling with a disability has been shown to be complex; previous clinical research studying siblings, as well as first-person accounts, have reported a wide range of experiences and emotions (Grossman, 1972; McHugh, 1999; Safer, 2002; Siegel & Silverstein, 1994; Simon, 2002a; Strohm, 2002). Strauss and Corbin argued that “qualitative methods can be used to obtain the intricate details about phenomena such as feelings, thought processes, and emotions that are difficult to extract or learn more about

through more conventional research methods” (p. 11). This advantage of a qualitative approach was particularly appropriate for this research question, as prior quantitative work in this area has often produced conflicting results (Crnic & Leconte, 1986; Cuskelly, 1999; Skrtic et al., 1984). Some researchers have even specifically suggested a qualitative approach in order to provide the context that may be necessary to gain a greater understanding of siblings’ experiences (Skrtic et al.). Additionally, this research examined siblings in a specific role, as a college student. One practical implication of the study was to assist student affairs professionals in their work with siblings. Manning (1992) noted the advantages of using a qualitative approach in research on students and student affairs.

Creswell’s (1998) eight rationales for a qualitative approach provided a strong fit for the topic of college student siblings and the research question. The three rationales with the strongest fit are highlighted here. First, the research question under investigation was a “how” question, which is traditionally well suited for qualitative work. Second, qualitative approaches are particularly appropriate for topics in which “the variables cannot be easily identified, theories are not available to explain behavior of participants or their population of study, and theories need to be developed” (Creswell, p. 17).

Although college student siblings as a population have been explored previously in the research, further work is needed. In addition to the limited amount of research available, most of that research has been based in the quantitative tradition, the research currently available has produced conflicting results, and existing studies have not investigated how college student siblings experience college. Third, Creswell presented a rationale to “use a qualitative study because of the need to present a *detailed view* of the topic” (p. 17).

The presentation of a detailed view of the experience of college student siblings in this study goes further than the types of results that have previously been reported. Because most prior research (e.g., Abramovitch et al., 1987; Bischoff & Tingstrom, 1991; Burton & Parks, 1994; Dyson & Fewell, 1989; Hannah & Midlarsky, 1999; McHale & Gamble, 1989; O'Kane Grissom & Borkowski, 2002) relied primarily on quantitative methods, there has been a minimal presence of the voices of the participants. In addition, existing studies, such as the ones listed above, have primarily focused on specific outcomes such as siblings' behaviors, self-concept, and psychological adjustment. This information is valuable in understanding college student siblings' experiences but a more holistic view of their lives is also important. A qualitative approach provides a more complete picture and avoids the earlier pitfalls of only examining discrete aspects of college student siblings' lives in a disconnected fashion. The results of this qualitative study are a complement to much of the existing quantitative literature.

The specific qualitative methodology used in this study was grounded theory. Grounded theory emerged in the 1960s out of sociology and was co-originated by Glaser and Strauss (1967). They described their approach as “the discovery of theory data systematically obtained from social research” (Glaser & Strauss, p. 2). This differs from the deductive approach used in quantitative research; in grounded theory the process is inductive and the resulting theory is grounded in the data (Charmaz, 2003a). Another component of grounded theory is constant comparison (Charmaz, 2003a; Glaser & Strauss, Strauss & Corbin, 1998). Data and the emerging categories are compared on many levels as part of the data analysis (Charmaz, 2003a). Charmaz (2000) highlighted significant aspects of grounded theory:

(a) simultaneous collection and analysis of data, (b) a two-step data coding process, (c) comparative methods, (d) memo writing aimed at the construction of conceptual analysis, (e) sampling to refine the researcher's emerging theoretical ideas, and (f) integration of the theoretical framework. (pp. 510-511)

The first element listed, the relationship between the data collection and data analysis stages of research, is important in understanding grounded theory and is described in more detail in the discussion of this study's procedures. Qualitative research often needs to be flexible with regard to research design, allowing room to adapt to the emerging data (Jones, 2002); this is also a critical part of grounded theory (Charmaz, 2002). Charmaz (2000) views grounded theory methods as guidelines rather than a set of strictly defined procedures to be followed in a prescribed manner.

Grounded theory approaches have been used in a variety of fields, although the creators, Glaser and Strauss, eventually began to differ in their views (Charmaz, 2000; Creswell, 1998). Glaser (1992) strongly criticized Strauss's update of grounded theory (Strauss & Corbin, 1998), arguing that its methods force data rather than letting it emerge. Charmaz argued that despite the split between the two approaches to grounded theory, both "sides" of the debate share a positivist foundation. Both assume that the researcher will simply discover the truth in the data and believe that there is, in fact, an objective truth to be discovered (Charmaz).

In contrast, constructivist grounded theory does not assume the existence of an objective truth or reality, but instead "aims to include multiple voices, views, and visions in their rendering of lived experience" (Charmaz, 2000, p. 525). In addition to recognizing the presence of multiple realities, a constructivist grounded theory approach seeks to fully understand the meaning of the data. This includes paying attention to what participants *don't* say and seeking clarification about what participants say; for example,

a researcher may assume a shared meaning that is not actually shared by the participant (Charmaz). Another major assumption of constructivist grounded theory is that the researcher's role in data analysis goes beyond simply recording and interpreting; the researcher's interaction with the participants is a key component of the data:

A constructivist grounded theory recognizes that the viewer creates the data and ensuing analysis through interaction with the viewed. Data do not provide a window on reality. Rather, the "discovered" reality arises from the interactive process and its temporal, cultural, and structural contexts. Researcher and subjects frame that interaction and confer meaning upon it. The viewer then is part of what is viewed rather than separate from it. What a viewer sees shapes what he or she will define, measure, and analyze. (Charmaz, pp. 523-24)

Constructivist grounded theory requires the researcher to be aware of these assumptions and take them into account throughout the data collection and analysis process. This is helped by the iterative nature of the process; coding and analyzing the data before conducting additional interviews allows the researcher to identify concepts, thoughts, feelings, and beliefs that need clarification. In subsequent interviews the researcher can learn how participants make meaning of these concepts, thoughts, feelings, and beliefs.

The theory that emerged from the current study was an interpretative theory, which differs from more positivistic definitions of theory (Charmaz, 2006). This study followed guidelines for constructivist grounded theory as described by Charmaz, who favors an interpretive approach to theorizing. Charmaz presents the following definition of interpretative theory, which is consistent with the theory presented in this study:

An alternative definition of theory emphasizes *understanding* rather than explanation. Proponents of this definition view theoretical understanding as abstract and interpretive; the very understanding gained from the theory rests on the theorist's interpretation of the studied phenomenon. Interpretive theories allow for indeterminacy rather than seek causality and give priority to showing patterns and connections rather than linear reasoning. (p. 126)

The inconsistencies in results from previous studies of sibling outcomes (Boyce & Barnett, 1993; Cuskelly, 1999) highlight the complexity of the sibling experience. A constructivist approach to grounded theory, with an emphasis on multiple voices and experience, was well suited for this study because it could accommodate complicated and conflicting themes. The purpose of this study was to examine the experiences of college students who have a sibling with a developmental disability and create a conceptual model that illustrated these students' experiences. Within a qualitative tradition of inquiry, a constructivist grounded theory approach was most appropriate for addressing this research problem for several reasons. First, this methodology offers the opportunity to develop a theory or conceptual framework about the experiences and development of a neglected population, college student siblings. Strauss and Corbin (1998) stated that "underlying this approach to qualitative research is the assumption that all of the concepts pertaining to a given phenomenon have not yet been identified, at least not in this population or place" (p. 40). This assumption was valid for the research question: How do college students with a sibling with a developmental disability experience college?

Additionally, grounded theory can also be useful when examining issues within the field of student affairs. Evans, Forney, and Guido-DiBrito (1998) have noted that "student affairs practice without a theoretical base is not effective or efficient" (p. 19). McEwen (2003) also noted the value of theory within the profession:

Since the primary goals of student affairs practitioners are to facilitate students' development, to understand and design educationally purposeful environments, and to be experts about organizations and how they function, it is our responsibility, both professionally and ethically, to know and understand the individuals, groups, and institutions with whom we work. One way to do this is through theory. (pp. 154-155)

There is currently no theory available to help professionals understand the specific experiences and development of college student siblings. This study used grounded theory methods to develop a theory on this population and help bridge this gap in the literature. Cox et al. (2003) have noted the lack of theory about siblings as a whole, providing additional support for using grounded theory methods in this study. Finally, one practical implication of this study is to assist student affairs professionals. Brown, Stevens, Troiano, and Schneider (2002) have suggested that grounded theory can be useful when examining research problems of interest to student affairs professionals. College students, whether they are siblings or not, often inhabit a complex environment that requires an approach that focuses on context; a constructivist grounded theory approach is well suited for accomplishing this work.

Participants

There were nine initial participants in this study and seven participants who completed the study. All of the participants in the study had a sibling with a developmental disability and were either currently enrolled in an undergraduate institution or had graduated within the past two years. Of those who had already graduated, two were interviewed within four months of graduation and one was interviewed within two years of graduating. The participants were enrolled in or had attended colleges or universities throughout New England. Participants ranged in age from 19-24. Six participants were currently enrolled at private four-year undergraduate institutions and three participants had graduated from private four-year undergraduate institutions. Of those still enrolled, three were sophomores, one was a junior, and two were seniors. Seven women and two men were interviewed; the split between women and

men participants was not unexpected. Participation rates in prior research (Cleveland & Miller, 1977) suggested that women may be more likely to participate than men. Additionally, an administrator of SibNet, an Internet mailing list for adult siblings, noted that 95% of the approximately 500 members of are female (D. J. Meyer, personal communication, January 21, 2005). None of the participants commuted to school from their family's home; all lived in on-campus or local off-campus housing. Although recruitment efforts focused on a wide geographic area and different institutional types, the diversity of the sample was limited in terms of race/ethnicity, religion, sexual orientation, socioeconomic status, and institutional type. The majority of participants were White, Catholic, and heterosexual and all attended private four-year institutions; participants generally described their family's socioeconomic status as middle class or upper middle class. All of the participants' parents were still married. One participant was a first-generation college student, five participants had one parent who had not completed college, and for three participants, both parents had completed college or an advanced degree. The siblings of the participants varied on dimensions such as type of disability, severity of disability, and birth order.

A description of each participant has been included and these profiles will help provide a context for the discussion of the findings in Chapter IV. The names used in the descriptions and in Chapter IV were pseudonyms selected by each participant. Participants were given the opportunity to review their profiles and make corrections or changes.

Hannah

Hannah is a White 21-year-old female who recently graduated from a private college with a degree in anthropology and pre-med; she was in her senior year during the interview process. Hannah wanted to be a doctor; she applied to several medical schools during her senior year but was not accepted. She moved back in with her family after graduation and planned to work and re-apply to medical school. Hannah's family lived beyond a reasonable driving distance from her college. Hannah had one sibling, a 24-year-old brother with Down syndrome. Hannah described her family as middle-class and both of her parents completed undergraduate degrees. During her senior year her brother moved into a group home very close to her family's home. Hannah identified as heterosexual and was not currently dating. She studied abroad while in college. Hannah was the only participant in the study who had been previously involved with sibling issues. She identified as Catholic and said that while she was not strongly religious, she enjoyed the routine of attending church.

Aurora

Aurora is a White 19-year-old female and was a sophomore in college. She had one sibling, a 29-year-old half-sister. Aurora's sister had cerebral palsy and cognitive delays; she was unable to walk, talk, or feed herself. Her sister lived at home with her parents. Aurora described her family as upper middle-class; her father completed an undergraduate degree and a professional degree and her mother completed high school. Aurora was majoring in secondary education and math and planned to be a math teacher. She worked with a campus school for people with disabilities and was also on the dance team. Aurora identified as Catholic but did not attend religious services or activities and

said she was currently not sure what she believed. She identified as heterosexual and had a long-distance boyfriend. Aurora attended a private, religiously affiliated college that was a 3 ½ hour drive from home.

Jeff

Jeff is a White 19-year-old male and was a sophomore in college. Jeff was the oldest sibling and had two siblings. He had a 17-year-old brother with toxoplasmosis who was severely brain damaged; he couldn't see, talk, or walk and used a respirator and a feeding tube. Beginning at birth his brother had several serious medical crises that he was not expected to survive; the most recent medical crisis was approximately one month before Jeff's high school graduation. Jeff also had a sister, who turned 16 during the interview process. Both siblings lived at home. He was a communications major and wanted to have a career in advertising. Jeff was a first-generation college student and his parents both immigrated to the United States in the 1970s; both parents completed high school. Jeff was accepted to be a Resident Assistant during the interview process. Jeff's father also had a brother with a disability. He identified as heterosexual and had broken up with his girlfriend just prior to the first interview. He identified as Catholic and went through a period of religious questioning in high school; he felt more comfortable with his religious identity now but disagreed with some aspects of the Catholic Church. Jeff attended a private, religiously affiliated college that was a 3 ½ - 4 hour drive from home. Aurora and Jeff attended the same school and are friends; Aurora referred Jeff to the study.

Deanna

Deanna is a White 19-year-old female and was a sophomore in college. She was the oldest sibling and had 4 siblings. She had an 18-year-old brother with dyslexia who was in college. She had a 17-year-old brother who lived at home; he had a neurological impairment, seizure disorder, processing delay, and anxiety disorder. She also had a 16-year-old brother with no disabilities and a 13-year-old sister with dyslexia, these siblings also lived at home. Deanna described her family's financial situation as "comfortable" and noted that they lived paycheck to paycheck. Her father completed high school and her mother completed both an undergraduate degree and a 2-year nursing degree. Deanna was a special education major and planned to become a special education teacher after graduation. She had several jobs and placed a high priority on financial independence. Another significant activity for her was dance. Deanna identified as heterosexual and broke up with her boyfriend during the course of the interview process. She was raised Catholic and had also attended a Protestant church, which she enjoyed. Religion was not as important to her currently and she didn't actively participate in religious activities. Deanna attended a religiously affiliated, small private liberal-arts college that was a 2 hour drive from home.

Sarah

Sarah is a White 20-year-old female and was a junior in college. She was the youngest sibling of seven; three of her siblings (ages 22 – 25) were full siblings and three were half-siblings, although she noted that her family generally didn't make that distinction. She had a 24-year-old sister with mental retardation, apraxia, pervasive developmental disorder, and autism spectrum disorder; her sister currently lived at home.

None of Sarah's other siblings had any developmental disabilities. Sarah also had a 22-year-old brother and a 25-year-old brother, both of whom were living away from home at college. Her other siblings were older, married with families, and lived no more than 10 minutes away from her parents. When she was 6, Sarah's father began a 10 year sentence in prison for a white-collar crime; he returned to the family when she was 16. Sarah described her family as middle-class; her mother completed undergraduate and graduate degrees and her father completed high school. Sarah was a special education major and planned to either become a special education teacher or a lawyer/advocate for families with children with disabilities. Sarah worked off-campus, volunteered with the Special Olympics, and was a Resident Assistant. Sarah identified as heterosexual and was casually dating someone. She identified as Catholic and attended church weekly. Sarah had a mild case of a neurological disorder which she said had no effect on her life. Sarah attended a religiously affiliated, small private liberal-arts college that was a 3 ½ hour drive from home.

James

James is a 21-year-old male who had recently graduated from college with a degree in English. He remained in the city where his school was located; at the start of the interview process he was not working or heavily involved in a job search. Just before the final interview James found out that he had received a grant that would enable him to start a non-profit advocacy group that would continue the political activism that he focused on during college. James identified as heterosexual and was in a long-term relationship with a woman who was an undergraduate at his university. James was the oldest child in his family and had multiple siblings with developmental disabilities and

two siblings who had died, including one with Down syndrome. James had three living siblings and two deceased siblings. James' brother was 18 and had Asperger's syndrome; James described his brother's behavior as "anti-social" and "violent." James also has a 16-year-old sister, who had a twin sister who died when she was one month old. His 16-year-old sister had no developmental disabilities but did have a chronic medical condition that was not life threatening, as well as depression. James had another sister who was 10 years younger and had Down syndrome; this sister died when she was 4 years old due to a heart condition. Finally, when James was 15, his family adopted a baby girl with Down syndrome; other than Down syndrome this sister had no medical conditions and was now 6. All siblings currently lived at home although his brother went away to college but left after 6 weeks. Both sisters were in school and his brother did not currently work or go to school. James described his family as upper-middle class; his mother completed undergraduate and graduate degrees and his father completed high school. James lived on campus throughout college and his main activities were his fraternity and heavy involvement in a political activism group. James identified as Jewish and regularly participated in religious services. James had a learning disability but did not feel it presented much of an issue for him and he did not identify as learning disabled. He attended a private liberal arts university that was a 3 ½ hour drive from home.

Jane

Jane is a White 20-year-old female who was a senior majoring in communications. She was the oldest of 6 children. She had a 17-year-old sister with mental retardation who lived at home and attended a private school. She also had a 14-year-old brother, 12-year-old sister, 9-year-old brother, and 6-year-old brother; they all

lived at home and none had any developmental disabilities. Jane was heavily involved in community service activities with her family and also coached a Special Olympics swim team in her hometown. Jane had already started businesses with both of her parents and planned to pursue a career path as an entrepreneur after graduation. Jane described her family as upper middle-class and both parents have professional degrees. Jane studied abroad while in college. She identified as Catholic and attends church weekly but described herself as not active religiously. Jane identified as heterosexual and broke up with her boyfriend during the course of the interview process. She attended a large private university that was a 30 minute drive from home.

Phyllis

Phyllis is a biracial (White and Hispanic) 22-year-old female who recently graduated with a degree in advertising communications. She was the youngest of three siblings; she had a 23-year-old brother with unspecified psychiatric issues and ADHD but no developmental delays and a 24-year-old brother with Down syndrome. Both brothers currently lived at home. Phyllis described her family as middle-class. Both parents served in the military; her father completed an undergraduate degree and her mother completed high school. She was unemployed at the time of the interview and was planning on pursuing a career in the creative side of advertising. Phyllis had some part-time jobs while in school and did not participate in any extra-curricular activities. She identified as heterosexual and was in a relationship. Phyllis was raised Catholic but did not participate in any religious activities or identify herself as religious. She attended a large private university that was a 3 ½ - 4 hour drive from home.

Phyllis was unable to continue in the study past the first interview due to travel obligations. At the start of her participation in the study she had no definite travel plans.

Colleen

Colleen is a White 24-year-old female who graduated from college with a degree in psychology. Colleen moved home with her family after graduating, except for a summer spent in another city. Colleen was currently working as a researcher and some of her time was spent investigating high functioning autism. She planned to go to graduate school for clinical psychology and continue her work as a researcher while also starting a small clinical practice focusing on individuals with neuro-developmental disorders, including autism. Colleen was the oldest child in her family and had two younger brothers; one brother was 17 and had high functioning autism and obsessive-compulsive disorder and her youngest brother was 15 and had no developmental or physical disabilities. Colleen described her family as upper middle-class currently but they were less financially comfortable when she was younger. Her mother completed a Ph.D. and her father “almost” completed a Ph.D. Colleen attended a religiously affiliated university for her first year of college and then transferred to a single-sex college (about a 2 ½ hour drive from home). Colleen identified as bisexual; she dated women in college and has only dated men since graduating college; she was not currently dating anyone, primarily due to her extensive work schedule. Colleen had polycystic ovarian syndrome and had experienced associated mood-related symptoms. Colleen was Catholic but did not participate in any religious activities and or identify herself as religious.

Colleen participated in one interview and did not respond to e-mails or voice mail about scheduling a second interview.

Procedures

Participant Selection

Participants for the study were selected through purposeful sampling, an approach that “focuses on selecting information-rich cases whose study will illuminate the questions under study” (Patton, 2002, p. 230). For this study, participants needed to meet three main criteria:

- Be currently enrolled in a college or university or have graduated since May 2004.
- Have a sibling with a developmental disability.
- Be between the ages of 18-24.

The United States Department of Health and Human Services’ definition of developmental disabilities, given below, served as a general guideline for determining if participants with a sibling with a developmental disability were eligible for the study:

Severe, chronic disabilities attributable to mental and/or physical impairment, which manifest before age 22 and are likely to continue indefinitely. They result in substantial limitations in three or more areas: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency, as well as the continuous need for individually planned and coordinated services. (Administration on Developmental Disabilities, 2002)

Students with a sibling with a disability such as mental retardation, Down syndrome, and autism were eligible, and other disabilities were considered individually based on the above definition. A specific type of purposeful sampling, maximum variation sampling, was used in selecting participants who met the criteria for the study. Maximum variation sampling, which “documents diverse variations and identifies important common patterns” (Marshall & Rossman, 1999, p. 78), was used to try to obtain the most diverse sample possible in terms of gender, race/ethnicity, religion,

socioeconomic status, sexual orientation, class year, and institutional size and type. The low response to extended recruitment efforts made it difficult to obtain a more diverse sample.

Recruitment efforts began in September 2005 and continued through September 2006. The primary recruitment methods were advertisements (Appendix A) and contacting people who were likely to have contacts with college student siblings (Appendix B). A posting about the study was sent out twice on SibNet, an Internet mailing list for adult siblings with approximately 500 members. Upon recommendation of Don Meyer (personal communication, September 22, 2005), who administers SibNet, the posting was adapted slightly to include my own status as a sibling and his approval of the posting. Online ads were placed on craigslist.org, an online community-based resource, and the online classifieds on *The Phoenix*, a free weekly newspaper distributed in the Boston area. An ad was also placed in both the online and print versions of the *Weekly Dig*, a free weekly publication distributed in the Boston area. I contacted several individuals who were likely to work with college student siblings: staff at agencies that sponsored Sibshops or other sibling support programs, faculty who taught education or special education courses at college and universities throughout New England, and campus and state coordinators at Best Buddies, a volunteer organization in which college students are matched with people with disabilities and develop friendships. Finally, word-of-mouth was used at my workplace, which employed many college students and recent college graduates.

Including responses to recruitment for both the pilot interview and the study interviews, 18 people expressed interest in the study. Four individuals who responded did

not meet the qualifications for the study due to their age and/or the type of their sibling's disability. Three of those individuals also lived outside the New England area. Two potential participants returned the information sheets but did not ultimately participate in the study, one of these students decided that the compensation was not sufficient. Two potential participants received the information packet but did not complete and return it. Overall, there were five responses to Craigslist postings, five responses to SibNet postings, three responses via faculty contacts, two responses to the ad placed in the *Weekly Dig*, one response to an online ad in *The Phoenix*, and one referred by another participant. One person who did not participate did not specify how she heard about the study and did not respond to any requests for that information. Of the nine people who ultimately participated in the full study, three were referred by faculty, two via SibNet, two via Craigslist, one via *The Weekly Dig*, and one via another participant.

Postings for ads and flyers (Appendix A) and recruitment information provided to gatekeepers from local agencies and academic departments (Appendix B) included information about the purpose of the study as well as participant qualifications and details about the procedures. Gatekeepers were also offered the option of receiving flyers electronically or as a hard copy. Siblings who expressed an interest in participating were sent a letter with more detailed information about the study (Appendix C) and an interest form to complete and return if they were interested in participating (Appendix D). The purpose of the interest form was to collect contact and demographic information. Potential participants were given the option of receiving the packet as a hard copy through the mail or an electronic copy sent via e-mail; all potential participants chose to receive and return the information via e-mail. Arrangements for interviews were based

on participants' availability and convenience. Participants received a \$30 gift card at the completion of the study, which they selected from a list of five national retailers. Two participants didn't continue with the study past the first interview. One participant was unable to continue due to unexpected travel plans and the other participant's reasons were unknown; she never officially withdrew from the study but did not respond to any e-mails or voice mail messages about scheduling a second interview or continuing with the study. After consulting with other researchers, the decision was made to include the data from their initial interviews in the data analysis.

The flexible nature of qualitative research extended to determining sample size. Jones (2002) noted that "questions about appropriate sample size have less to do with actual numbers of participants or cases and much more with the quality and depth of information elicited through the research process" (p. 465). Patton (2002) suggested setting a minimal number of participants in the research design and allowing for changes as the study progresses. Based on a review of recent grounded theory research studies that focused on college students, it was anticipated that there would be approximately 10 participants in this study (Nawabi, 2004; Stevens Jr., 2004; Troiano, 2003). Therefore, nine participants would be an appropriate sample for this study, assuming that saturation of the data was achieved. After initial data analysis began, later sampling had a theoretical rationale. Theoretical sampling differs from conventional ideas of sampling because it refers to sampling ideas, not people (Charmaz, 2003b). Theoretical sampling occurred after data collection and analysis had begun and was used to identify codes and categories that needed further development or exploration (Charmaz). Theoretical sampling will be discussed in more detail as part of the data analysis process.

Data Collection

Data for this study were collected through the use of multiple, in-depth interviews with college student siblings and document analysis. Interviews are not the only way to gather data for a grounded theory study (Charmaz, 2000), but can be a very effective way to collect rich data (Charmaz, 2002). Document analysis was not originally planned, but after completing the initial interviews, I found that most participants had written about their sibling in the college admissions essays and also focused on their sibling in papers and projects for college courses. Pre-existing texts can be useful in enhancing data analysis in grounded theory studies (Charmaz, 2006) and I determined that including materials written by participants would allow me to gain additional perspective on their experiences as college students. College admission essays could also provide valuable insights into participants' early thoughts about college; this could be helpful because participants would be sharing their thoughts when they were actually applying. After receiving approval from the Institutional Review Board for this change in procedure I spoke with each participant at their next interview about possibly sharing written materials. Current participants in the study who wished to share written materials were asked to review and agree to a revised consent form. Participant recruitment information was revised to include the request for written materials and the revised consent form (Appendix E) was used for all subsequent participants in the study. It was made clear to all current and potential participants that sharing written materials was optional and would not affect their participation in the study. Some participants submitted written

materials as hard copies and others in electronic form. Identifying information was removed from all written materials prior to data analysis.

Three in-depth interviews were conducted with each participant. The iterative process of data analysis suggests that multiple interviews are needed to fully develop the theory (Charmaz, 2002). Additionally, multiple sequential interviews are preferable in grounded theory research because they allow the researcher to more fully learn about the participants' experiences, return to previously discussed topics to explore emerging theoretical concepts, and discover potential missteps in early data analysis (Charmaz). The number of interviews needed with each participant was also based on a review of other recent grounded theory studies on topics related to college student development (Jones, 1997; Stevens Jr., 2004; Troiano, 2003).

A pilot interview with one sibling was completed to review the appropriateness of the interview protocol and questions, including the order and wording of the questions. The participant in the pilot interview responded to a posting on craigslist.org and was compensated with a \$15 gift card. The participant in the pilot interview was a 28-year-old White female who had a 30-year-old sister with Down syndrome. The participant in the pilot interview felt the interview protocol and questions were appropriate and also commented that she felt more comfortable talking about her sibling experience because I disclosed at the beginning of the interview that I had a sibling with a disability. The pilot interview revealed some gaps in the question guide and the need for more in-depth questions. As a result, I added more questions to the initial interview about family structure, other siblings in the family, and the abilities of the sibling with a disability; I also added more potential follow-up questions. Another change dealt with the collection

of additional demographic information, such as sexual orientation and socioeconomic status; asking these questions during interviews and having participants fill out a form with these questions were both considered. The participant in the pilot interview agreed with the decision to ask these questions as part of the interview process, rather than on an additional demographic information form. This information was collected in order to have a more complete understanding of each participant.

Each interview was scheduled at a location and time that was mutually convenient for both the participant and me; the majority of interviews were conducted on the student's campus. The average time of first and second interviews was approximately an hour and third interviews tended to be shorter, with an average time of 35 minutes. Participants were asked to select a pseudonym either prior to the first interview or at the end of the first interview. With the participants' permission, all interviews were recorded using a digital voice recorder. At the beginning of the first interview participants reviewed and signed the informed consent form (Appendix E); specific information about confidentiality, recording the interviews, and their right to stop participating at any time were discussed. To ensure confidentiality, the recordings and transcripts were labeled only with a code or the participant's chosen pseudonym. Basic demographic and background information were obtained prior to the first interview through the intent form returned by each participant (Appendix D).

In order to be consistent with constructivist grounded theory and produce rich data, interviews were flexible and had the following intention: "emphasize the participant's definitions of terms, situations, and events and try to tap the participant's assumptions, implicit meanings, and tacit rules" (Charmaz, 2002, p. 681). Questions were

primarily open-ended in order to draw out the participants' stories and meanings and to "both explore the interviewer's topic and fit the participant's experience" (Charmaz, p. 679). The interviews used Rubin and Rubin's (2005) structure of qualitative interviews:

Interviews are structured conversations. You organize an interview by combining *main questions*, *follow-up questions*, and *probes*. Main questions are worked out in advance to make sure you cover all the major parts of your research problem, whereas the follow-up questions ask for explanation of themes, concepts, or events that the interviewee has introduced. Probes help manage the conversation by keeping it on topic, signaling the desired level of depth, and asking for examples or clarifications. The main questions help you make sure you are answering your research puzzle; the follow-up questions and probes ensure that you get depth, detail, vividness, richness, and nuance. (p. 129)

Although a strict interview protocol was not adhered to, a question guide was developed for use in interviews (Appendix F). Specific main questions were designed for both the initial interview and the second and third interviews; some of the main questions had potential sub-questions on the same topic. As described by Rubin and Rubin, follow-up questions and probes were used as needed during the interviews. A few of the questions in the guide were adapted from Charmaz (2002). Throughout the data collection and analysis process additional questions were added to the question guide; these additions have been noted in Appendix F.

The initial interview with each participant focused on rapport building and learning about the participant's background and experiences; this first interview also helped identify issues that could be explored in later interviews. Primary questions for the first interview included items intended to learn about the participant's background and family, what their college selection process was like, and how their daily life as a college student has been influenced by having a sibling with a disability.

At the beginning of the second and third interviews the participant was given the opportunity to discuss the transcript from the previous interview and any reactions or additional thoughts since the last interview. In these subsequent interviews I continued to explore participants' specific experiences in college and their view of the influence of their sibling's disability. The second and third interviews also provided an opportunity for theoretical sampling of concepts and themes that had begun to emerge from analysis of earlier interviews. For the second and third interviews, main questions included topics such as participants' relationship with their family since beginning college, their views on the future, their identity, and thoughts on potential support services for siblings. Some of the concluding questions asked participants to take a larger view of their experience in college, such as what advice they would offer siblings who were beginning college and how they felt their college experience might be different if they did not have a sibling with a developmental disability. Examples of primary questions and sub-questions included:

Starting with the process of deciding to go to college and selecting a college - did having a sibling with a developmental disability play a part in that process? If so, how?

Possible sub-questions:

- Were your family's expectations about where you should go to college the same as yours? If not, how were they different? What were your thoughts and feelings about that difference?
- Are you attending the college you wanted to attend? If no, why not?
- Where else (if applicable) did you apply? What factors contributed to your decision to go here?
- What made you want to go away to school/live at home for school? What factors influenced that decision (as appropriate) *Question Added*

Do you talk about your sibling with your friends or classmates? Why/Why not?

Possible sub-questions:

- How do you decide when/if you talk about your sibling?
- How do you view yourself in comparison to your friends and classmates?
- Have any friends or classmates reacted in a way that stands out for you? What kinds of reactions have they had? How do their reactions affect you?
- Do you know any other siblings on your campus? If yes, what is it like to know another sibling on your campus?

Interviews were transcribed both by me and a professional service; I transcribed 9 interviews and 14 were transcribed by a professional service. After the transcript was completed all identifying information was removed before it was sent to participants or analyzed. Interviews were transcribed as soon as possible but due to time constraints the amount of time between the end of the interview and the transcript being sent to the participants for review ranged from 1 day to 20 weeks. Participants were given the option of having a hard copy of the transcript mailed to them or sent electronically as an e-mail attachment. All participants opted to receive the transcripts via e-mail. Participants were asked to review the transcript and make comments via e-mail, on the electronic copy of the transcript, or at the beginning of the next interview. Subsequent interviews with participants were not conducted until the recording from the previous interview had been transcribed and coded as part of the data analysis process. Due to scheduling issues and school breaks the amount of time between interviews ranged from 3 weeks to 24 weeks. Feedback on the transcripts from the participants was incorporated into the coding process.

Data collection continued until saturation occurred; saturation is defined as follows:

- (a) No new or relevant data seem to emerge regarding a category,
- (b) The category is well developed in terms of its properties and dimensions demonstrating variation, and

- (c) The relationships among categories are well established and validated.
(Strauss & Corbin, 1998, p. 212)

This decision was based on the interviews and completion of initial coding. As the theory emerged, the categories were carefully examined and it was determined that additional data collection was not necessary.

Data Analysis

Constructivist grounded theory methodology entails using theoretical sampling for the selection of participants throughout the entire stage of data analysis, gathering the data, and carefully analyzing the data collected using a coding procedure, which will result in the creation of a theory. The specific data analysis procedure used in this study followed guidelines described by Charmaz (2000, 2002). The components of this process are initial (or open) coding, focused coding, theoretical sampling, raising some focused codes to categories, and then using those categories to develop the conceptual theoretical framework (Charmaz, 2002). Additionally, during data analysis, the researcher continually writes “memos” on many different aspects of the analysis process; these memos are solely for the use of the researcher.

Unlike many other research methodologies, the data are not all analyzed at the end of data collection. Instead, the data are examined continuously throughout the process. Although data analysis is discussed separately from sampling and data collection, it is important to realize that in grounded theory these processes are linked very closely together (Charmaz, 2000; Strauss & Corbin, 1998). The processes of data collection, data analysis, memo-writing, theoretical sampling, and the development of the grounded theory are all closely related, and it is often difficult to tease apart these processes in a linear way.

The first stage of data analysis began with initial coding. After an interview was transcribed, initial coding was completed by going through the transcript on a line-by-line basis and coding the data (Charmaz, 2000). There were 2,136 initial codes that emerged from close examination of each line of text and described “actions or events within it [the data]” (Charmaz, p. 515). When possible, codes were active, describing processes and actions occurring in the data. An advantage of action codes is that they “give us insight into what people are doing, what is happening in the setting” (Charmaz, p. 515). Coding the data line-by-line included asking questions about different aspects of the data, comparing data, and considering the participant’s context, assumptions, and meanings (Charmaz, 2003b).

After the initial coding on all interviews and documents had been completed, the next stage of data analysis, focused coding, began. Focused coding involved selecting the most frequent and important codes from the initial coding stage (Charmaz, 2000, 2003b); I identified 82 focused codes (Appendix G). Just as initial coding led to focused coding, focused coding provided the important link to the development of the categories used in the final theoretical framework. Charmaz (2003b) described the importance of this stage: “focused codes provide analytic tools for handling large amounts of data; reevaluating earlier data for implicit meanings, statements, and actions; and subsequently, generating categories in the emerging theory” (p. 443). Focused codes became categories, as defined by Charmaz (2004): “By raising a code to the level of a category, you treat it more conceptually and analytically. Thus, you go beyond using the code as a descriptive tool to view and synthesize data” (p. 41). In addition, comparison of the data is an important component of data analysis in grounded theory (Charmaz, 2003b; Glaser &

Strauss, 1967; Strauss & Corbin, 1998). Throughout the entire process the researcher will “compare statements or actions from one individual, different incidents, experiences of varied participants, and similar events at different points in time” (Charmaz, 2003b, p. 442).

Once an initial set of codes was raised to categories, writing memos became a critical part of the analysis process. These often informal written memos were for the benefit of the researcher and were a way to manage and analyze the data, make comparisons, further an understanding of the categories, and fit them together into the emerging conceptual framework (Charmaz, 2000, 2004). Charmaz (2002) explained the importance of memo writing in grounded theory work:

Memo writing is the intermediate step between coding and the first draft of the completed analysis. This step helps us to spark our thinking and encourage us to look at our data and codes in new ways. It can help us define leads for collecting data – both for further initial coding and later theoretical sampling. Through memo writing we elaborate processes, assumptions, and actions that are subsumed under our codes. Memo writing leads us to explore our codes; we expand upon the processes they identify or suggest. Thus our codes take on substance as well as a structure for sorting data. (p. 517)

Memo writing continued throughout data analysis, and memos were often developed into parts of the final written project (Charmaz, 2004).

It was at this point in the analysis process that theoretical sampling became part of the data collection and analysis cycle. Theoretical sampling can involve returning to previously collected data to further examine the themes, concepts, and relationships that have emerged from the data; it can also involve returning to previous participants to explore these emerging categories as well as interviewing new participants and exploring these ideas (Charmaz, 2003b). Theoretical sampling helped to refine the categories and

further the development of the final conceptual framework in important ways, as described below:

Theoretical sampling helps us to define the properties of our categories; to identify the contexts in which they are relevant; to specify the conditions under which they arise, are maintained, and vary; and to discover their consequences. Our emphasis on studying process combined with theoretical sampling to delineate the limits of our categories also helps us to define gaps between categories. Through using comparative methods, we specify the conditions under which they are linked to other categories. After we decide which categories best explain what is happening in our study, we treat them as concepts. (Charmaz, 2000, pp. 519-20)

Theoretical sampling in this study consisted of using prior interviews and analysis to develop new interview questions and inform future interviews as well as repeated examination of previously analyzed data when a new idea emerged.

The cycles of coding, raising codes to categories, writing memos, and theoretical sampling provided the foundation for the theoretical framework. Data collection stopped when categories were saturated, “when new data no longer spark new insight” (Charmaz, 2003a, p. 107). The emerging theory became more abstract but remained grounded in the data; excerpts from the raw data were incorporated to illustrate the categories (Charmaz, 2003a, 2004). The analysis process continued until the resulting theory fulfilled the following goals:

For a grounded theory to have explanatory power, its theoretical categories should be abstract, explicit, and integrated with other categories. Thus, grounded theorists complete the following tasks: locating the context(s) in which the category is relevant; defining each category; delineating its fundamental properties; specifying the conditions under which the category exists or changes; designating where, when, and how the category is related to other categories; and identifying the consequences of these relationships. These analytic endeavors produce a fresh theoretical understanding of the studied process. (Charmaz, 2003b, p. 444)

A qualitative research software (QRS) program, Atlas.ti, was used in this study to organize and manage data from multiple interviews with participants as well as documents provided by participants. Advantages of using QRS include consistency, speed, representation, and consolidation (Weitzman, 2000). In November 2005, shortly after data collection began, I attended a two-day Atlas.ti training workshop. The software was used to analyze all interview transcripts and documents; after interviews had been transcribed, the documents were opened in Atlas.ti and the software was used as a tool in the coding process. It is important to note that Atlas.ti does not code data; it only provides a format for the researcher to code the data. The use of Atlas.ti also assisted in the analysis process by providing a way to easily search large amounts of written data for similar codes or words. Memos were written using Atlas.ti and could be linked to the relevant raw data or code. Atlas.ti also has the ability to create visual representations of the data and codes, called network views, and these network views were a useful part of the analysis process. These visual representations can be easily manipulated and provided a valuable way to explore connections and develop the theory. Even though computer software was utilized for organization and management, paper copies of transcripts were often used and closeness to the data was maintained through line-by-line coding.

Ensuring the Goodness of the Research

This study aimed to fulfill the guidelines for research goodness, as defined by Arminio and Hultgren (2002): “Goodness requires that the elements of the meaning-making practice are illustrated” (p. 446). Basing the assessment of qualitative research on the concept of goodness is important because it makes the criteria for judging research consistent with the basic principles of qualitative research (Arminio & Hultgren).

Goodness of research is evaluated using six dimensions: epistemology and theory; methodology; method; researcher and participants as multicultural subjects; interpretation and presentation; and recommendations (Arminio & Hultgren). The six dimensions of goodness, and how this study incorporated them, are described below.

Epistemology and Theory

It was important to describe the epistemological foundation of the study because “epistemological assumptions represent a belief system, not merely something someone does. Epistemology explains the way one views the world” (Arminio & Hultgren, 2002, p. 450). The epistemology guiding this study was constructivism, defined by Crotty (1998) as “...the view that *all knowledge, and therefore all meaningful reality as such, is contingent upon human practices being constructed in and out of interaction between human beings and their world, and developed and transmitted within an essentially social context*” (p. 42). Constructivism can be an appropriate and useful epistemology for research that focuses on student affairs and higher education (Broido & Manning, 2002) and thus was appropriate for this college student based study.

A study cannot have goodness without a discussion of its theoretical perspective, particularly since this is related to the choice of methodology (Arminio & Hultgren, 2002). Crotty described a theoretical perspective as “the philosophical stance informing the methodology and thus providing a context for the process and grounding its logic and criteria” (1998, p. 3). Within the epistemological framework of constructivism, the theoretical perspective for this study was symbolic interactionism, “the putting of oneself in the place of the other” (Crotty, p. 75). Symbolic interactionism has been associated with grounded theory since the methodology was founded (Charmaz, 2000; Crotty). The

core idea of symbolic interactionism is closely related to both the epistemology and methodology used in this study.

Methodology

The choice of constructivist grounded theory as the methodology is a clear link to both the epistemological foundation of constructivism and the theoretical perspective of symbolic interactionism. In constructivist grounded theory meaning is constructed by both the researcher and the participant, and it is crucial for the researcher to find out the context, meaning, and hidden assumptions disclosed by the participant (Charmaz, 2000).

These core aspects of the methodology can be seen within symbolic interactions:

This role taking place is an *interaction*. It is *symbolic* interaction for it is possible only because of the “significant symbols” – that is, language and other symbolic tools – that we humans share and through which we communicate. Only through dialogue can one become aware of the perceptions, feelings and attitudes of others and interpret their meanings and intent. (Crotty, 1998, pp. 75-6)

The close and congruent relationship between the epistemology, theoretical perspective, and methodology bolsters the goodness of this research. Goodness specifically related to grounded theory methodology requires that “the theoretical construction is grounded in the data as well as supported in the related literature and that the linkages are made clear and compelling” (Arminio & Hultgren, 2002, p. 453).

Method

Ensuring goodness in qualitative research requires that the researcher uses methods that are consistent with the methodology, selects participants who are appropriate for the study, provides thick, rich description of the data, and completes an audit trail of the data (Arminio & Hultgren, 2002). Additionally, both the researcher’s connection to the topic and the choices made in the research design should be clear to the

reader (Arminio & Hultgren). Each of these elements of goodness in the methods of this study will be described. The data collection method, multiple in-depth interviews, was selected for its compatibility with constructivist grounded theory methodology and usefulness in obtaining thick, rich data from participants (Charmaz, 2002). In addition, previous work in counseling enhanced my ability to conduct interviews that resulted in thick, rich data. Purposeful sampling and theoretical sampling were used to select participants who would be the best source of data about the topic (Charmaz, 2000; Patton, 2002). Throughout the study rationales for choices in the research design were presented. Finally, as the researcher, my own connection to the topic was discussed and my role as the researcher was offered.

An inquiry auditor examined the data from the study and verified the analysis by taking the following steps: “Pursuant to grounded theory, this individual examines the integrative or key categories, the selection of a central category (sometimes called core category), and the interconnections in developing the emerging theory, and confirms the product” (Brown et al., 2002, p. 182). This audit of research by an individual not involved in the project is common in qualitative research and helps ensure that the study is both dependable and confirmable (Miller, 1997; Patton, 2002). An inquiry auditor who was familiar with college students and student affairs and qualitative methodology and independent of the study was chosen for this critical task. The inquiry auditor read all transcripts and documents and reviewed the initial coding, focused coding, the key and core categories, and the emerging theory. The inquiry auditor also examined printed versions of network views created with Atlas.ti. The entire coding and analysis process was discussed with the inquiry auditor, who verified the analysis (Appendix H).

Researcher and Participants as Multicultural Subjects: The Representation of Voice

This dimension of goodness emphasizes the researcher's responsibilities as conduits of the participants' experiences: "Researchers must reflect upon their relationship with their participants and their relationship with the phenomena under exploration. Moreover, researchers must be mindful of the power they display in representing the voices of their participants" (Arminio & Hultgren, 2002, p. 454). My coursework and background in counseling have strengthened my skills in this type of reflection and enhanced my capacity to carefully analyze the context of people's lives. Additionally, the use of constructivist grounded theory as the methodology for this study was key in fulfilling this element of goodness. Constructivist grounded theory puts the participants' voices in a primary position without ignoring the role of the researcher:

In short, constructing constructivism means seeking meanings – both respondents' meanings and researchers' meanings.

To seek respondents' meanings, we must go further than surface meanings or presumed meanings. We must look for views and values as well as for acts and facts. We need to look for beliefs and ideologies as well as situations and structures. By studying tacit meanings, we clarify, rather than challenge, respondents' views about reality. (Charmaz, 2000, p. 525)

Interpretation and Presentation

This dimension of goodness, the interpretation and presentation of the research, addresses the critical process of meaning making (Arminio & Hultgren, 2002).

Interpretation and presentation is a complex process, and goodness in this area requires several responsibilities. Researchers must spend time engaged with their data and discovering meaning within the text: "To follow goodness researchers are required to examine, expose, explain, and then illustrate with examples this unloosening and uncovering. There is a clear link between the text, coding or thematizing, and

interpretation” (Arminio & Hultgren, p. 456). In addition to the extended engagement with the data, two other aspects of constructivist grounded theory methodology helped achieve this aspect of goodness. First, the coding process involved repeated viewings and analysis of transcripts in order to fully develop the emerging theory. Second, continuously writing memos helped to document and further the analysis, assist in the thematizing of the data, and connect the actual text to the theory.

Establishing the trustworthiness of the research study is an important step in the assessment of qualitative research (Lincoln & Guba, 1985) and is defined through this question: “How can an inquirer persuade his or her audiences (including self) that the findings of an inquiry are worth paying attention to, worth taking account of?” (p. 290). Trustworthiness in qualitative research has generally been divided into four aspects: credibility, transferability, dependability, and confirmability (Lincoln & Guba). The use of goodness to evaluate qualitative research does not emphasize the fixed categories of trustworthiness but advocates similar concepts and method; trustworthiness is still necessary to demonstrate goodness (Arminio & Hultgren, 2002). The traditional framework is used for the descriptions below, with discussions of goodness as appropriate.

Marshall and Rossman (1999) stated that credibility is crucial in order to “demonstrate that the inquiry was conducted in such a manner as to ensure that the subject was accurately identified and described” (p. 192). Methods to ensure credibility used in this study included member checks, negative case analysis, and the use of peer debriefers (Brown et al., 2002). Member checks involved providing participants with transcripts of their interviews and written analysis of the data and asking for feedback:

If the investigator is to be able to purport that his or her reconstructions are recognizable to audience members as adequate representations of their own (and multiple) realities, it is essential that they be given the opportunity to react to them. (Lincoln & Guba, p. 314)

Negative case analysis involved looking at data from participants that didn't seem to fit with the analysis and making sure that the final theory had the flexibility to credibly account for the variation (Lincoln & Guba). Peer debriefers offered feedback throughout the entire data collection and analysis process, and their role can be described as follows: "The peer debriefers serve as sounding boards for the researcher, offering different lenses to analyze the data and serving as meaning makers" (Brown et al., p. 181). The two peer debriefers were both doctoral students and were familiar with qualitative research. They reviewed the conceptual model at several points during its evolution and their roles as sounding boards were critical in the development of the final model. In addition to the valuable feedback and perspectives offered by the peer debriefers, they were also helpful in discussions about the differences between my experiences as a college student sibling and the experiences of the participants in the study.

To satisfy the second requirement of transferability, "the researcher must argue that his [or her] findings will be useful to others in similar situations, with similar research questions or questions of practice" (Marshall & Rossman, 1999, p. 193). This is more of a concern for later researchers who wish to use the findings from a previous study with a different population or practitioners who want to apply the findings in a practical setting (Brown et al., 2002; Marshall & Rossman). Transferability is not emphasized in determining goodness.

The last two aspects of trustworthiness, dependability and confirmability, are discussed together because the same technique, an inquiry audit, can be used to

demonstrate both qualities (Lincoln & Guba, 1985). Dependability “ensures that the data represent the changing conditions of the phenomenon under study” (Brown et al., 2004, p. 181). Confirmability asks the following question: “Do the data help confirm the general findings and lead to the implications?” (Marshall & Rossman, 1999, p. 194). An inquiry auditor familiar with qualitative methodology examined the actual data and materials from the research and verified the final analysis to help ensure both dependability and confirmability (Brown et al., Lincoln & Guba). Miller (1997) described key aspects of the audit conducted by the inquiry auditor:

It is an extensive investigation of the researcher’s record-keeping, or the “audit trail” left by the researcher. It is a systematic evaluation, typically conducted by an external or independent auditor.

The purpose of the audit is twofold: to examine the *process* and the *product* of the inquiry. The former addresses the dependability of the study, and the latter addresses the confirmability of the study. (p. 6)

The combination of member checks, negative case analysis, peer debriefers, and an inquiry audit helped to demonstrate the trustworthiness of the study, which in turn demonstrated the goodness of the study. In addition to these measures, goodness also required that the analysis consider multiple points of view and the influence of culture (Arminio & Hultgren). Constructivist grounded theory methods require the researcher to explore how individual participants make meaning of their experiences and make sure that the data are situated within the context of the participants’ lives (Charmaz, 2002). One specific way this happens is through the first stage of data analysis: “Initial coding helps the grounded theory researcher to discover participants’ views rather than assume that researcher and participants share views and worlds” (Charmaz, p. 684). In addition to

recognizing that multiple points of view exist, this type of approach to research also helps to ensure that cultural influences are included in the analysis.

Recommendations for Professional Practice

The final aspect of goodness deals with the purpose and future use of the research: “It is not for the sake of research itself that researchers should embark on this work, but rather to improve the lives of others. Interpretive research is initiated for the purpose of improving the world through more informed action” (Arminio & Hultgren, 2002, p. 457). This research clearly met these criteria of goodness by including practical applications of the research as part of the significance of the study and offering specific recommendations for the use of the results.

Role of the Researcher

In qualitative research the researcher is considered to be the instrument (Patton, 2002). Additionally, an important aspect of constructivist grounded theory is the acknowledgment that the researcher has a role in how data are viewed and analyzed (Charmaz, 2002). Although a constructivist grounded theory methodology has the assumption that “data reflect the researcher’s and the research participants’ mutual constructions” (Charmaz, p. 678), it is still extremely important for me to avoid fitting the data into my own preconceived categories. My dual roles as researcher and sibling meant that I needed to be careful not to project my own background on the data or assume that participants shared the same experiences, thoughts, or feelings. In addition to maintaining this awareness throughout the study, there were several tools used to ensure that my identity as a sibling did not influence the interpretation of the data. These strategies

included the previously discussed use of member checks, peer debriefers, and an inquiry auditor.

Ethical Considerations

This research followed guidelines of the four areas of ethical behavior in qualitative research discussed by Christians (2000): informed consent; deception; privacy and confidentiality; and accuracy. All participants signed an informed consent form approved by the Institutional Review Board (Appendix E). This consent form described the procedures in the study, promised confidentiality, and informed participants that they could withdraw from the study at any time. The contents of the consent form were carefully reviewed with each participant at the start of the study. This research did not involve any deception, and the purpose of the study was clearly provided to all participants. The privacy and confidentiality of the participants were maintained by not using their names or identifying information on any recordings, recording labels, or written materials. Participants were asked to choose a pseudonym to be used in all written work. All participants were informed that verbatim excerpts from their interview would be used in the written work. All written material reviewed by the inquiry auditor and peer debriefers were labeled only with a pseudonym and followed the same level of confidentiality. The professional transcription service used for some of the transcribing follows a confidentiality protocol and deleted all audio files and documents once the interview was transcribed. There was no outside access to any research materials as they were stored in a locked private residence. The researcher was available to address any concerns or questions participants had about privacy and confidentiality.

This study attempted to minimize any possible risk to participants. When potentially sensitive issues arose during interviews, care was taken to make sure that participants were comfortable with the discussion. As suggested by Charmaz (2002), interviews were never ended immediately after discussion of sensitive topics: “The rhythm and pace of the interview should bring the participant back to a normal conversational level before the interview ends” (p. 679). It was made clear through the consent form and verbal communication that participants could withdraw from the study at any time. Participating in the interviews may have increased students’ interest in sibling issues or awareness of themselves as siblings. All participants were given a resource guide with websites, books, and local organizations that may be helpful for siblings (Appendix I).

Summary

This chapter discussed the rationale for the use of constructivist grounded theory to address the primary research question. The procedures used in the study for participant recruitment, interviews, and data analysis were detailed. This chapter also reviewed how the study aimed to meet the standards of goodness of research. Finally, the role of the researcher and ethical considerations for this study were addressed.

CHAPTER IV

FINDINGS

The purpose of this study was to examine the experiences of college students who have a sibling with a developmental disability. Interviews with nine current college students and recent graduates, along with papers and essays written by some of the participants, provided the data that were used as the basis of the emergent theory and conceptual model. The first stage of line-by-line coding resulted in 2136 initial codes and the next level of coding included 82 focused codes. Analysis of these concepts led to the development of the emergent theory, which was comprised of the core category and five related key categories. Within the text, the *core category* and *key categories* are indicated by italics and their subcategories have the first letter of each word capitalized.

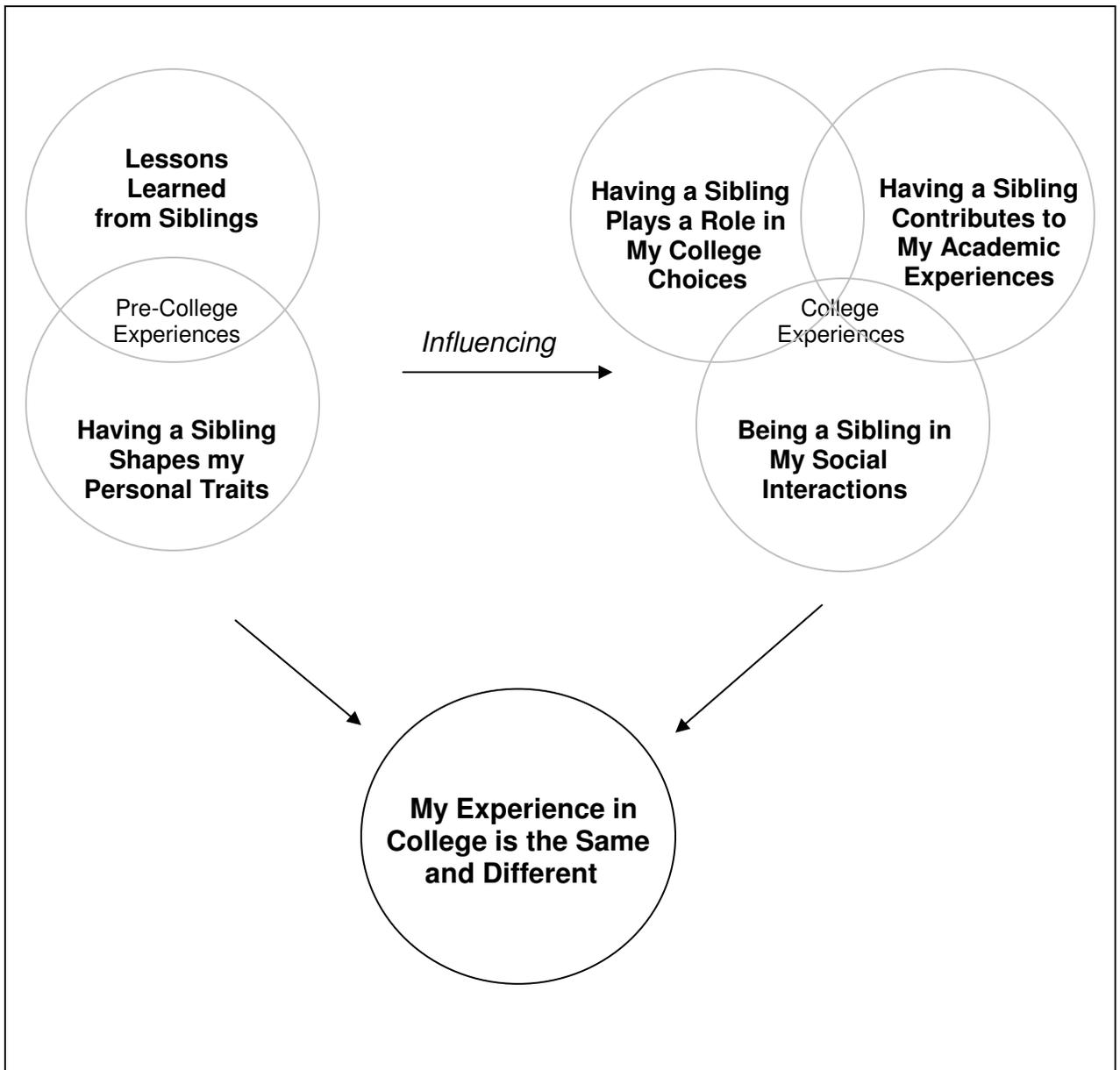
Overview of the Theory

The emergent theory described the experiences of college students who have a sibling with a disability and contained a core category and five key categories. These categories evolved from the analysis of the participants' interviews and written materials and were grounded in those data. The core category, which incorporated the essence of participants' experiences, was *My Experience in College is the Same and Different*. This core category reflected the paradox inherent in their lives as college students: they identified many specific ways in which their college experience was distinctive but on a global level they didn't consider themselves to be different from other students. There were five key categories that were related to the core category of *My Experience in College is the Same and Different: Lessons Learned from Siblings, Having a Sibling Shapes My Personal Traits, Having a Sibling Plays a Role in My College Choices,*

Having a Sibling Contributes to My Academic Experiences, and *Being a Sibling in My Social Interactions*. A visual representation of the theory is included in Figure 1.

The five key categories were classified into one of two groupings based on their relationship to students' time in college; these groupings were labeled Pre-College Experiences and College Experiences and are represented visually by overlapping circles. The two overlapping circles on the left side of Figure 1 were considered part of students' Pre-College Experiences and the two related key categories were *Lessons Learned from Siblings* and *Having a Sibling Shapes My Personal Traits*. The three overlapping circles on the right side of Figure 1 related to students' College Experiences and were ways that growing up with their sibling affected their lives as college students; the three related key categories were *Having a Sibling Plays a Role in My College Choices*, *Having a Sibling Contributes to My Academic Experiences*, and *Being a Sibling in My Social Interactions*. As a whole, these five categories illustrated the specific ways in which having a sibling with a developmental disability influenced participants' lives as college students, via both pre-college experiences and college experiences.

Beginning on the left side of Figure 1, the two key categories considered to be Pre-College Experiences were the first type of influence on participants' college experiences and began before they entered college. These key categories, *Lessons Learned from Siblings* and *Having a Sibling Shapes My Personal Traits*, included subcategories describing the specific lessons and personal traits that participants felt were developed as a result of growing up with a sibling with a disability. *Lessons Learned from Siblings* was comprised of five subcategories: Valuing What You Have, Appreciating Differences and Being Nonjudgmental, No Self-Pity, Never Give Up, and



Experience of College Student Siblings

Figure 1. Visual model of the experiences of college students with a sibling with a developmental disability.

Having Hope and Faith. *Having a Sibling Shapes My Personal Traits* contained three subcategories: Having Patience, Understanding Others, and Being Mature and Responsible. As indicated by the arrow leading from the Pre-College Experiences categories to the College Experiences categories, participants sometimes felt that they entered college with specific attributes, such as patience or appreciation for differences, which were influenced by their sibling and could affect their College Experiences. For example, one participant felt that she developed patience as a result of growing up with her brother with a disability and she thought that this patience benefited her in her out-of-class activities and her future career. Additionally, as illustrated by the arrow leading from the Pre-College Experiences categories to the core category, *My Experience in College is the Same and Different*, these lessons and traits also contributed to their feeling that their experience as a college student sibling was both the same and different. An example of this relationship within the theory is another participant who felt that, because of his experiences with his siblings, he was more open-minded than many of his peers.

Looking at the right side of Figure 1, the three key categories considered to be College Experiences represented the ways in which participants' lives as college students were specifically influenced by having a sibling with a disability. These three key categories corresponded to distinct aspects of their experiences in college: *Having a Sibling Plays a Role in My College Choices*, *Having a Sibling Contributes to My Academic Experiences*, and *Being a Sibling in My Social Interactions*.

The first of the key categories within College Experiences, *Having a Sibling Plays a Role in My College Choices*, dealt with the specific choices that participants made about college and how those choices were shaped by growing up with a sibling

with a disability. These choices began during high school with the college selection process and continued throughout their time in college; some of these choices were influenced more heavily by their sibling and other choices were affected minimally, if at all. The subcategories within *Having a Sibling Plays a Role in My College Choices* were: Choosing a College, Choosing a Major, Career Plans, Participation in Out-of-Class Activities, and Planning for the Future. The second key category within College Experiences, *Having a Sibling Contributes to My Academic Experiences*, dealt with how participants' learning and academic experiences, including classroom interactions, were affected by their having a sibling with a developmental disability. The subcategories within *Having a Sibling Contributes to My Academic Experiences* were: Papers and Projects, Personal and Academic Benefits, Classroom Discussions, and Hearing Inappropriate Language in Academic Settings. The third key category within College Experiences was *Being a Sibling in My Social Interactions*, which included participants' relationships, interactions, and behaviors in social settings. The subcategories within *Being a Sibling in My Social Interactions* included Transitioning to College, Friendships, Dating and Relationships, Talking about Siblings, and Hearing Derogatory Language in Social Settings. As indicated by the arrow leading from the three College Experiences key categories to the core category, participants felt that their experiences with these particular aspects of college contributed to their feeling that their lives as college student siblings were both the same and different. As an example, one student believed that her transition to college was different from other first-year students and more challenging because her sister had a disability.

Finally, the core category of *My Experience in College is the Same and Different* captured participants' experiences as college student siblings and reflected their perception of themselves as college students. Participants' discussions of their college experience overall tended to include statements reflecting the idea that they were generally the same as other students. In addition to the fundamental idea of *My Experience in College is the Same and Different*, the core category also included three subcategories: Uniqueness of the Sibling Experience, This is All I Know, and Identifying as a Sibling. These subcategories were fundamental components of their entire sibling experience and offered additional insight into the reality of their lives as siblings.

Each of the key categories related to the core category by contributing to participants' view that their lives as college student siblings were both the same and different. Not all participants had experiences related to every category and not every category led them to feel different. Certain aspects of their college experience, such as participation in study abroad, rarely, if ever, led participants to feel that their experience as a college student was different. Other aspects, such as appreciation for differences, choosing a major, learning more about themselves through an academic experience, or hearing derogatory language in social settings, were more closely associated with the idea that their college experience was different from other students.

Each of the five key categories and the core category, including their respective subcategories, will be discussed in more detail and are illustrated by excerpts from participants' interviews and written materials. Some excerpts were edited slightly for readability by removing phrases such as "um" or "yeah" or removing repeated words; these minor changes did not alter the content or context of the excerpts. The key

categories will be explored first, beginning with the two key categories grouped together as Pre-College Experiences and followed by the three key categories grouped as College Experiences. The last category to be discussed will be the core category.

Key Categories

Lessons Learned from Siblings

Lessons Learned from Siblings was one of the key categories considered to be part of the participants' Pre-College Experiences and is represented by one of the overlapping circles on the left side of Figure 1. Participants described many ways in which growing up with a sibling with a developmental disability taught them important lessons and helped shape their outlook on life. The way they viewed the world was an integral part of them and both directly and indirectly influenced their experiences in college. The category of *Lessons Learned from Siblings* is comprised of five subcategories: Valuing What You Have, Appreciating Differences and Being Nonjudgmental, No Self-Pity, Never Give Up, and Having Hope and Faith.

Lessons Learned from Siblings and the next category, *Having a Sibling Shapes My Personal Traits*, were similar because both reflected aspects of participants' lives that weren't always explicitly related to their lives as college students. When asked about how growing up with their sibling influenced them, participants spoke about their outlook on life as well as different aspects of their personalities. They were often able to make connections to parts of their college experience but it seemed that these were important parts of their lives that would have existed whether they went to college or not. Although the lessons and traits that emerged from the data didn't initially seem to be concrete parts of participants' experiences in college, it was clear that these concepts shaped

participants in fundamental ways and needed to be part of the theory that would represent their college experience. It became clear that I needed to take a wider look at what the “college experience” really meant and acknowledge that, for the participants, the influences on their college experience began well before college.

Every participant identified at least one fundamental aspect of themselves that was affected by their sibling and most spoke about several. All of the participants learned lessons from their siblings and those lessons were different for each individual. The language used by participants suggested that there was a difference between lessons and traits, with personal traits tending to be more a part of their personality.

Valuing What You Have

Some siblings were grateful for different things in their lives and understood the importance of valuing what they had. Aurora and Hannah appreciated their abilities, including their ability to learn. Hannah’s ability to value her own intellect influenced two significant aspects of her college experience: her decision not to drink alcohol and her commitment to academic achievement: “I’ve always really appreciated my ability to learn. I’ve always tried to use that to the best of my abilities. I mean I’ve always put a lot of effort into my academics, just in that sense.” Hannah viewed drinking as something that could possibly lead to dangerous situations and chose not to use alcohol: “I really appreciate my ability to learn and be intelligent I guess, ‘cause I’ve seen people who don’t have those abilities and knowing that things can go wrong when you drink and stuff it’s not worth the risk.”

Aurora described how her sister’s appreciation for things leads her to enjoy others’ strengths and abilities: “she always like, loves to watch me dance and see like me

do things that she can't, so it's interesting because then I appreciate things I can't do or like, don't do." Aurora has written about other things she is grateful for: "Her [Aurora's sister] inability to perform everyday tasks forces me to appreciate the advantage of a fully functional body and mind," and "She reminds me to appreciate everything I have been given in my life and to treat everyone with the same respect I would want to receive."

Jeff's experiences with his brother's continual health crises inspired him to always have hope and faith and instilled in him a deep sense of gratitude: "you have so many things you don't realize and you just, have to be happy with what you have and appreciate everything now."

Appreciating Differences and Being Nonjudgmental

Growing up with a sibling with a disability often helped participants to appreciate differences and try to withhold judgment of other people. Hannah believed that her brother helped her develop an awareness of the diversity in the world, which was related to her decision to major in anthropology. During her college search the diversity at the school she eventually chose was appealing: "I liked the international aspect...they promote diversity."

Sarah felt that her parents and siblings contributed greatly to her views about differences between people but also believed that going to college broadened her view even more and gave her a deeper understanding of diversity. James also viewed his parents as a major influence in being able "to accept people as they are." Sarah's family background, especially growing up with her sister, has taught her not to judge people:

I think having a sister with a disability has really helped me not judge people. I mean, of course, I judge people....But there are situations where now I won't

judge people because no one expects a lot of the things that happened to my family or that are incorporated into my family. Whatever happened to me, I mean I come off as this, I can come off as this really cute prissy girl...but they never expected like some of the stuff that has happened. “Ah, you’ve done prison for ten years?” “Yeah, I did.” “Can you believe it?” “No, we look good now.” We are doing really well, but like, yeah, so there’s things that like I’m not ashamed of. They just make you grow as a person, so, I guess that’s it.

Deanna also felt that growing up with a sibling with a disability made her less judgmental: “I’m pretty tolerant and you know, I’m kind of just friends with everybody, and I’m, you know, I try not to be too judgmental and stuff like that.” James expressed a similar opinion: “I’d like to think that I’m more like, open minded or tolerant, or in this area specifically knowledgeable, because of my experiences at home.”

For many participants, having an appreciation for differences naturally included differences related to disabilities. Jane observed that many people are afraid of people with disabilities and felt that her perspective was different:

I think, for myself, I always now, I think, look at the bright side of people and see that there’s a whole another layer. And it’s more than just tolerance I guess, I don’t even think that word is strong enough. It’s more like, I’m not afraid. I think more people are scared of what they don’t know and don’t understand.

Hannah viewed disabilities as just another type of difference, one related to intelligence, and embraces an inclusive definition of diversity:

I think I’m a lot more accepting of differences than some people. I know at [Name of School] there’s a lot of emphasis, particularly on racial diversity...and I think, my view of diversity is a little more comprehensive, there’s a lot more to diversity than just racial diversity.

No Self-Pity

Several participants expressed the view that it was pointless to dwell on their sibling’s disabilities and that it was important to recognize that everyone had challenges to overcome. For Jeff, this meant “making the most of things” and not complaining:

Nothing can ever really be too hard. Like, you complain about like, work and stuff, but there are things, like, that's worse than that. There are people who have bigger problems than you. So, I'm not big into complaining at all...I don't like it when people complain a lot. And I'll tell them that. That I took from my mom, telling people things when I have problems with them. Just like, easygoing, don't, just appreciate, don't really worry too much, like things always end up better than we expected.

Colleen acknowledged that taking care of her brother can be difficult but avoids self-pity:

"I don't ever feel like, sad for myself. Every family has their burdens." Jane offered a similar view:

I have realized how fortunate I am that my sister is, you know, so well off. Like I'm so, she's so lucky, and I'm happy for her and thankful that she, you know, you see sometimes there's broken families and the children with special needs, or children with, you know, more special needs than my sister has...She has so much in her life that really, we just are so thankful that we have [name of sister] in our lives and that she, the situation is as good as it is. Her disabilities are not that terrible.

Never Give Up

Perseverance was another important lesson that participants learned from their siblings. Phyllis described growing up with her brother as rewarding because "he's taught me so much about like patience and perseverance, like nothing stops him from doing what he wants to do." For Deanna, her brother's progress after years of struggles and a negative prognosis was inspiring and taught her "not to give up...you never know what could happen." Jeff was inspired by both his brother and his parents and he applied the idea of never giving up to academic work:

I think it goes back to like how he affected me, in terms of when you take something on, to really put your all into it, and try and make it work, and not quit on something if it's not going your way, or if it's hard, and I think I got that from my parents, who just never really stopped... 'cause sometimes you're tempted to just throw in the towel, I guess. Don't want to sound cliché, but like, you just, even with school work, if a class is getting difficult, you're just tempted to just not study, and just take the C, and who cares. It's like, no one's gonna see it

anyway. But, it just, trying to get out of that mode, and trying to, you know, like, do well in everything.

Having Hope and Faith

Having hope and faith was important to several participants and the degree to which that was associated with organized religion varied. Deanna's brother's progress over the years taught her perseverance, but it also made her more hopeful. She didn't connect this hopefulness to a religious context but it was derived from her experiences with her brother.

Jeff attended a Jesuit high school and attended a religiously affiliated college; he has questioned some of the tenets of the Catholic faith in which he was raised but has been able to make peace with his religious beliefs. Jeff felt that there was a connection between his religion and his experiences with his brother:

My religion always talks about you have to have faith and, you know, maybe something doesn't seem like it makes any sense, but just give it a chance and like see what'll happen, and I think that kind of parallels a lot of the things that have happened like with my brother being in the family, like things could look absolutely horrible and wrong, but if you just stick in there, then it'll like turn itself around, I guess.

For Jeff, growing up with his brother helped him develop both faith and hope. Watching his brother "bouncing back" from multiple medical crises and seeing him survive even after doctors declared that he wouldn't make it was influential and emphasized the importance of having hope.

Sarah was another participant who attended a religiously affiliated college and viewed religion as an important part of her life. She saw a clear connection between her religious beliefs, having faith, and having a sibling with a disability:

I think that, like, I have a lot of faith so I think that connects to it in a sense that I am able to say "oh why did this happen?" There's a reason and like for anything,

not just a sister with a disability or like, and I believe that God makes people or creates people with disabilities, I think it's to make the rest of the world better. I really think that it's just everyone is different. It's another difference in people and I think that that's okay and I think that God did it for a reason....It's just like, I've just got to believe. I mean I believe in God and I believe in my faith and that just makes it easier for me. Sometimes I just want to be like why the hell is it like this? But I'm just like, ho hum, maybe it is for a reason. I just keep saying there's a reason. I don't know what it is right now but there is one, you know? So I guess you have to have faith, I have faith and that's what I think has gotten me through a lot of things in life, not just understanding disabilities and stuff.

The key category of *Lessons Learned from Siblings* shared some similarities to the next key category, *Having a Sibling Shapes My Personal Traits*, as both were part of participants' Pre-College Experiences. As shown by the arrows in Figure 1 leading from *Lessons Learned from Siblings* to both the three key categories in College Experiences and the core category, *Lessons Learned from Siblings* was related to both participants' College Experiences and their belief that *My College Experience is the Same and Different*. For example, Hannah's awareness and appreciation of diversity is an example of the relationship between the Pre-College Experiences category of *Lessons Learned from Siblings* category and the College Experiences category of *Having a Sibling Plays a Role in My College Choices*. She felt that her prior awareness of diversity was partially connected to her choosing to major in anthropology, a field of study that she felt also valued diversity. Jane's comments about her appreciation for people's differences reflect her belief that this attitude sets her apart from others and demonstrate the interaction between *Lessons Learned from Siblings* and the core category *My College Experience is the Same and Different*.

Having a Sibling Shapes My Personal Traits

Along with *Lessons Learned from Siblings*, *Having a Sibling Shapes My Personal Traits* was the second key category considered to be part of participants' Pre-College

Experiences and is represented by one of the overlapping circles on the left side of Figure 1. For many participants, having a sibling with a developmental disability was integral in the development of some of their personal traits. The three subcategories of personal traits that emerged were Having Patience, Understanding Others, and Being Mature and Responsible.

Having Patience

Patience was a common quality learned from having a sibling with a developmental disability; Hannah, Deanna, Phyllis, and Aurora all credited their siblings with teaching them patience. Aurora and Phyllis spoke generally about learning patience through growing up with their sibling, and Hannah and Deanna elaborated on developing patience and how this trait serves them well. Hannah described this learning process in her admissions essay for medical school:

I have learned the importance of patience and the art of explaining things from helping my brother understand the plot of a movie or the meaning of a word. I have waited while he tried to read all the signs at the zoo, and that takes a lot of patience!

Hannah and Deanna both felt that their patience served them well in current jobs and would be helpful in their intended careers. Hannah noted the importance of patience in a medical setting in her medical school admissions essay: “Patience and flexibility are skills that come in handy all the time, especially in situations where one has to explain information to others, as doctors do every day.” Deanna saw the usefulness of patience when working with students:

I think it’s made me much more patient and much more understanding now that I’m taking classes and I’m in the school with you know, a lot of the kids have IEPs [Individual Education Programs] and stuff like that, it’s made me much more patient and much more understanding.

Understanding Others

Many participants felt that growing up with a sibling with a disability had enhanced their ability to focus on and understand others. Jane, Jeff, and Deanna all described themselves as “understanding” and each used additional descriptors such as sympathetic, caring, and compassionate. Some of Hannah’s self-described strengths related to her brother included “working with other people” and “teaching” or “explaining” things to others.

Colleen and Jeff both included a focus on others as part of their identity. Along with family, Jeff said that other people were a major part of his identity: “anything that involves like social interaction, exploring new things, trying new things. Having fun, doing– making people laugh, making them happy. Anything that really involves other people.” When talking about her 9th summer working at a camp for people with disabilities, Colleen said: “I guess that’s a big part of my identity is really taking care of people and I guess maybe you [laughter] hear that a lot in the research, it’s sort of what we know.”

Aurora sometimes found some of the influence from her sister hard to articulate but felt she was attuned to other people: “I mean it gives me a sense of awareness of what other people need, you know like, I’m, I don’t know exactly.”

Being Mature and Responsible

Feeling mature and responsible was a theme in interviews. Some participants connected this to early caretaking responsibilities, and others just felt it was part of their personality. Several participants viewed themselves as more mature than their classmates, and Jeff and Colleen both directly attributed that to growing up with a sibling with a

disability. They were careful to avoid placing any blame on their families. Although they both described their maturity as “forced,” they seemed to understand that it was part of the reality of having a family member with a disability. Colleen explained the relationship between caretaking and early maturity:

So you know there’s that part of it, of maybe being forced to be a little more mature than you ordinarily would because the expectations in the home are— my parents didn’t really ever pressure me into taking care of him more than I would have to baby-sit for whoever, but it was, a big part of me growing up, was caring for him.

Jeff expressed a similar sentiment and also credited growing up faster than other families with instilling a sense of appreciation:

I guess kind of looking back I realize that I was forced to grow up a little bit quickly...compared to everyone else. But I think that’s made me appreciate time more now and to kind of, holding on to, you know, time now and youth and not wanting to grow up so quickly.

Caretaking was a substantial part of Jeff’s life growing up, and he viewed himself as “the little helper”:

That was like, huge when I was little because my dad, like I said, was working a lot, more so in the beginning as he was just getting the businesses started. Now he’s kind of home more and it was, I just remember hospitals, going to the hospitals, carrying the bags, pushing the, like the stroller and everything. Helping my mom, like, cooking, cleaning, everything, like, I’m really into cooking now from like everything that she taught me. So it was just, I was very much like, the little helper, of you know, throughout the very beginning up until like, I left for college.

Jeff continued to be a “helper” among his friends and this is discussed in a later section.

Being responsible, independent, and financially self-sufficient was extremely important to Deanna. She felt that this was influenced by the combination of a large family and a sibling with special needs:

I think the fact that coming from such a big family and you know, I didn’t get all the attention. You know, my mom had to divide her attention five ways and then

a little more on [name of brother w/disability] for obvious reasons. So I was always, you know, pretty independent as far as you know, I got a job and I would go to work and I you know, participated in my own activities like we all kind of did our own thing and it was very important for me to be financially independent, too.

Sarah and Jane also come from larger families, although from different perspectives. Like Deanna, Jane is the oldest and Sarah is the youngest. Despite these differences, Deanna, Sarah, and Jane all felt that, at times, they have taken on the role of “mom.” Deanna and Jane act as a “mom” to their younger siblings. Sarah stepped into this role with her friends, who call her “mom” and describe her as “the 40-year-old woman.” She also recalled an early sense of maturity while growing up:

Chronologically I’m the youngest, but maturity, I’m definitely, I was definitely the oldest, especially with my dad away and stuff. Like, my mom went back for her masters when my dad went away...so I did a lot of caretaking, and, I mean, my brothers just didn’t take it upon themselves, they could do it if they wanted to, but...they knew I would. So I had a lot of, it wasn’t even like it, it was pressure, but it was more like, I was more independent so I took a lot of it upon myself to, you know, I would help out with dinner, I would help out, you know, homework if it needed to be helped, you know, so, stuff like that, it was kind of like, I took a huge part in that.

Sarah was also a Resident Assistant (RA), a position that generally requires a level of maturity and responsibility. She was not the only participant to work as an RA during college; during the course of the interviews Jeff applied and was selected to be an RA for the following year. Neither he nor Sarah explicitly tied this position to being a sibling but Jeff’s inclination to take care of others is present in his discussion of why he wanted to be an RA:

My RA freshman year was kind of sucky, and he didn’t really do much...I really didn’t have too much of a problem because I was always one to keep my door open and try and like meet new people, but there were a lot of kids on my floor I didn’t even know existed until, you know, end of second semester. And I knew I wanted to be with freshmen, with people who didn’t know each other, to try and get people to, you know, make friends. That really appealed to me. And just the fact that I would be meeting a whole new group -- you know, group of guys,

people like on my floor, and staff members too. I just -- I really wanted to meet new people, and I thought it would be fun to kind of be the -- a programmer in terms of like doing activities and stuff, especially if you get to use school money to do things. That was a big perk, considering I like to go into the city a lot and plan events anyway, so might as well do it for a larger group of people. And people had told me all the time I was...that I would make like a good RA.

As seen in Figure 1, *Having a Sibling Shapes My Personal Traits* was connected by an arrow to both the three key categories that made up participants' College Experiences and the core category of *My College Experience is the Same and Different*. The influence of one of Jeff's personal traits, maturity, is connected to one of his college experiences, his friendships, and the role he plays in his friendships is described in more detail in the discussion of the key category *Being a Sibling in My Social Interactions*. The relationship between *Having a Sibling Shapes My Personal Traits* and *My College Experience is the Same and Different* can be seen in several of the participants' comments about being more mature or responsible than their classmates.

Having a Sibling Plays a Role in My College Choices

Having a Sibling Plays a Role in My College Choices was one of the key categories considered to be part of participants' College Experiences and is included in the set of three intersecting circles on the right side of Figure 1. For the participants in this study, having a sibling with a developmental disability influenced different choices they made regarding their time in college. These choices included the process of deciding where to go to school, what activities to participate in once they were on campus, what to major in, what career path to follow, and what they planned to do after graduation. This category developed out of questions about the major aspects of participants' time in college; an exploration of students' college experiences as a whole seemed to require that I investigate the major and minor touchstones that are common to college students. Many

of our discussions began when I asked about their college selection process and continued chronologically throughout their college experience. However, these discussions didn't always progress in a linear fashion. For example, Sarah brought up her thoughts about her future early in the interview process; as a senior, Sarah was clearly more focused on her future planning than how she selected a college. Others brought up different choices before I ever asked, such as Hannah, who brought up the connection between her major and growing up with a brother with a disability.

Throughout the interviews, participants' descriptions of their various college-related choices made it clear that having a sibling with a developmental disability shaped those decisions. There was a great deal of variation in this category; nobody felt their sibling shaped every aspect of their college experience and some parts of their time at college were not affected at all. The subcategories included in *Having a Sibling Plays a Role in My College Choices* were Choosing a College, Choosing a Major, Career Plans, Participation in Out-of-Class Activities, and Planning for the Future.

Choosing a College

For the students in this study, the decision to continue their education past high school was not influenced by having a sibling with a developmental disability; college was generally a foregone conclusion, particularly for those students who had expressed specific career interests while they were in high school. With the exception of one student, parents placed little pressure to stay close to home for college and seemed to understand their child's desire to go away for college. Participants felt that any pressure from their parents to choose certain schools or locations had nothing to do with their sibling with the disability. This was true even for those participants who had many

caretaking responsibilities at home. Many parents assumed that their child would be going away for school and expressed their desire for their child to have a “traditional” college experience. For example, Aurora said that “my parents wanted me to go away, they felt that was important.” Overall, the college selection process was not strongly affected by sibship but there were some distinct influences.

The cost of college and financial aid was a concern for many of the participants and their families and this played a part in the college selection process. However, there was no connection between college cost and siblings; no one talked about being restricted in their college search because of financial limitations related to their sibling’s disability.

The most common way that having a sibling with a disability affected how students chose a college related to distance. None of the participants lived at home while attending college and the majority chose schools that were a 2 - 4 hour drive from their families. The two exceptions were Hannah and Jane and their choices were polar opposites: Hannah attended a school far from her family and Jane chose a school that was less than 30 minutes from her family. Hannah was the only participant who placed no restrictions on distance from home during her college search: “I was just kind of going through whatever colleges I thought would fit me best and I didn’t pay that much attention to location.”

James stated that his siblings didn’t influence his choice of colleges although it did contribute to his desire to go to a school that wasn’t very close to home:

It wasn’t really that I wanted to live far from them so much as I wanted to live with not my family...And this is partly like my brother being difficult and me feeling a little bit constrained by that at home but much more like, usual family issues of, I want to live away from my parents so I can like go out at night and that sort of thing. And like, living at home requires like eating dinner when my family serves it and watching my siblings every day and usual family

responsibilities that are normal to expect of someone like me, you know, the oldest sibling that I could easily avoid by going off and living somewhere infinitely more desirable where there's lots of people my age and lots of fun things.

For Colleen, distance from home was the only aspect of her college selection process that was influenced by having a sibling with a disability. She specifically decided against one school because it was too far away from her family:

I didn't go to [name of school] because I wanted to stay close and I think that's really the only part of, that's really the thing that affected my college career the most. I really wanted to stay close by and other than that I you know, there wasn't really that many differences between having an autistic sibling but that was like, I wanted to be close.

Jeff's strong sense of family led him to choose a school that offered a sense of family and he felt that his brother's overall influence on his sense of self was a factor in his college selection process:

I don't think it's something that I was consciously making a decision about...it's become so much a part of me, and shaped who I am that, it's like, in the background and I guess made me choose like, where I wanted to go... 'cause I'm really close to my family. Family is everything. And one of the main reasons, like that is because my brother just binding us all together...and one of the main things when I was looking at colleges was, if I felt comfortable there and if I felt a family atmosphere...I didn't really have like a checklist, I just kind of walked on campus, got a feel for the people and, it was just a feeling.

For many participants, the decision to go away for school had little to do with their sibling but came from a desire to be independent, experience something different, or have the "typical" college experience. Phyllis felt that had she stayed at home for school, "it would have driven me crazy...not because of [name of brother], but in general. Like it would be the same thing." Deanna originally considered attending college in California in order to have some independence from her family but ultimately decided against it:

I think it was more, become independent and kind of, be on my own because I always felt like I was just kind of one of five. You know what I mean? Like, I

wasn't my own person, and I really...just wanted to completely separate myself and be independent, but at the same time, I, you know, knew I'd probably be homesick, and that's why I'm happy here. I think I've found a balance, where I'm far enough away where I am independent, but I can still drive two hours, if I really needed to, to go home, not that I would want to every weekend, and I don't.

Aurora was also looking to develop more independence and her post-college transition was another consideration:

I thought it would be better for me growing up, so that I have a sense of independence because, I guess I kind of do at home, more now that I'm in college but you know, like, there was still, had a leash on me at home, you know, and coming to school, it's like, I do have to fend for myself and do things for myself because my parents aren't at home and can come up and do something for me, you know, so, I thought I needed this transition so that, when I do leave home after college, it's not a big shock.

Despite some pressure from his mother to stay close to home, Jeff had several things motivating his desire to go away for college, including the appeal of being the first one in his family to go away:

I think I always felt like you had to go away for college. Like, and also in my family, no one else had gone away to college. Everyone had stayed local. And I was just tired of staying local...it was stepping out of my comfort zone, in a sense, and the fact that no one else in my family had ever done it made me want to do it more. And I just thought it would be kind of cool to live on my own for a little bit, to just see how it was...I always wanted the – not stereotypical college experience, but something close to it, so I wanted to live in the dorm and, you know, I wanted to go to a football game, and I wanted to go to a party, but I wanted to go to a good school, because I didn't have the stereotypical high school...I kind of wanted to try something different.

When talking about limiting their college search by distance, both Jeff and Aurora mentioned the importance of getting home easily if required, such as “if I had to come back home” or “I could get home in any situation.” Neither explicitly related that to their sibling, although Jeff said that “I guess he could have affected that.” Although Jeff was close to his entire family, it was possible that he was thinking about his brother's medical history when making sure he could get home quickly. Jeff described several serious

medical crises throughout his brother's life, including times when his family was told by doctors that his brother wouldn't survive. The most recent of these crises occurred the month before Jeff graduated high school and was in the midst of the final stages of his college selection process. This time period was challenging and it was difficult to take care of the administrative details related to the acceptance process but Jeff never got to the point of reconsidering his choice:

It was just like, in the beginning we didn't know what was going on, so it was just kind of like a blur, and really like, I was just going through the motions, send in your application, fill all this stuff, 'cause it needs to be -- get done, but there are like other things happening right here, so I really wasn't thinking about like college. And I think part of me was just expecting him to get better by the end of this, more towards the end, because in the beginning we thought he was -- wasn't going to get better. Our minds weren't anywhere else, but when there was a turn, kind of towards the middle, I just expected he would pull through it, so I really didn't -- maybe had it prolonged, or it lasted a little longer than it did, I would have started to rethink things.

For several participants, their college choice wasn't specifically influenced by their sibling, but more by their family as a whole. Sarah took her entire family into account when choosing a college and tried to find a balance regarding distance from home: "I wanted to be close enough but far enough away and...it was a good fit. I was going to go where I felt comfortable and that's what I decided to do." Phyllis described a similar influence from the entire family: "I think not just him in particular but my family, like as a whole. I didn't want to go too far away. It was a bit scary for me." Jane also felt that her choice was swayed by a combination of her sister and her entire family, including her family's heavy community involvement:

I mean, I couldn't imagine myself going far away and I definitely just had like a top three schools and they happen to be in [name of city near hometown], and that's, you know, it did make the most sense for me....I don't think it was like, well let's sit down and let's do pros and cons. Or oh well, I couldn't leave my sister. More so just that, as a result of my sister, and my parents, I mean, I think

that if we weren't volunteering for special needs, we would be volunteering for something else. That's just a part of who we are, so it got, you know, there were so many things....And my sister happens to play a huge role in all of them, as do the rest of my siblings because we're always there. We're always coaching and volunteering and doing things like that together.

Although her parents strongly felt that she should go away for college, Aurora still experienced some sibling-related frustration during her college selection process.

Aurora's sister became extremely agitated whenever she and her parents would discuss different options for college:

[It was] frustrating because, like, she would just get so upset, start crying, become very loud and angry and like, I didn't understand it, in a way. Like, she knew that it had to happen and it was just annoying that she couldn't get it into her head that it's gonna happen and even though it's in two years, a year, you know, you still have a lot of time, but it's, and then, it's like, you wanna, you want her to understand that I'm not gonna be living at home after college anyway...And that I'm going to have a separate life. But, I mean, we just took her out of the room, she went and calmed down, you know, and then I could talk to my parents about whatever I needed to. But, it was hard, because I wanted her to understand but she couldn't. And didn't want to.

Choosing a Major

For some participants, their sibling had an influence on the major they selected. For Sarah and Deanna, growing up with their siblings led them to major in special education and pursue careers in those areas. Sarah has found her sister's progress over the years inspiring and felt it led her to her major: "what she's done is amazing and, it's also geared me to like, my major and like, I'm able to apply so much more to what I do." As special education majors who planned on entering the field, Deanna and Sarah had a lot of overlap between their major and career plans. The influence of their siblings in these areas is discussed more fully in the Career section, which directly follows this one.

Phyllis saw a more indirect relationship between her sibling and her major/career choice. With a major in advertising communications and a minor in visual arts and

psychology she was interested in a career on the creative side of advertising. She felt that she and her brother, who liked to draw, had the arts in common and they often colored together and had “craft time.”

Hannah’s major was not traditionally associated with disabilities but she felt that her brother strongly influenced her decision to major in anthropology: “Just that chance to explore diversity and to look at other cultures and to understand other people...my brother has a lot to do with why I chose that.” Additionally, Hannah was able to focus on disability studies as part of her anthropology major.

Career Plans

Having a sibling with a disability was an influence on career choices for many students, whether their career plans related to disability issues or not. For most of those students it influenced them to choose a specific career or field, but for one student it steered him away from a particular career.

Three participants were pursuing careers directly related to disabilities. Colleen was already working as a research assistant and her focus was genetic research, primarily Tourettes syndrome, obsessive-compulsive syndrome, attention deficit hyperactivity disorder, and high functioning autism. She planned to earn a Ph.D. in clinical psychology and do both research and counseling focused on neuro-developmental disorders, particularly counseling children with Asperger’s syndrome. Colleen said that there was “definitely” a connection between her work and having a brother with Asperger’s. Sarah and Deanna were both special education majors and headed toward careers related to disability. Deanna planned to be a special education teacher. Sarah was considering that career path as well, along with the possibility of education/disability law and parent

advocacy. Both identified their siblings as influences on their career interests. Sarah saw a connection between her sister and her goal to help people with disabilities and their families:

And I really want to be, like, an advocate for people with disabilities. And I think that seeing, that having a sister with a disability really has impacted that. Without a doubt. I probably wouldn't be as interested in my field if it weren't for my sister...But, it impacts me and I feel like I can relate a little bit more to families and you know going through different schools. And I don't want to see that happen, you know, I want to make sure all the rights are served...But I am just so fascinated by the way things can work and how kids can be included in classrooms and all that other stuff. And I think a lot of it has to do with my sister, without a doubt.

Deanna's major and career goals were also strongly influenced by growing up with a sibling with a disability. Like Sarah, she felt her experiences with her sibling would be helpful in her career:

But I love like working with the kids, and I think what spurred me to want to be a teacher is because I think that I saw like all the difficulties that my parents had with school systems and stuff, and especially I'd say my brother is like the number one influence why I was interested in special education, that I wanted to be a special education teacher because I feel like having a sibling with that disability kind of has like -- gives you something extra, that's more personal. So that's why I wanted to pursue that.

Like Deanna, Sarah was also affected by watching her mother fight for her sister's educational needs, which shaped her views of the field of special education:

I don't want battles at IEP meetings because kids aren't getting services, like, that's kind of what I'd want to do and I've seen that with like my mom and my sister, as far as my mom going to all those meetings and like, just never getting what...my sister needed...out of it. I think that's been a huge part of my life.

Deanna also felt her commitment to her career in special education set her apart from other students:

I'd say like a lot of kids here aren't really sure what they want to do or where they're going, and I knew that I wanted to be a teacher and that my brother was a big influence in the special education decision...Because I feel like I have more

invested in these classes because, you know, it means more to me, where, you know, like 70% of the kids here just, you know, doing whatever....So I'd say it was easy for me to pick what I wanted to do in a career, and like...most kids don't really - not really sure or don't really have...anything like deciding factors for them.

The influence of a sibling on career plans was not limited to the participants who were pursuing careers directly related to disabilities. Hannah and Aurora both described their future careers as something that “helps” people and saw that as a possible connection to growing up with a sibling with a disability. Hannah hoped to earn a medical degree and become a doctor, and Aurora wanted to be a high school math teacher. Although neither career was connected directly to disabilities they both felt that having a sibling with a disability influenced their desire to be in helping careers. In her medical school admission essay Hannah identified strengths she developed because of her brother that she believed will help her be a better doctor. In addition to patience, she also cited her flexibility and familiarity with medical concerns as advantages.

Jane had already begun working on achieving her career goals, which involved becoming an entrepreneur, and had started businesses with both of her parents. She described two ways her sister has influenced her career interests. First, Jane had a strong commitment to incorporating volunteer/non-profit work for people with special needs into anything she does in the future:

And also too I think, everything that I do, I would like to have the backbone of it be some sort of non-profit or charitable work and I think that that's something that my mom has taught all of our siblings, that, you know, what are, who are you going to help?...First, we help ourselves and then who else are we going to help based on our efforts from what we're doing? So, that's something and we all can see that we can make such a big change individually.

Second, as noted in the excerpt above, community service work was a priority for Jane's entire family. Her early experiences with those projects stoked her desire to be in leadership positions in the future:

I think I do a lot more for children in my life and I do a lot more for special interest organizations and in particular, special needs and Special Olympics, and that's always something that I'll do...everything that we have done for my sister, I mean with Special Olympics and with her school and her education and it's been just such a family project that I was put in leadership positions at a young age, within volunteer organizations...I think based on that the leadership that I was put in, I now just strive for excellence and to be a leader in everything and I actually have decided to continue more of a path of being an entrepreneur than anything else and I think that's because, I wouldn't now want to graduate and then be put in a low level position because I'm so used to being a leader in my community and in, you know, really meaningful projects and I would love to just continue with that and to strive for the best.

For Jeff, having a sibling with a disability influenced his career goals in a way that was different from what was mentioned by other participants. Jeff didn't really choose his career because of his sibling, but he rejected a specific career because of his sibling. Despite his mother's strong urgings towards a medical career, Jeff specifically didn't choose to pursue a career as a doctor. He attributed this to spending so much time in hospitals with his brother:

Mom always told me to become a doctor so I could take care of my brother [laughs] and kids like him. And I kind of was like, I saw like too much of the hospital scene and, it's like, I respect everything that they do and all the work that they do, but it's not something, like, I want to do for myself. Like, I don't want to make my living off of that. I'd rather have it like, keep the family connection, or the personal bond to it than make it like, a career. And it's just something that never [pause]. I don't want to say like, I saw too much of it that I was just tired of it...It was just, something that I couldn't see myself doing. 'Cause, you see a lot of things in the hospital, especially when you're younger and like, it makes you a little bit sad, especially when you have to deal with like, so many kids that don't always make it. And it's just not something I wanted to be around, everyday.

A few of the participants considered the financial aspects associated with different careers in conjunction with their sibling and the future. Jeff wanted to have a career that

provided him with enough money to be able to spend enough time with his family. Based on comments he made about his post-graduation plans, it appeared that this goal applied to his immediate family as well as his future wife and family. James had also thought about his future financial situation and how it related to his family; he contrasted his own future career and financial planning to that of his sister, who was currently in high school:

And, [name of oldest sister] is very conscious of this, trying to plan for them and like, she'd make sure that she got a job where she'd be able to support herself and our family. Whereas, I feel like as long as I have a job where I support myself and don't need help from our family, then I'm doing at least what's needed of me. Though, more might be good later depending on how circumstances develop. I don't know exactly how my family's fixed financially...so it's more of a back of my mind, long term issue at this point.

Jane also had conversations with her mother about ensuring her sister's financial future and they were both trying to establish financial security for themselves and her sister:

We're really trying to create some sort of financial situation for my sister that she can support herself and she can have a role in it, and so through my mom's real estate endeavors, thus far, she's always been thinking of, how is this something that not only can my sister be involved with to financially support herself and make residual income and will never want someone to have to support her. She wants, you know, her finances to be all set when she's older and other kids with, you know, disabilities, this is a huge issue.

Participation in Out-of-Class Activities

Several participants felt that their sibling had affected their involvement in out-of-class activities in some way. When asked about influences of her sister on her life as a college student, Aurora spoke about her desire to be fully involved during college:

I'm just wanting to be involved in things, I mean I don't want to just be a bump on the log, you know, going through the motions, being a college student, going out and partying kind of thing, I want to actually do something, be involved, kind of.

Aurora, like many of the other participants in the study, was involved in out-of-class activities related to disabilities. Sarah, Deanna, and Jane all felt that their involvement with activities or organizations connected to disabilities was related to growing up with a sibling with a disability. Sarah was involved in several activities related to disabilities. In high school she volunteered in her sister's classroom and greatly enjoyed the experience; Sarah feels that her experience "carried over when I came over here." She described her participation in Special Olympics as "rewarding beyond belief" and found that, as a RA, disability issues sometimes served as a common bond with some of her residents.

Jane was also involved in several different activities and was very committed to them, despite the struggles to balance her schedule at school:

The children who are in the public school system often get ignored or are in situations such as my sister's classroom like in the basement off the cafeteria. It's just like, you just want to be their advocate. I mean you just want to help in any way possible. And I know that when I left for school and I had decided, okay well I'll try a year and see if I can still coach the swim team and be at school at the same time. And it was so challenging. And then the next year tried to find someone else to try and coach the swim team. And I can't find anyone and you know, it's so hard to find people who consistently will want to continue to help out. And that's just been a huge challenge and so I just feel like unless someone's going to fill that, you know, I guess I have the time, I have the capability.

Jane's volunteer activities were a major part of her life and a clear priority for her; she viewed this as one way that she differs from her friends and classmates:

I think I feel like I have a greater social responsibility than a lot of my classmates and I know we've touched a lot upon all the volunteerism I do...But I have seen that you can make a such a huge direct impact, which I don't think a lot of...my peers have experienced that. And it is really empowering and, and you do feel like all of a sudden, wow, if I can do it, I should be doing it.

These experiences had a profound influence on her, and she felt a lot of her volunteering and sense of social responsibility related to both her sister and her mother.

James was one of the few participants who had never participated in any disability related activities; while in college his main focus outside the classroom was his fraternity and a political action group. However, he did feel that his siblings and family had some effect on his on-campus political involvement:

[It was influenced] to some extent. I know that my mom was involved in some forms of political activism -- now, with disability awareness or way back, with population planning. And so, I was sort of mindful of the political groups on campus from the beginning...And having siblings with disabilities, like I said, made me, at least, think about the disability awareness groups on campus. Other than that, I don't think, really.

Planning for the Future

Having a sibling with a disability sometimes influenced participants' views of their futures and how they planned for the future. Some aspects of choices related to planning for the future are discussed in other sections, such as career choice and dating/relationships. Several participants talked about the idea of balancing their own needs with the needs of their sibling. As she got closer to graduation this was something that Sarah thought about more and more:

It's a challenge for me to decide, well, do I stay in New England, like, be where I am comfortable and where I really enjoy being, or like, and how do I keep that relationship with my sister, how do I make sure that she's okay, and that, you know, my parents are ok and stuff like that. So, that's kind of like something that I, in the next like, 15 years, I'll be thinking about a lot more, I think...my dad's getting older, my mom, I still consider her fairly young, but like, my dad, he's getting older and he's had some medical issues and stuff like that so, I mean, I just think about sometimes, like, oh jeez, what am I going to do? Like, what are they going to do? But, I don't know, it's one of those things, we'll cross that bridge when it comes kind of thing.

Within the context of career choices, Jane and her mother had thought about her sister's future. Although Jane hadn't considered issues such as guardianship for her future, she had thought about staying near her family: "I mean, I don't know if it was just

my sister that played a role in me staying so close to home, but I know that it does play a role in me staying close to home in the future.”

Colleen ultimately moved home after graduation. There were several reasons for that decision but one of them was to help out with her brother.

There was a range in the degree to which participants had thought about how their sibling could affect their future planning and the choices that they made. Some reported preliminary discussions with their parents and others hadn't talked about it. Like several other participants, Jeff felt that his parents were still too young for this to be a major concern. He had not discussed his brother's future care with his parents, although he had his own assumptions:

I just assume like he'll always like be with them. And if anything happened to them he would be with me or my sister...it's just never something that came up, and I don't like foresee it being an issue. Only 'cause God willing, my parents are like gonna be here for a while, and you know, so is he.

James also noted his parents' age in his thoughts about future care for his siblings. James felt his sister was more concerned about the future than he was. His concerns about the future were short-term:

I guess, since at this stage of my life I'm planning like, maybe zero to two years in advance...it's not something I'm too worried about yet. My parents are in their late 50s and certainly able to take care of themselves and my siblings...for quite some time yet.

Aurora's conversations with her parents about future care for her sister seemed somewhat contradictory and complex. During her first interview she mentioned her mother's desire to not burden Aurora with future care: “she talks about the future occasionally, you know, how she doesn't want to burden me with having to take care of

her [Aurora's sister]." During her second interview I asked Aurora how her sister influenced her thoughts about the future:

Occasionally my mom will say "you know, well, when the time comes you're going to have to take over"...So, I don't know how much she, she doesn't like to talk about it too much because she doesn't want to get me worried or get me thinking about it just yet. So, I mean I'll probably have to take over her financial issues and things of what she's actually going to be doing later on in life. I don't, I just think of, am I going to be living with her like I am now? Or am I going to put her somewhere? Have her buy her own house? Have this, that? You know, some, occasionally I think of that.

Later in the same interview Aurora described conversations with her parents that represented a variety of attitudes toward future planning. Aurora reported that there have been "a few times" when her mother said "that even though we don't like to say it, it would be better if my sister passed before my parents did, so that way, you know, we won't have to worry about what is going to happen." Aurora also recalled a recent conversation with her parents in which they told her that the house next door was up for sale and asked if they should purchase it for future use. This conversation left her confused:

So, they do talk about building a house for her, so, then they would have joked, like they were kind of joking that it would be them, my sister in the middle, and then me on the other side...So, but I do feel that, that they would want her to live in her own house with that live-in aide and not have me burdened with like living with her...I really thought it was a joke [laughs]. And then, when I came home it came up again and it, I think, they might have been slightly serious about it, but I don't know...I kind of said "are you kidding? I don't want to live in their house"...So, I just, like, that would be weird. And I don't know if I could, really want to live next door. [laughs] That would be like an Everybody Loves Raymond kind of situation.

Additionally, just as her sister became upset when Aurora's going to college was discussed, there was similar behavior around discussions of Aurora's future:

I know my family and I have talked about, like, kind of, kind of in a joking way but kind of serious, like, about whenever I do get married and have children and.

My sister doesn't like to talk about that too much, she gets upset. We're not exactly sure why.

Aurora was a sophomore and with two more years of college to complete, so she still had time to define specific post-graduation plans. She had some thoughts about her future and thought that her plans would probably be similar to those of her friends.

During college Hannah had discussions with her parents about being named as a back-up guardian for her brother. She was relatively involved with discussions about her brother's future. During the interview process he moved from her parents' house to a group home a few minutes away. Although her parents had never asked her to live close to home in order to be near her brother, Hannah has decided to be close to home for that reason: "I guess it's always knowing that I'll probably be the one taking care of him in the future."

Deanna's view of the future was somewhat similar to Hannah's. Although her parents have not asked her to take on future responsibility for her brother, she has thought about how that might fit in with her future. She felt that this responsibility sets her apart from her peers:

I do want to be closer to my family because of the responsibility, I know a lot of people who say, you know, they don't want to be with their, be near their family. They want to be completely independent, or they want to get as far away as possible, and all of them still receive money...from their parents every week, so I'm not really sure how that's going to work. But I'd say there's a stronger desire for me to stay close to my family, not just because I'm going to miss them, but also because I feel a responsibility for my brother, too, which I don't know if anybody else feels, you know, a responsibility to stay there and to take care of another sibling.

As indicated by the arrow leading from *Having a Sibling Plays a Role in My College Choices* to the core category *My Experience in College is the Same and Different*, there was a clear relationship between the two categories. Participants

described several college choices that led them to feel that their college experience was different, such as Sarah choosing a career related to disabilities and Deanna thinking about her brother and the rest of her family when she considers her post-college plans.

Having a Sibling Contributes to My Academic Experiences

Having a Sibling Contributes to My Academic Experiences was another key category considered to be part of participants' College Experiences and is included in the set of three intersecting circles on the right side of Figure 1. Because many participants had described connections between their sibling and their choice of major, it wasn't surprising that learning and academic experiences were also affected. However, the development of this category revealed additional aspects of learning and academic experiences. Initial discussions about this part of participants' college experiences focused mostly on academic work and participants talking about their sibling in the classroom. The early realization that most participants had written about their sibling in admissions essays or academic papers led to the decision to ask participants to share these written materials; these additional data contributed to the overall theory development. Further discussions revealed that through their academic experiences, some participants learned a great deal about themselves and gained an increased understanding of their family and sibling. It was not surprising that students pursuing degrees related to disability felt that growing up with a sibling with a disability gave them an advantage but this benefit was more unexpected and demonstrated the depth of siblings' learning and academic experiences.

Participants' learning and academic experiences were influenced by their siblings to varying degrees, which was consistent with the range of their academic interests. As

might be expected, Sarah and Deanna's focus on special education meant that they often had a strong connection between growing up with a sibling with a disability and their academics. Although Sarah and Deanna felt the influence of their siblings on their learning on a more regular basis, other participants were affected as well. The subcategories included in *Having a Sibling Contributes to My Academic Experiences* were: Papers and Projects, Personal and Academic Benefits, Classroom Discussions, and Hearing Inappropriate Language in Academic Settings.

Papers and Projects

One of the most common intersections between siblings and academic experiences was through papers and projects. Almost every participant in the study focused on their sibling and/or disability issues at least once as part of an academic assignment. Sarah and Deanna, the two participants majoring in special education, drew upon their experiences with their siblings frequently. Sarah described the intersection between her academic work and her sister:

Pretty much everything I write in special education classes, pretty much relates to my sister. Well, it's 'cause it's the only, it's the most familiar thing, it's the thing I can relate to the most...my letter to the [education department] admissions committee, has to do with how influential my sister has been in my decision to ...become a special education elementary major, to possibly teach or possibly work with people with disabilities, so that has a huge impact.

Writing about siblings wasn't exclusive to special education majors; Aurora, Jeff, and Phyllis all discussed papers or projects that included their siblings. Jane didn't write specifically about her sister with a disability but did focus on disability related issues by writing a speech about the special needs swim team she coached. Colleen focused heavily on autism through her coursework and also touched on her brother and her role as a personal care attendant for a young woman with disabilities:

I know everything about autism, I've read all the books of, all my papers at [name of school] were about autism so it's a real interest of mine because of him....[I didn't write about] my brother but every paper that I could make about Autism at [name of school], I made it about autism because it's what I knew.

Hannah began focusing on disability and sibling issues in 8th grade and continued this focus during college. One major project was for a research methods course in which she interviewed other siblings.

Although James mentioned his siblings in a merit essay he couldn't recall any academic work related to them; he felt there wasn't much connection between his family and his coursework or major. Of all the participants in the study, James' major (English) seemed to be one of the least related to disabilities. He mentioned some interest in taking disability-related courses during his time in school but scheduling issues led to his not being able to take such courses.

Personal and Academic Benefits

Many participants mentioned ways in which growing up with a sibling with a disability enhanced their learning and academic experiences. They discovered both personal and academic benefits. For some, their experiences in the classroom gave them a better understanding of their self and their family, which sometimes helped their sibling relationship. Sometimes being a sibling provided an academic "edge" or allowed other students to learn from their personal history. Aurora had a different view of how her sister had influenced her academic life. When I asked her if her college experience would have been different if she didn't have a sibling with a disability, Aurora addressed her level of academic achievement:

Probably, because I don't know if I would have been as much of an achiever as I have been and am because of her. You know, so therefore I may not be at [name of school]. I may not have strived for as much in my life, so, I've always thought

what would my life be like if she didn't have a disability and that's hard to think about because also she is the product of my mother's first marriage. So, then again, you also think would my mom have gotten a divorce if she didn't have a disability? That's another issue so I may not actually be here. I guess it's just, I probably wouldn't have been an achiever....it's like, you want to be a success for your parents, 'cause, it's like, you know, not that my sister's a failure or anything, but she can't do much to make my parents proud, you know, or, that's hard to say, but....So I guess it's just like let me do this for them to show them that they have a great daughter or something, I don't know.

Several participants found that their learning and academic experiences provided them with an increased understanding of themselves and their family. For Hannah, being away at college provided her with the opportunity to look objectively at her family, her role as a sibling, and a broader notion of sibship:

I think it gave me more of a chance to be [pause] to reflect on the situation. I know, I mean, 'cause I signed up for SibNet when I came here, and a lot more of my interest in sibling issues started when I came here. So, I think it just allowed me to look at the situation from a more objective view and to look more at my role in my family, where things fit, what I thought about disability and society, just stuff like that.

Hannah also described being more aware of the dynamics within her family and how her brother's disability has influenced those dynamics. More so than other participants, Hannah had previously thought about herself as a sibling yet she felt she gained additional perspective during college:

When I came here I know I broadened it out and was looking a lot more at, from just, I mean with SibNet, see other people's views and stuff, I think I opened it out more, not just looking at my situation but looking at a variety of situations.

Along with her involvement on SibNet, Hannah's research project on siblings exposed her to other siblings and gave her a holistic view of sibship.

Reflections from classes and papers helped Aurora recognize the influence her family has had on her:

Probably just actually realizing that, you know, as I've reflected myself and why I am the way I am, you know whatever classes or papers I had to do, you know, I've actually come to realize that they have had such an influence on me. So, I probably didn't realize that too much in high school.

For the students who were pursuing careers in special education there was often another element to this increased self-knowledge because they could learn specific things about disabilities that helped them understand their sibling better and perhaps improve their sibling relationship. There were often additional personal benefits from their classes and assignments. As part of a class assignment Deanna interviewed her mother about her brother and the resulting paper gave her a new understanding of her family and her brother's specific challenges. Like Hannah, Deanna found that she was able to take a different view of her family and was able to use her newfound knowledge to try to improve her relationship with her brother:

But as far as my brother [name] is, before, we'd argue with him just the same and I think now like that I'm getting into more stuff at school with my major in like special education I can kind of take a step back and look at his problems from like an outsider's point of view. So I'm much more understanding than I was before because before I just didn't really notice, you know, his disability but now I'm a little more sensitive to like what pushes his buttons and stuff like that.

Deanna also found that the interview with her mother, in which they communicated in a more professional way, helped her see "the big picture" and realize how different her family was as a result of their struggles to help her brother: "And so that's when I kind of realized that how difficult it was for my parents although they did a pretty good job of hiding how much stress it was."

Sarah also benefited personally from her special education classes and was often able to make connections between her sister and what she was learning about disabilities.

These connections made her understand her sister better, sometimes providing her with explanations for previously puzzling behavior:

I definitely have an advantage because when people say, when the teachers explain things I'm like "I understand that." My sister, because we were talking about how people with mental retardation have heavy feet. They'll walk really, really heavy. And I never put that together and I'm like "no wonder my sister walks through the house like an elephant." And I was like "it makes so much sense now." It sounds like a herd of elephants every time she walks through the house. And I never realized that and so I like could relate to that. And I just think it's helped me understand disabilities, understand differences and stuff like that a lot more.

The previous excerpt from Sarah also illustrates another benefit, the idea that she has an edge in her classes because she can personally relate to the material being taught. Deanna shared a similar view and felt she had an "advantage" in her classes because of her personal connection to disabilities:

I feel like I have an advantage over my peers who haven't had any you know, situations or influences by anybody with a disability because I've grown up with it and so I'm kind of seeing it from both sides, you know, on a personal level but then I have something to directly look at, at the professional level. Because a lot of my peers haven't spent any time working with special ed students yet.

Deanna felt that if she hadn't grown up with a sibling with a disability she would not have taken as much away from her classes and wouldn't be as invested in them. She believed that this will also enhance her teaching career later but noted that the complexity of her brother's disabilities required her to go the extra mile in her schoolwork:

[Without my brother] I don't feel like I'd be able to get as much out of my education classes...just plain and simple, like it means a lot more, and it's a lot, it's easier for me, I guess, to be able to go home and have my brother as a resource, but it's also, it's harder because he's such like a puzzle, so I have to do a lot more, and I have to, you know, work harder to get, you know, the answers, like when we did the interviews.

Participants also felt that their background as a sibling helped to contribute to the learning of everyone in the classroom, not just enhancing their own learning. Despite the

advantages that they may have had in understanding the material presented in their classes, Sarah and Deanna didn't view it as a one-way street. They felt that they had a lot to contribute to the learning environment and often saw their experiences as beneficial to their classmates and professors. Their professors often seemed to appreciate their contributions and occasionally solicited their comments in relevant discussions. Deanna enjoyed the opportunity to share with everyone in the class:

I do like share with my teachers, especially my special ed teachers, you know, my experience and stuff like that, because a lot of times, they'll ask me if I want to contribute or add something, and for the benefit of my peers, I think it would be like a good thing. And since my brother is such a unique case, like doing an interview for my special ed teacher, she found it really interesting, and you know, some stuff that she had never heard of and like, you know, the case and stuff like that.

Sarah felt comfortable talking about her sister's disabilities in the classroom and sometimes thought of them as "instructional tools" for both herself and the entire class:

A lot of it makes so much more sense now...that I've studied a lot of education. A lot of the disability, like, the characteristics that I wasn't, like that I...pick up on so much more now that I've studied it and I understand it so much more.

Colleen felt she had a great deal to offer her classmates and was not afraid to be outspoken about her interest in autism:

I definitely developed the reputation as like the autism girl because in class, I have this wealth of knowledge that I could draw on much more than anything that would be covered in text books or something. I always had an opinion like whenever we talked about vaccines, you know, I would talk about- - I would get all uppity...people recognized that I had a wealth of knowledge about autism and that I was interested in it.

Classroom Discussions

There were two main ways that having a sibling with a disability influenced participants' roles in classroom discussions. The first was an overall influence on their response to class discussions. The second, and often more common influence, was the

decision to disclose the fact that they had a sibling with a disability. Lack of participation in discussions related in some way to disabilities or their siblings didn't necessarily reflect a discomfort about sharing personal experiences or concerns about others' reactions. Aurora reported being "struck" by comments about mental retardation in a psychology class but not speaking up. She attributed her silence to the fact that she generally doesn't participate in class discussions: "I probably didn't because, just 'cause I don't participate."

Several participants also noted an influence of their sibling on participation in discussions in classes overall. Deanna and Sarah both felt that their participation in class discussions in special education classes was enhanced by their experience of growing up with a sibling with a disability. Hannah's and James's experience demonstrated that this influence was not limited only to education classes. Hannah mentioned an overall influence: "I think it changes how I look at things sort of and my background's obviously different from other people's, and I think you always bring that to class in discussions and such." James noted that while he may not actively have been participating in a class discussion, "my intellectual responses would have been different" from others in the classroom. When asked to elaborate on the specifics of those responses, James explained that he tried to be sensitive about any invisible differences:

I hate to fall on cliché but I feel like it makes me more politically correct than other people...That in a classroom discussion, even if I'd already met everyone in my class and felt comfortable with them and whoever's leading the discussions, that I would avoid saying things that could possibly offend part of someone else's history...even though they haven't mentioned it and there's no expectation for me to realize that it's there...Whereas I feel like other people will take liberties in an intellectual discussion where you're supposed to be comfortable anyway, of saying things that might be considered appropriate until someone objects.

During classroom discussions participants sometimes had to make a decision about whether or not to disclose that they had a sibling with a disability. None of the participants reported any negative reactions to talking about their sibling in an academic setting. Although no one reported negative responses to talking about their sibling in class, the decision to disclose was usually something participants carefully considered. In academic settings, as well as the social settings discussed later, participants often exercised a certain amount of discretion in the disclosure process. One major criterion for participants' sharing in academic and social settings was relevance, but participants identified other factors that could come into consideration. In James' case, he never spoke about his siblings in an academic environment because he never found it to be relevant. Hannah considered how people would react and sometimes relied on a "gut feeling" when deciding whether or not to talk about her brother. Concerns about reactions often influenced her decision: "I guess that's one of the reasons why I don't like telling classes as a whole, 'cause it's hard to judge individuals within the class."

Several participants described the context of bringing their sibling into a class discussion. Aurora spoke up in a course about students with special needs: "so that's like a perfect class, like talking with IEPs and if I have a question I'll just be like, 'oh, well in my experience, I was just wondering, you know, this and that.' I'll talk about it there." Colleen felt that she often had the reputation as "autism girl" and had no qualms about discussing autism or her brother in the classroom:

It's never something that I would ever choose to hide. And I don't feel uncomfortable bringing it up. Autism is really not, something that's emotionally charged right now....I never really held back or thought maybe this isn't the appropriate time and I'll say well I have an autistic brother and blah, blah, blah.

Earlier excerpts from Deanna's interviews demonstrated that she also felt very open about discussing her brother's disability in the classroom and with professors.

Sarah described the process she goes through when deciding when to talk about her sister in classes:

I think there's factors that influence when I do and I don't...like, when I don't know what I'm talking about I don't go talk about it...I readily talk about it, just as, because a lot of people haven't been around other people with disabilities and I think, I think it gives a good opportunity, it's a good opportunity to explain, like, first-hand, but it's also interesting because I get to hear other people's, like, when talking about their experience with people with disabilities, I really enjoy listening to that, and I'm like "Ok, well, I don't need to say anything now." You know, like, let them talk let, like, I'll learn from that because I don't know anything about that or, that, wow, that makes sense, that's why [my sister] used to scream "Jessica, Jessica, Jessica" [a random name Sarah's sister used to yell out] when she was eight, you know, like that makes sense to me know. So, yeah, I mean, that had some kind of effect.

While taking a biomedical ethics course, Hannah heard several class discussions that related to her experiences as a sibling. She felt it would "have been hard to bring up in class" but did speak privately with the professor about it:

There were several times in the biomedical ethics I took, when we had a guest speaker, I don't remember about what but someone, when we were doing the question and answer bit was, we were talking about, you know, getting rid of disabilities, you know, prenatal testing, that sort of thing. And, someone was like "Well, I would imagine most people who are related to someone with a disability wouldn't want, you know, would want prenatal testing and stuff so that they wouldn't have to go," you know, I was thinking that, well, actually, I wouldn't necessarily think that most people with siblings with disabilities might and I didn't say anything, it was like, I was trying to decide and class was almost over though...I didn't say anything, though I mentioned it to the teacher later.

Hearing Inappropriate Language in Academic Settings

The topic of language, such as people using the word "retarded" as an insult, came up numerous times in interviews. Most of the discussion centered around peers or social situations, which is covered in the next category, but there were some instances of

inappropriate language in an academic environment. Sarah noted that while she has heard people use words like “retard” in classes, it doesn’t really affect her learning in any way: “I mean if it’s in context and it’s correct to use, it’s a different thing....it’s an irritant but it doesn’t like drive me away from my work or anything or anything like that.”

Several participants wished that faculty members would be more thoughtful with the language they used. Although reports of faculty members using inappropriate language were rare, it was a concern. When asked what faculty/staff/administrative members should know about siblings on campus or what siblings might need from them, many of the suggestions for faculty related to language. Hannah mentioned the importance of keeping up-to-date with terminology:

I guess just perhaps to be aware of current terminology, especially if you’re teaching something like a biomedical ethics class, to be aware that, you know, these are issues that are probably going to be harder for people with sibs and to maybe, at least be more open to talking with people, be aware that people may be having more issues and in science classes too perhaps, you know, terminology....just to be aware of, you know, how you say things and what you say.

Sarah commented that faculty should be conscious of the language they use, not just about disabilities, but about sexuality, religion, and so forth, because there are invisible aspects of students that they could be commenting negatively on. She had heard faculty (although not education faculty members) use the word retarded inappropriately but feels that sometimes even the professors in the education department “don’t touch it sensitively enough.” Hannah and Deanna had the same advice for faculty members, and Deanna echoed Sarah’s comments on the idea that because sibship isn’t a visible identity people wouldn’t be aware that they are speaking to someone with a sibling with a disability.

As the arrow going from *Having a Sibling Contributes to My Academic Experiences* to the core category of *My Experience in College is the Same and Different* indicates, there is a connection between these two categories. One example of the relationship between the two categories is the personal connection many students described between their experiences as a sibling and their classroom experiences, such as the ability to relate better to material being taught.

Being a Sibling in My Social Interactions

The third key category related to students' College Experiences was *Being a Sibling in My Social Interactions*. There were some similarities between this category and the prior category, *Having a Sibling Contributes to My Academic Experiences*; issues relating to language and participants disclosing that they had a sibling with a disability were common in both academic and social settings. In both settings participants heard negative language and often used "relevance" as a factor when deciding whether or not to talk about their sibling. Despite these similarities the differences between these two settings emerged and developed into separate categories. For example, participants' discussions of hearing inappropriate or derogatory language in a social setting had a different tone than similar incidents in the classroom. When they heard peers or friends use terms like "retard" outside the classroom, participants seemed to react more strongly and were more likely to confront the language use. Additionally, participants reported more incidents of derogatory language as part of their social life than in academic environments.

Interpersonal relationships were another key part of this category and participants' experiences growing up with their sibling often shaped their friendships and romantic

relationships. Participants reported several ways in which having a sibling with a disability influenced social aspects of their college experience. As with previous categories, the degree of influence varied among participants. Some aspects of participants' social experiences, such as socializing, were minimally affected and other parts, such as deciding when to talk about their sibling, were more common. The subcategories included in *Being a Sibling in My Social Interactions* are Transitioning to College, Friendships, Dating and Relationships, Talking about Siblings, and Hearing Derogatory Language in Social Settings.

Transitioning to College

Most students reported a relatively smooth transition to college and seemed to have the same adjustment issues as their peers. Aurora did feel that her experience was different because of her family:

It is slightly different just because it was harder for me to get here than others, because it, the transition from home was different. You know, 'cause other, my other, you know like friends and classmates and that, they, their siblings are like "oh, goodbye, have fun!" you know, "see you whenever," and their relationships with their families are different than mine. I feel like mine may be a little bit closer because of her, so, you know, just that break from them was harder.

There were some disability-specific issues related to transition, that connected with how well the participants' sibling was able to understand that they were leaving home to go to college. Aurora's sister became very upset whenever Aurora and her parents spoke about her going away to college. Aurora reported that this improved once she and her family visited the campus of the school she ultimately chose "So, as soon she came here, she loved it, she loved the campus. So once she actually saw it, then we could start talking about going to college 'cause she realized how cool it is and how nice."

Aurora also felt that while her sister experienced some sadness after she left for college,

Aurora had taken some steps during high school to help make the transition a little easier for her sister.

Aurora was not the only participant who had difficulties with a sibling understanding the idea of college or who needed to prepare a sibling for her/his departure for college. Jeff took similar steps to try and make his brother's transition easier:

You could tell like, when he goes somewhere new, he's constantly paying attention to all the new sounds. So, it was fun to, kind of like tell him what was going on and like, where I was and my mom said he was really sad, like, when, when we said goodbye and he was in the car, he was like, kind of somber the whole ride home, like he knew something was different and I wasn't like coming, I wasn't going, he wasn't going to hear my voice every day. And it was just a great thing to have him on campus, 'cause I felt like, I explained to him why I was here. Like, I remember, before coming to college I would talk to him at night, you know, tell him what was going on, tell him that I was leaving but I was coming back. And I think when he came here at, just, for him to hear everything, for him to know, for being a part of it, I think, made a difference for him.

Phyllis was also unsure how well her brother understood what it meant for her to go to college:

He had trouble grasping the whole situation, what was happening....I did talk to him about going to college and it's hard for me to understand if he really, fully comprehends the situation. But I would talk - I would keep the line of communication open. If he had any questions I'd let him know. But at that point like he didn't really understand it. It wasn't until I was gone for a few months that he got it. He'd say "when are you coming home?"

Phyllis's brother continued to ask her about coming home throughout her time at college but she did find that her brother's visits to campus helped him understand things better: "He had a better sense when he first visited me and it just kept getting progressively like a better sense of what's going on."

Not every participant found that their sibling had trouble with their transition. However, it is important to note that their siblings' levels of cognitive functioning varied greatly. For example, Jeff, Aurora, and Phyllis all had siblings with more cognitive

deficits while James, Colleen, and Deanna had siblings with developmental disabilities but fewer or no cognitive delays. James did describe his brother's extreme reaction to an earlier transition away from home, when he went abroad for two months during high school:

All through when I was [abroad]...he would refuse to speak with me on the phone. I think he had like abandonment issues, like how dare I leave him at home to deal with life when I ought to be there taking his shit and like accepting him. And then the day before I flew home he took a lot of sleeping pills out of the medicine cabinet and he ended up having his stomach pumped or whatever and I don't think he like thought about it very hard or realized he would have had to take way more sleeping pills than he did to actually kill himself but it was still like the thing that we're always like mentally referring back to whenever he makes these threats that we can't just completely tell him he's being ridiculous.

However, James said that his brother's response to that absence wasn't troubling to his brother when James left for college. James felt that going away to college was somewhat different because he was not as far as when he studied abroad:

If he were to get himself together, he could hypothetically have visited...So, I don't think he could have made the same complaint that I had placed myself off the map and there was no way for him to get to me...He could have complained that I was gone, but I could have easily come back with, "I'm not that -- really that far."...And also, [me being abroad] may have prepared him [James' brother] for college to some degree.

Friendships

Participants identified a few intersections between having a sibling with a disability and friendships during college. Most participants felt comfortable talking about their sibling with their friends and some enjoyed the opportunity to have their friends meet their sibling. Participants sometimes grappled with when it was appropriate to disclose their sibling status or experienced friends using offensive language; these issues are explored later in a subcategory. The most common ways that friendships were affected by having a sibling seemed to be an influence on the type of people participants

chose to be friends with and disability serving as a bond between friends. However, there were other ways that friendships were affected. Jeff's role in his friendships is an example of the influence of Pre-College Experiences on College Experiences. His sense of responsibility, developed through helping his mother and brother, shaped his behavior with his friends:

I think I've kind of assumed the caretaking and household responsibilities at school....With a lot of my friends, so it, I guess it's kind of something I just took with me and when I get back home it'll start up again there. Like, I clean the dorm constantly because I live with a bunch of slob. I cook whenever I can, if I can borrow someone's kitchen. I'm like the advice giver, kind of deal. So it's something I didn't really drop when I got to college, changed, I just kind of took it with me.

Jeff also credited the influence of his brother on his "being a hard worker" in his friendships: "making friends, making sure you keep friendships close and working, and figuring out problems you have with other people."

Some participants felt limited by their college friendships because many of their college friends didn't really know their families. Both Deanna and Sarah expressed this view, described here by Deanna:

Friends that I've just met here, and only here, haven't met my family; they've never seen my house. They don't really know too much about me before college. I mean, I've told them stuff and we all share stories but there's a difference when you actually go through with somebody actually there for all that and you know the friends that I'm talking about and stuff like that. It's different.

Several participants felt that whom they chose to be friends with was affected by their sibling. Both Deanna and Hannah were careful to choose friends who were accepting, as Hannah explained here:

At the moment, well, I'm more picky about friends I think than a lot of people are and I think that comes from having a brother with a disability and being aware of who's going to be accepting the people just in general too, you know, not necessarily about disability but accepting of anybody.

Siblings and disability issues sometimes served as a foundation for friendships.

Aurora and Jeff attended the same school and were friends. They both enjoyed the opportunity to talk to someone else who can relate to their experiences, as Jeff described here:

We'll talk about our siblings all the time and like, if someone made a stupid comment to her and she needs to vent about it, she'll mention it to me 'cause she knows like, I'll know what she's talking about it. It's just something that we kind of know is part of someone else. Like I know it's a big part of her and it's just kind of in the background and we just kind of have this understanding that like, we've both in similar situations and we both know the feelings and stuff...It's [pause] it's really cool because I always saw myself as like being so different when I was younger. Like, I had like, my brother, who was you know sick and everything. And, to know that like, someone else went through similar experiences, had like, same reactions to things about. It's just, [pause] I don't want to say it made me feel better, because that would imply that I wasn't feeling good about it. But, it was just endearing or I guess, comforting to know that like, I could have that bond.

Aurora also acknowledged that talking to other siblings can reveal differences based on family circumstances:

It's interesting 'cause you can, like, relate to them. They also happen to have, a few more, like, at least one other sibling who does not have a disability, so they do have a different lifestyle, so it's interesting to find out how, you know, how maybe if they are held back or not held back or you know, how they do have another sibling to talk to, meanwhile, I don't, so, you know, then it, that also reminds me that in a way, I'm, kind of feel like I am an only child, sometimes.

Participants found that their experiences as a sibling could enrich their relationships even when the other person didn't have a sibling with a disability. Although disability wasn't a bond in any of his friendships, James felt his relationship with a fraternity brother was deepened because they both had lost family members:

So, this was something worth talking about for me because I felt like I would be able to offer him sympathy based on being able to relate and then we talked about that after he realized this connection and it doesn't really come up frequently now but it's still something that I guess we have for each other. And now that we live

together with one other person, three of us total, instead of with 40 other people it's more of a useful bond I think.

For Sarah, people with disabilities served as a gateway to friendship with one of her residents, who had previously worked with a person with autism. They met when Sarah was her orientation leader and the other student's enthusiasm about her experience working with a person with autism prior to college was a commonality. Sarah suggested a disability related organization that she might enjoy participating in on campus:

It really sparked, like, a good relationship between us...she said "Well, I remember you telling me at orientation, you talked to me for so long about [name of program] and then," and she's like "and that's why, you know" and that's how, it really sparked her conversation, I don't know how it did...she feels very comfortable coming to talk to me...now she's doing [name of program] and she talks to me about it. And she's like "Tonight *this* happened" and she comes and tells me all about it and so it, it's really developed a good relationship between the two of us. It's just one example of it.

Dating and Relationships

There were some similarities between participants' experiences with friendships and dating and relationships. Just as they wanted their friends to be accepting and understanding, participants had similar expectations for potential romantic partners. There were additional expectations as well; participants wanted partners who would understand the importance of their family life and appreciated it when boyfriends and girlfriends had a positive relationship with their siblings. Aurora described the positive relationship her boyfriend had with her sister:

I think with my boyfriend now, he gives her a lot of attention, like when he sees her, she loves him. We always joke how she's gonna steal him away from me and stuff. So, I feel like having someone who relates that well to her is very positive and you know, I think I need people who appreciate her, you know and will give attention to her and stuff. Just makes it easier.

Deanna said, “I need to be with somebody who’s patient and very understanding and very accepting and open to meeting all different kinds of people.” She also added that she wouldn’t want to be with someone who had “bias towards” her brother. James was pleasantly surprised by how well his girlfriend was able to understand and get along with his brother, who often behaved in difficult ways. Hannah had decided to postpone dating until she was established in her career but acknowledged that “anybody who I’d dated just would have to consider, be willing to accept my brother and he’s always going to be a part of my life.” Although Sarah was dating someone during the interview process she didn’t consider dating to be a priority. She appreciated it when her boyfriend in high school made an effort to include her sister in activities and says that while her sister didn’t have a major influence on her dating life, she did pay close attention to the language used by potential dates:

I mean actually I won't lie. If someone says “that’s retarded,” it immediately changes my opinion of that person. It's an awful thing I think, because people are just so, sometimes they are just ignorant and they don't realize it, just immediately says, ugh, why did you say that? You were great until that moment. Like you really were, now I have to think that you said “that's retarded” and I hate that. I hate that because you don't even know what you're saying right now. You know? So, I think that that kind of impacts it but not tremendously because I think that people just need to know that there, sometimes that hurts people's feelings.

Deanna and Jane both planned to live close to home after graduation and wanted to be with partners who understand their close relationship with their families. Jane talked about the challenge of having someone who could truly understand that relationship:

I couldn’t imagine for a very long period of time, living away and you know, you have conversations with your boyfriend, “oh, what are we going to do? What do you think like, where could you live? And let’s dream of the dream house and where would it be?” And for me it never is very far away. And it’s hard, especially with him, for him to understand how my sister impacts those decisions. And he’s an only child and I’m the oldest of six. And like my brother, I just saw him finish what, kindergarten and where would be those milestones? I don’t

want to be across the country for all those big events and all those baseball games that are yet to come and we're always at each other's events.

Another aspect of dating was how and when to talk about their sibling with a disability. The decision to share information about their sibling(s) will be discussed in more detail below but this excerpt illustrates James' evolution in his thinking about talking about his siblings with potential girlfriends:

There was one point in my life when it seemed like a good sob story...Meet someone, "I have these siblings -- some of them are messed up. Some of them are dead. Like me." But that was mostly, like, closer after -- after [name of sister] died, after [name of youngest sister] was adopted and had Down syndrome. I got over that pretty quickly. But, it's also, like, if I'm getting to know someone or when I got to know my first college girlfriend and the second college girlfriend, who I'm still with now -- when do I share this information? If she's talking about her sister, does that mean I should mention my siblings? And then, separately, does that mean I should mention my siblings' disabilities? And, in a romantic relationship it means, it usually is, "yes," and it's worth it to me to explain so that someone can understand me better because I feel like it's something that's part of me now.

Talking about Siblings

Just as participants reported no negative reactions to talking about their sibling in the classroom, this was also the case in social settings. Generally, the closest thing to a negative reaction was some form of awkwardness. The only questionable responses James could recall were comments assuming that his deceased sister with Down syndrome had mental retardation: "to my knowledge, my sister [name] was not retarded. So, sometimes if someone assumes that Down syndrome is, you know, 100% correlated with retardation, then I'll object." Jane described one type of awkward response:

I think, me talking about it sometimes will make other people uncomfortable. As I said, they won't answer and you know, they won't say anything else 'cause they just don't know what to say. Like, what, what do you then say. Like do you say "oh, I'm so sorry"...no one died, like it's not a "I'm so sorry" thing. And they just don't know what kind of follow-up questions to ask.

Disclosing information about their sibling with a disability often resulted in fielding more specific questions, such as the nature of their sibling's disability. Aurora said that "a lot of people are, will just ask like, 'how is that?' A lot of them say 'why is she like that?' I think that's the most common question, is why." Aurora also enjoyed the reactions to the uniqueness of her sibling relationship: "they're like, 'oh wow! That's kind of you know, interesting' or, so it's kind of nice to talk about and like to have some different experience that people don't know about, it's interesting." Several people enjoyed answering questions, were proud of the knowledge they had about disabilities, or welcomed the opportunity to educate others about disabilities. Although some students found that talking about their sibling could highlight ways in which they were different from their peers, they often viewed those differences as positive. Jane valued those opportunities, although she acknowledged their limitations in some of these interactions:

I always appreciate when people ask more questions and it's not just, kind of a dead end, "oh, ok." You know, and they ask something that, that is a little bit more meaningful, you know "what does she enjoy" or you know, what, "where does she go to school?" and "tell me a little bit about that." And I think that education is great and I love to tell people about it but, most people aren't, they don't even listen I don't think, half the time when you talk about anything.

Another aspect of talking about their sibling was making the decision to share information about their sibling. Participants didn't necessarily have a specific set of guidelines that they used to decide when to talk about their sibling but there were some common threads. One major factor was relevance and social norms for conversations. Participants revealed that they had a sibling with a disability or talked about their sibling at appropriate points in conversation. Jane explained that she talks about her sister "just when it's appropriate and it adds meaning to the conversation...I don't usually just bring it up...just to talk about it." Aurora had a similar view:

I guess most of the time, you know, my family situation wouldn't really affect the relationship so I wouldn't bring it up. Not unless like, our family situation comes up in conversation, you know, I guess that would be the only time that I would tell them. So, otherwise, they don't really need to know, not a big deal.

Sometimes participants relied on what Hannah called a "gut feeling" when deciding whether to mention their sibling in a social situation. Sarah seemed able to tell who would be most receptive:

I know I'm not ashamed by any means. I'll say my sister has disabilities, but, you know, I know who to tell and who not to tell or who to talk about it with, or who's going to care and who's not going to care...it's people I feel comfortable with...I'm not afraid to say it to somebody I'm not comfortable with, but like, if somebody want, somebody who's interested in it, I'll know just by... their reactions and the way I communicate with them is a huge part.

The idea of being "comfortable" was also important to Hannah. Within her small circle of friends, everyone knew that she had a brother with Down syndrome but her comfort level in talking about her brother could vary greatly and she usually preferred to talk to her friend who also had a family member with a disability. Her willingness to share was strongly related to how much understanding she felt she would receive:

I'm a lot more comfortable talking about it with my friend that has a cousin with a disability than I am with my other friends, so I guess it's somewhat, I guess, whether, how I think the person will understand, or you know, what, if they'll understand what I'm talking about...I think they all understand to some degree, it's just what degree of understanding they have of it I guess. I mean friends that I don't talk to quite as often I probably am less likely to bring it up with.

Additionally, Hannah, who described herself as a fairly private person in general, found that she was often more comfortable talking about her family with her one friend who also had a family member with a disability.

James was often selective when discussing his siblings and noted that answering questions or telling people about his siblings often became "complicated":

There are [factors I consider before talking about siblings], and I'm not really to the point where I've developed a certain regimen for what gets mentioned when. It first became apparent to me in high school -- the very end of high school -- probably, like, four years after [name of sister] had died -- that I didn't want to put in every conversation, "I have two siblings who died already."...first of all, no one knows what to say back and second of all, after I had shared that with a couple of people, it became more private information that I didn't want to dilute by spreading to everyone I met and I didn't want to have to explain or make people feel comfortable again with me again after saying it to them. And for a while I just didn't know what to say about it and then, in college I would tell only people who were really close to me or only people I had known a long time or only when it came up specifically -- often with some other link like the ones I just mentioned. If one of my brothers or sisters was brought into a conversation, then someone will say, "Oh, how many siblings do you have?" And then, it's a conscious choice of either, "Well, I have one brother and two sisters," or "I am one of four living out of six siblings." And then it's complicated.

James' dilemma when asked questions about his family was not uncommon, and many participants mentioned that routine, introductory questions required a choice about disclosing their sibling's disability. Jane responded to the questions in different ways at different times and also felt that her ability to answer questions has improved as she has gotten older:

I mean it comes up sometimes. It comes up a lot when you play that game where, "do you have any siblings? What do they like? Are you close with your brothers and sisters?" And, it's always hard for me because my sister is the one who's right below in age. Yet we're not as close because of her developmental disabilities and learning disabilities, so it's not the same as other people who would have sisters in high school...Or, at that age level. So that comes up occasionally. Or other times it's like, "oh, I have a sister," you know, it's more nonchalant and it doesn't need to come up...I've become more eloquent in the way that I have spoke[n], do speak about it and I think that it, it's easier now to talk about. Especially where I work for so many advocacy groups for kids with special needs that it's, it's really easy and I'm proud of all the knowledge that I have and the way that I can talk about it and she's such a gem anyway, so, she's great to talk about. A lot of times though, people will say to me, 'cause I'm in college, and they'll say "oh, ok, so how's old's your sister, you know." And so she's 17, which most kids would be seniors in high school...so then they always say "oh, so pretty soon your parent, you know, you'll get done and then they'll have another college tuition." But they won't, because, you know, as of right now she's still in the school that she's in for a couple years. She does plan on going to college, though. But, it's not the same

as other people. It's like, ok, sometimes I just laugh, you know, and, and other times if people know me better, they don't say things like that.

Jeff also took into account how relevant the topic was when he talked about his brother:

I'll always mention, like if someone's like "Oh, do you have any brothers and sisters." I'll say that like "I have like, a brother, you know, and a sister." I don't immediately go and tell someone, like "Oh, my brother is handicapped." It's kind of something, it'll just come up in conversation or not like, or they'll be like "What grade is your brother in?" I'll be like "Oh, he's handicapped, so he's home schooled." And then usually they'll ask, you know, more and if they don't, I don't really like, push anything on them.

Sarah had a similar view about sharing information about her sister:

I just became comfortable with, if it came up in conversation I wouldn't come out and be like "My sister has a disability" just out of nowhere, but like if it came up in the conversation somehow, you know, we could relate it to that, then, you know, I would talk about it, but...If I ever said, you know my sis- they'll ask who still lives at home and I'll say Well, you know now, I'm like "My sis- my sister lives at home." "Well how old is she?" I'm like "she's 24." "Why does she still live at home?" Or like, you know, you get the "Well what does she do?" and you know, "Well, she, she goes to day hab, she's you know, she's developmentally delayed, she goes to day hab..." You know and I explain, like that, it usually doesn't come in depth, unless they ask.

Hannah mentioned an additional aspect of sharing about her sibling, one that was not a factor for other participants. One thing that Hannah seemed to appreciate about going away to college was the ability to have a choice about telling people about her brother:

It's been interesting going to college 'cause it's something I can not share with people here, especially since I'm so far away. If I don't tell people about it, then they don't know, whereas like, in high school, my brother went to the same high school.

As Hannah noted, she and her older brother attended the same high school; they graduated the same year and even took two classes together. As a result, many of her teachers and classmates knew that she had a brother with Down syndrome and she had no control over who knew; most people knew her as "X's sister." The desire to escape this

did not appear to be a factor in her choosing a college so far away from her sibling, but it was an important benefit to her and one that she mentioned in every interview. She enjoyed that “the people here know you outside of that context.”

Hearing Derogatory Language in Social Settings

Most participants were sensitized to hearing other people’s use of terms like “retard” or other inappropriate language. Based on my own experiences as a sibling and discussions with other siblings, I know that hearing such negative language can have an effect on siblings. As a result, I was curious to learn about students’ responses to disability-related language and asked about this during interviews. Interestingly, Jeff, Sarah, and Deanna all brought the topic up before I asked about it and for all of them it was in response to the same question: “How has having a sibling with a disability affected your daily life as a college student?” Jeff brought it up immediately when I asked this question:

I think again it’s one of those things that’s like, in the background. Like sometimes, if people are making like jokes, about someone who has a disability, or someone says like “Oh, you’re such a retard” or something. Like, that’s something that...some of my best friends here joke about stuff and they’ll say it and they know that it’s just something that, they know that like, I have a brother with a disability and it just kind of slips and I told them a bunch of times, that, you know, “I don’t appreciate that, it’s not really funny.” So, they’ve gotten better, but like, I can’t, I guess because it’s become such a, like, stupid colloquial thing to, you know...use...Most people I know don’t mean anything malicious by it...So, it’s not something I, would say like every time I someone says it I, you know, get angry and...you know, tell them to stop. I’ve learned kind of like, they don’t really mean anything by it, but if it gets to a point where I think “ok, that’s a little too much,” I’ll say something. I have no problem pointing someone out and, or, so I guess that, in terms of like or just making fun of people in general, even if they don’t have a disability.

Sarah also felt that language was a large part of her everyday life:

But it is a huge, like, it’s a huge part of my daily life just because, if I hear the word “retarded,” using, used derogatory, I’m like “Excuse me?”or you know

like, “he’s a tard.” I’m like “What? No. That’s not like-”...I’m like “don’t say that.” And like it’s, it’s like the name it, claim it, stop it, I guess you could say, but that’s, it just bothers me. I’m like, “Don– Please just don’t say it around me, I just don’t appreciate it” and “you, you’re ignorant and you don’t know what you’re saying right now” is what I really want to say, but I try to refrain from that.

Deanna had a slightly different response and talked about being more aware of her own language use:

[I’m] a lot more careful about what I say 'cause you know, you use the common, like insults here and there, like they’re nothing in conversation but I realized that you know, that’s a bad habit to get into, especially if I’m trying to be a teacher so I’m very conscious of that.

Deanna may not have been aware of the words she chose earlier because her brother’s diagnosis was not mental retardation, so it may not have been a sensitive topic for her earlier. Deanna expressed additional thoughts about hearing other people using derogatory language in her last interview. At the end of her last interview Deanna asked me how other participants had been influenced and I provided her with a few topics that had come up, including derogatory language. Deanna noted that this was an issue for her as well and that hearing people use language that was derogatory towards people with disabilities “hits a nerve.”

As noted in the discussion about dating and relationships, Sarah found that her opinion of people changed when she heard them call something “retarded.” Deanna also mentioned this issue in our discussion about language during her last interview: “it kind of puts like, a little black mark on the person...just choice of words, how it’s like, ‘Yeah, you’re not so perfect’.” So it definitely has an influence of how I view them as, you know, people” Hannah had a similar reaction:

It’s always something that, yeah, I notice, in, you know, strikes me -- I think, you know, you make note of it, who said it, where you heard it, that sort of thing, you

know. You think twice next time you talk to that person, you know. I mean it does impact on my view -- person of this source.

For many students, there was also the issue of confronting people when they heard offensive language. Some were aware that by bringing it up, they opened themselves up to charges that they were being "too PC" or "too sensitive." Hannah described this response:

It's just interesting how people aren't aware sometimes or then when people are, they're like, "oh, well, it's just being too politically correct and blah, blah, blah." It's like this is a current medical diagnosis. It's not, you know, something that really does impact people or, you know, even if you're not using it or you don't think you're using it in a way that's, you know, because it's derived from the fact that it's mental retardation, it reflects on how you view people with mental retardation if you've always heard it as this insult people fling around, and I mean it's just so weird how people think of it and argue against the fact that "you shouldn't be that sensitive about it."

Although some of the participants had concerns about negative reactions if they objected to inappropriate language, many felt comfortable speaking up in certain situations. As noted in the excerpt from Jeff's interview, he has corrected friends, although generally wouldn't say anything to a stranger. Although Colleen didn't "react emotionally" to language such as "retard," she felt comfortable confronting people about it: "I think it's very low class but I don't personally get affronted. I will always say something because I know how hurtful it can be to other people."

Hannah, who was introverted and rarely confronted people about language use, still managed to address the issue in a way that could be more far-reaching than confronting language use on an individual basis. During her senior year Hannah joined a campus group that focused on disability awareness and a campus speaker the group sponsored used the word "retarded" during some presentations. As a result of these incidents, Hannah suggested making table tents for one of the public spaces on campus

that educated people about the word "retarded" and some of the ways using "retarded" can be hurtful. Sarah seemed to have been particularly effective in educating the people closest to her. On at least one social occasion she didn't even have to confront someone who used the word; one of her friends did it for her:

If someone says it around me— I've seen it once— one kid, one of my guy friends said it and then I just, I didn't say anything, but one of the girls who was there that knows that it irritates me said something to him and reprimanded him. And I looked at her and I was like "I can't believe she just did that."

James felt that his ability to cope with and respond to inappropriate comments improved throughout college:

I think I was originally very thin-skinned about it... That, if someone had said something about either death or Down syndrome or even people with autism or Asperger's syndrome especially, that I might originally have like carried a grudge or even said something right away that I might have regretted later, that only through experience did I figure out that there are more helpful and understanding, productive ways to respond. Notably I feel like if someone says something in a group setting that I might want to clarify or even take issue with, that nowadays I would wait until I have that person alone to talk about it, whereas originally I might have brought it up and it might have been unproductive and awkward to say anything at that time.

Other participants have also learned to be less affected by offensive comments and some recognize the cultural context for language. Sarah, like others, learned to be less affected by the comments and tried to "brush them off." Jeff also took into account the target of the language and would react differently if comments were directed at a specific person with a disability:

I just kind of— you know, like it kind of goes through my head and I don't know if I really get mad at first because I know like they're not doing it to, you know— they're not like attacking. Like it's just become— it's taken on a completely different meaning, I think... I don't really get angry, just kind of— I guess I accept that it's taken on another meaning, but then like if it ever got to a point where it was obvious that they were making fun of— not like a stupid comment someone made but actually like a mentally challenged person, then it would— but that's

never really happened. It's just— I've kinda understood that it's taken on a different meaning. It's unfortunate that it has.

Aurora responded in a similar way and was more likely to be bothered by comments that targeted individuals:

I think I might be sort of desensitized with that because, just like in elementary school especially, that when kids always start experimenting with those words and start throwing them around so I mean I guess I've always been exposed to it. I never really thought of it in an offensive way at first. And then the older I get and the more I have discussions about these things in classes and stuff like that I realize how offensive some of these words can be, but I feel like a lot of kids from our generation are just don't think about it in an offensive way. When I hear it, I don't know, it just kind of doesn't faze me sometimes and I know people aren't trying to offend anyone or think that it is...If someone were to say "that's retarded" I wouldn't be fazed by it, but if someone's talking maybe about someone, especially if that person does have a disability, then that will register.

Jane didn't get personally offended by the phrase "that's retarded" but had corrected her boyfriend for using it in front of her. Like other participants, Jane tried to recognize that it was not usually meant as a personalized insult:

The things that people don't understand, but I guess I've always just understood that it's not people's fault if they say something like that, it really sometimes is just a level of understanding. They don't understand what that means or, how many times I probably said "that's so gay," and like meaning that it's a bad thing. But do I really believe that that's a bad thing, no, so you know it happens. I think it's more just a society slang thing...I think I once had a conversation with my boyfriend. I think he said that once and I was like "okay, you know I'm not— like, you know my sister. You know what that means like, come on." And he was like, "yeah, I guess you're right." And it's hard, though, to get things that are in your vocabulary anyways. Or you know, you're not personally attaching that kind of a meaning to that, and so I don't really take offense to it in any way.

Jane was not the only person to make the comparison between the phrases "that's retarded" and "that's gay," Sarah and Jeff also compared the inappropriate use of "retarded" to people using the word "gay" as an insult.

As with the other key categories that comprised College Experiences, *Being a Sibling in My Social Interactions* also connected to the core category of *My Experience in*

College is the Same and Different, as indicated by the arrow. The issue of hearing derogatory language, such as someone calling another person a “retard,” was a clear example of a way that participants’ social experiences could contribute to them feeling different from other students.

Core Category: My Experience in College is the Same and Different

The core category that emerged from the data, which encompassed the essence of participants’ experiences as college students with siblings with a developmental disability, was *My Experience in College is the Same and Different*. This core category reflected the almost paradoxical nature of their experience: while they often considered sibling to be an important part of themselves and something that made parts of their college experience distinctly different, as a whole participants didn’t feel that their time in college was really that different from their classmates.

Excerpts from the interviews that illustrated the key categories frequently included references to feeling or being different or comparisons with classmates and friends. At the same time, there were also global comments about not “being different from any other student.” Generally, participants didn’t see their overall college experience as different from their peers but there were many specific aspects that participants thought were distinct. Participants also seemed to have been able to integrate the lives as college students with their lives as siblings.

When asked how her experience compared to her friends and classmates who didn’t have siblings with disabilities, Sarah acknowledged the profound influence that her college experience has had on her development, but at the same time noted that she doesn't think that her experience as a sibling was particularly unique:

I don't see it as much different...Because most of my friends, almost all of them, are— have more than one sibling or, you know, have at least one sibling...I mean the fact that I can share different experiences, I guess that makes it different, but really there's not much different...Like I said, and as far as having a sister with a disability— I mean there's always like the challenge— like talking— it's just sometimes like the connection is different because I can't explain like, well, my sister who is 24 threw a tantrum last night, and your sister who is 12 doesn't do that. You know, like so it's a little bit different in that sense, but my experience hasn't been— I mean at— much different at all, I think. I wouldn't assume so at least.

Jeff felt that his experience was different because of his distinct outlook on life, but, similar to Sarah, thought that other students were unique in their own ways:

I think so 'cause it like colors my outlook on a lot of things and that's something that they don't really have or maybe they do have but not from the same experience like you can learn it, just not— you know, you can learn it in different way of not by having a sibling with a disability. So I think it's different in that sense, but, again, it's like something hard to pinpoint like— like a concrete thing saying, "oh, this would have been different."

Towards the end of Aurora's final interview, I asked her if she felt that having a sibling with a disability made her college experience unique in any way. Aurora's response reflected the paradox of being the same and different and represented the idea that although there were specific differences, the overall experience often felt the same to participants:

Not really. Sometimes, you know, maybe. One of my roommates, her brother now goes here, another one of my friends her brother might come here, so I guess I know that she'll [Aurora's sister] never be able to come here, we'll never share an experience— you know, college experience or anything like that, but other than that we all have our siblings. You know, if they don't, if they don't come here then they're not as much part of our lives and our friendship because they're not here.

Jane's response to the same question was similar to Aurora's in terms of describing specific differences and global similarities:

I don't think so, I think that, as a whole, I mean I'm a lot closer to my family and I don't think really think that it's as a result of my sister...necessarily. But, I mean, I don't think that as many college students are as close with their family,

that they go home as often as I do...I think that having a sister who would be a senior in ... [high school], most college students would have their sister come visit them at that age...And my sister is not coming to visit me, just because, you know, circumstances make it different you know, so, that's different.

In their final interview, participants were asked what advice they would have for other college student siblings, parents of those college students, and faculty/staff/administration. The paradox of the same and different was also demonstrated by their recommendations. Many students, even those who identified as siblings and saw themselves as different in some way from their classmates, offered some valuable advice and at the same time expressed the view that the college experience as a whole wasn't different for siblings. Aurora had suggestions for both students and parents, but when asked about any needs that those working on campus should be aware of, she said that: "I don't feel like we're any different from any other student. I mean, maybe some other people do have a different experience where they do need something, but I haven't found that."

Jane expressed a similar view when asked what advice she would give to other students with a sibling with a disability and also acknowledged that it may be different with a sibling with more needs than her sister:

I mean other than standard college advice, I don't think that going to college and having a sibling with special needs does make that big of a difference...maybe more so in my case just because, I mean, my sister doesn't have any medical needs, she doesn't have any behavioral needs, so that, there would never be any kind of family emergency or anything that my sister would need extra help and attention with....I don't think that that should affect the college process unless there is some sort of, you know, possibility of there being like an emergency that you would want to be there for or part of your family for.

The core category included three subcategories that reflected their experiences as college student siblings: Uniqueness of the Sibling Experience, This is All I Know, and

Sibling as an Identity. These subcategories were fundamental components of their sibling experience and offered insight into the reality of their lives as siblings. Uniqueness of the Sibling Experience offers a holistic look at participants' backgrounds and illustrates the complexity in their lives. This is All I Know reflects the idea that for many participants, their experiences growing up with their sibling didn't seem unique to them because it was all they had ever known and was "normal" for them. Finally, Sibling as an Identity explores whether participants viewed themselves as siblings and how that identity factored into their self-concept.

Uniqueness of the Sibling Experience

This subcategory included general aspects of participants' experiences and was often less specific to their time in college. However, these themes were important because they offered a fuller understanding of where participants come from, how their lives have been affected by their siblings, and how they continue to be affected. The subcategory of Uniqueness of the Sibling Experience had three components: Positive and Negative Aspects of Being a Sibling, Sibling Relationships, and Daily Realities. Together, these aspects of the participants' experiences as siblings included positive and negative facets of growing up with a sibling with a disability, their relationships with their siblings, the importance of family in their lives, and the logistical issues that were sometimes associated with having someone with a disability in the family.

Positive and Negative Aspects of Being a Sibling

Participants' initial descriptions of what it was like to grow up with a sibling with a disability demonstrated the complexity of the experience and included both positive and

negative elements. Some enjoyed the fact that their sibling made them unique and appreciated their differences.

Several participants also expressed a sense of gratitude for their siblings and the experiences they have had. Phyllis felt that “it’s been rewarding to have a sibling with a disability, definitely.” Sarah described a similar view:

As far as it being, like, a blessing and rewarding, it’s really taught me so much, I have so much respect for people with disabilities, I wouldn’t trade having a sister with a disability for anything...seeing the successes that she’s had are incredible.

Sarah was not the only participant to incorporate the idea of a “blessing” when describing her experience. While Jane sometimes felt different from her classmates, it was a positive difference: “Sometimes, I feel like though I’m more blessed though...Because I have experienced something and I have another level of understanding and I have enough information that I can then make a positive difference.”

Deanna was another participant who saw the positive in growing up with a sibling with a disability; she reported that prior to the interview process she didn’t view her brother as an influence on her life but the interviews allowed her to see the effect he had had on her. When I asked her what it was like to come to this realization, she said, “I feel like I’m fortunate for having gone through an experience that nobody else has, because I feel like it contributed more to my personality and more to, you know, how I make my decisions and choose to live my life.” Like Deanna, Aurora also enjoyed the uniqueness of having a sibling with a disability:

I mean a lot of times people know, because, you don’t just assume that, you know, oh maybe they do have a sibling who’s disabled. And then once you tell me, they’re like, “oh wow! That’s kind of you know, interesting” or, so it’s kind of nice to talk about and like to have some different experience that people don’t know about, it’s interesting.

The positive view of having a sibling with a disability existed simultaneously with some challenges. Jeff described it as both "different" and "harder" but thought that it seemed harder in retrospect: "I guess, it's just, while it was happening or, I just never, I didn't know anything else. It was just was, you know, it's just how it was." Deanna said that sometimes it was an "extra struggle" and when initially asked what it was like to have a sibling with a disability, she said it was "difficult" when they were growing up. Sarah recognized the complexity of growing up with a sibling with a disability and called it "extremely challenging but extremely rewarding at the same time."

James' initial description of the sibling experience was mixed, which could be attributed to his more complex family history. He viewed growing up with his youngest sister, who has Down syndrome as primarily positive and "fun." James' experiences with his brother had more of an influence on his life and were more challenging; he described his brother as "annoying" and frequently dealt with his brother's difficult behaviors.

When discussing how their siblings have influenced their lives, participants sometimes found it difficult to separate the effect of their siblings from their family as a whole. Additionally, the importance of family was emphasized by many of the participants and this closeness to family was sometimes connected to having someone with a disability in the family. Participants asserted that family came "first," was "everything," and a "stronghold." Jane, Hannah, and Aurora felt that their closeness to their family set them apart from many of their peers. Hannah noted that "at times I'm more involved with things at home, like during the guardianship process." Deanna thought that her brother's disability emphasized the meaning of family: "I kind of feel

like when you have this like extra struggle, I guess you could say, like it makes family that much more important.”

Sibling Relationships

Participants’ recollections of their sibling relationships often painted the picture of unique sibling relationships, even if they didn’t always explicitly describe them as different. Some participants found that their sibling’s disabilities created obstacles in their relationships. Participants sometimes contrasted their sibling relationships and those of their peers or discussed differences in their relationships with other siblings in their family.

Several participants identified specific challenges or differences in their relationships with their siblings, sometimes connected with behaviors associated with their sibling’s disability. Sarah and James both felt that their relationships with their siblings could be difficult at times. Sarah recalls dealing with her sister’s sometimes incomprehensible behaviors as a child as well as stares from other people in public. She still found it difficult to understand her sister and has coped with her sister’s jealousy and competitiveness:

We have a great phone relationship, my sister and I, but when I come home, she has, like, if I want to do something with my mom, I can’t do it alone with my mom, she has to come, or she’ll like, she’ll throw a fit or she’ll just get really mad and like, my mom, but when I call her, she is just, she won’t stop talking, she’ll talk about everything under the sun, she’ll tell me she misses me. It was so funny, she was screaming at me one time before I left because of something, it was, something blew up, or I spent time with my mom and she didn’t like that! And like, something blew up and she called me after, 10, 20 minutes later I called home, I was like “I’m here right now, you know, I’m on my way back.” And she goes, “I miss you [Sarah] already.” I’m like “you hated me 20 minutes ago!” [laughs] So like it, I mean it, in that sense it’s been very challenging and I get, it really upsets me sometimes, I’m like, she really just doesn’t like me, like she really doesn’t like me. But in reality she, she does, but it’s a very difficult relationship.

James also dealt with his brother's behavior, which he described as "anti-social violent behavior" that included "daily suicidal/homicidal threats against all of our family." James discussed several examples, including his brother lying to a teacher about being physically abused, which prompted an investigation of his parents, and a suicide attempt. James has responded to his brother's behavior in a variety of ways:

I've tried multiple approaches depending on the situation. There have been a few times in my life when he would make some ridiculous claim where he goes off on like a rant, cursing all of my family members and our entire planet and I'll just like beat him up, but that was rare. It was mostly like, sometimes polite disagreement with him or sometimes impolite disagreement with him, mostly just like, he'll go off on a 5 minute binge of swearing and then I'll be like, "yeah, whatever." And walk away or change the subject or whatever. Kind of dealing with a really strange person you meet in public, just like not knowing how to handle it. And well, let's see, he has some very strange like stubborn, like political beliefs and world view, like he consistently maintains that humans are evil and should all be killed and that sex is an evil act because it produces more humans who are evil. And he believes that intoxication is evil. He refuses alcohol because he thinks it could lead to sex, which is evil...And he holds the environment and animals in high regard, thinks animals should and plants should inherit the earth because they're not evil and don't hurt people. He mainly thinks that humans more hurt people than help each other and therefore should be eradicated.

James didn't feel that he had a close relationship with his brother, although he was pleased to discover that his girlfriend demonstrated some understanding of his brother and got along with him. James didn't describe much of a relationship with his other sibling with a disability, his youngest sister, who was about to turn 6. He reported that they mostly played together, which he really enjoyed and felt that she was a real "bright spot."

Aurora was particularly attuned to the idea of the loss of a traditional sibling relationship, such as being able to share experiences. It is important to note Aurora was

one of two participants who only had one sibling and her sister's disability was profound. She spoke several times about the limitations of her relationship with her sister:

I guess she knows a lot of my social life but, you know, I can't talk to her as a sister, get advice from her, or get feedback you know, so it's complicated in that sense. She also, it's like she has the mental capacity of someone younger than me, even though she is 10 years older...So, it's hard to speak to her as someone older or at the same level as me and I don't know.

For Jane, her relationship with her sister with a disability was different from her relationships with her other siblings because Jane and her sister couldn't do certain things together:

It's harder to be as close with her because it, she's not at the, you know, same cognitive level as she is socially...So there's just a lot of situations that she can't be fully involved in, she doesn't enjoy concerts as much 'cause she has some sensory integration issues.

Jane also talked about her sibling relationship differing from her peers' sibling relationships: "they're more doing things together instead of one helping the other." However, she also tried to put this in perspective by considering how traditional sibling relationships often functioned: "But you know at the same time, no one really likes their sibling to ever really tag along."

Phyllis's relationship with her brother with a disability evolved as she has grown up; she moved from confusion, resentment, and embarrassment to what she described as a "special" relationship that she now deeply appreciated. She noted that their relationship even improved after she went away to college: "And with [brother] I think, our relationship even got better because I really just wanted to hold on to what our relationship, that- I would, when I go home like I spend a lot of time with him."

Aurora also experienced some changes in her relationship with her sister after she went away to college, especially her view of her sister. Aurora found that since being at

school and being around “more intellectual” people her sister’s cognitive limitations became more apparent: “I realize how many things she can’t understand. Like that, that’s like the biggest difficulty with communication with her is that I don’t know when I speak to her how much she understands of what I’m telling her.” When I asked Aurora what it was like to come to that realization, she expressed both sadness and acceptance:

It was interesting...it’s just something kind, I kind of accepted. Sometimes it’s kind of frustrating I guess, because it’s like, ‘cause I know she’ll never get, like, even though she is aging she’ll never really be a 30-year-old person, you know. So, it’s kind of sad in a way. But it’s something I’ve accepted... You know, that’s just the way it is.

Some participants’ relationships and interactions with their siblings were influenced by their parents, who sometimes had certain expectations of them. For example, while they were in college Colleen and James’ mothers both asked them to help their siblings in specific ways. Both of their brothers have Asperger’s syndrome, and they each talked about helping their brothers over the phone. Colleen’s mother would ask Colleen to help reinforce "normal" teen behavior, and James would be called by his mother or brother to help his brother with college assignments. James speculated that had his brother stayed in college (he dropped out during his first semester) the requests to help him over the phone could have become a burden, but he felt he could have enforced some boundaries about it. Colleen described the requests she would get from her mother:

When I was at [name of school] I got a lot of phone calls from my mom being “will you please talk him out of” etcetera, you know (laughter). I would be like, “well here at college [name of brother], the kids don’t think, like, dressing up as a pirate is cool,” you know, that kind of thing so yeah.

Colleen felt that phone calls from her mother affected her daily life as a college student in another way:

When he [Colleen's brother] would be having a really hard time at home I would have really a hard time at school. You know my mom, maybe she shouldn't have, but would always tell me about if he was having a really hard time and that would make it really hard for me to focus.

For Aurora, her relationship with her sister shifted when she went away to college and her mother sometimes became involved in their relationship by suggesting an overnight visit for her sister or communicating her sister's feelings. Aurora tried to balance her increased independence with her responsibility towards her sister:

I think it's disappointing for my sister at times, because I am doing more things that I haven't done in the past and I'm not as around as much so you know, she's not as involved in my life as she used to be...I didn't think about it that much until like my mom had actually mentioned to me once, you know, once or twice, that she misses me because I haven't been, like, if I was home for, say, the break and I was going out and doing things, you know, I wasn't actually home or when I was home she was asleep or at school or something, you know....Then it's kind, it's, [pause] it's like, oh, right, you know, I am still a sister, I still have a responsibility to be a sister and like talk to her and be involved. So, then I have to kind of, make sure I'm home at a time when she is and then spend a little bit of time with her.

Like Phyllis, Colleen had been embarrassed by the behavior sometimes exhibited by her brother with a disability and actually thought that her sense of embarrassment had increased somewhat: "he is less obviously disabled so when he is inappropriate or whatever or just very odd, it's sort of like, people are less understanding about it."

Colleen had also struggled with the different relationships she has with her two brothers:

Like right now it's sort of hard to treat both of my brothers equally because [youngest brother] is so much easier to get along with. And I'm living at home in part too, to help out with [brother with disability] but I think [brother with disability] sees my relationship with [youngest brother] and how easy it is and like how we just get along and he might not realize that it's because of his disability and not, like I don't like him less than [youngest brother]. It's just I interact with him differently.

Colleen also expressed a longing for this to change: "I wish we had a different relationship than what we have right now."

Deanna's brother with a disability had communication difficulties, which she thought was an obstacle in their relationship growing up. She felt that their relationship was improving, partly because a shift in medication has made him "more personable," but they weren't growing particularly close because she was away at college.

Aurora's sense of loss, described earlier, existed alongside deep feelings for her sister. During her final interview she described a recent feeling of connection with her sister and an appreciation for the uniqueness of their relationship:

My parents and her [sic] came up for a performance that I did, so my parents were in the bathroom and I was standing out in the hallway with her and I just -- something clicked in me and I was like wow! You know, now I really see our relationship and how we are so bonded. I guess I don't really think about it that often, you know, but something that day I was just like I feel the whole sister connection. So it's just interesting....I guess the way I was interacting with her. I realized that no one has the kind of connection with her at all and there's no one who could besides me.

Daily Realities

One additional aspect of the sibling experience was reported by two participants as an important piece of the reality of their lives with their siblings. These practical considerations were faced on a consistent basis growing up and continued to be relevant as college students. Aurora and Jeff, who both have siblings who are non-ambulatory, were the only ones to report this difficulty. Sometimes the logistical challenges related to their sibling's disabilities resulted in limitations on family activities. Jeff found that one of these limitations set him apart from other students:

The only thing I would say is a lot of people here have like -- I don't know if this is totally related, but have done like extensive traveling like throughout the world and stuff, and I really haven't only because like it's hard to take my brother places far away from like the hospital where he normally goes to where they have all his records and stuff. So I guess in that way my experience has been different 'cause when people talk about, oh, I've been to France and Spain and this place and that

place, and I'm like, ah, like East Coast has been fine, you know, with me and Canada.

Even shorter trips could be challenging because of Jeff's brother's medical needs:

Now he has like the respirator, the G-tube, that he's being fed constantly, 24 hours. The respirator he can go off of, he can stay fine without it, it's just, it's better to have it going to like keep the lungs healthy. So, it's just a lot of stuff to take around... So whenever, if you want to like, go to, like my grandmother's house it's a production, 'cause you have to carry around all this stuff.

Despite objections from his mother, when he was in high school Jeff's family hired a nurse to help care for his brother during the day. Prior to that decision, Jeff felt that there were times when he and his sister were "suffering" because they were constantly inside with his mother, who was caring for their brother.

Aurora's family also needed to consider practicalities related to her sister's disability and she expressed frustration over the resulting restrictions:

We can't go to certain places, we can't do certain things, I'm not allowed to go some places and do some places because she can't go there. Like, just, thinking of like, on vacations, our plans always have to be a certain way and like, we went on a group vacation and like, the people we were with they could go off wherever, but we have to have a plan because we don't know if it's going to work or not... You know, it's hard to be spontaneous, just do something.

Aurora also described the logistics involved when her parents and sister visited her on campus. Despite these arrangements and the fact that when only her parents visited "we can go off and do anything," Aurora enjoyed both types of visits: "sometimes I think it might be nicer when my sister comes just 'cause I know my whole family's here... You know, 'cause it's a little bit awkward and, when she's not, 'cause it's like, there's a piece missing... either way, it's both nice."

This is All I Know

Adding to the paradox of the same and different was that some participants didn't necessarily see their experiences as different because it was all they knew. For most participants, the ages of their sibling or small age gaps between siblings meant that they had never really known what it was like to not have a sibling with a disability. Some of these differences may only now be becoming apparent because, until participants left for college, most had not spent any substantial time away from their homes and families.

When I asked Sarah about her awareness of sibling support services, she had heard about them but never participated because she never felt any need for support services. Her elaboration on this lack of need illustrated the idea that having a sibling with a disability can simply be part of one's reality:

And I think that a lot of it has to do with when you grow up with someone with a disability you don't even get fazed by it. You don't know like, my sister had a disability, yeah, I knew that she had a disability, but like you're so used to it that you don't even know it...It's part of your life. It's not like it's something that comes up new and sparks every day. You know, it's like you expect it. It's there. It's just something that is part of your life.

Sarah felt that in addition to her sister's disability, there were other facets of her family life that could easily be seen as different, such as her father's time in prison and the large age gap between Sarah and her oldest siblings:

It's just like having a 43-year-old sister. That's normal. What? You don't have a 43-year-old sister that is 22 years older than you? That's normal for me. It's just, I don't know, it's just the way we grew up. That there wasn't anything different about it.

Jane expressed a similar idea, stating that the fact there were six children in her family was "usually the initial shock." Jane felt that her ability to talk about her sister has improved over the years and when I asked her what it was like to talk about what made

her sister different she highlighted the idea that having a sibling with a disability was normal for her: “it’s been like this my whole life since I can remember...So we’re only four years apart...But, I don’t really remember not having a sister...And so, it’s not something that is out of the ordinary.”

As previously noted, Aurora and Jeff were the participants with siblings with the most profound disabilities, including the inability to speak or move independently. Both Aurora and Jeff recalled wishing for a sibling who was “normal” or able to “talk to me” but despite these differences growing up with their siblings was all that they had ever known. Aurora noted that her relationship with her sister wouldn’t have been as involved if she hadn’t had a disability:

Sometimes I get disappointed, ‘cause it’s like, why can’t I just have, you know, a normal sister...But, then again, it’s like, I can’t picture it any other way...Because she is 10 years older than me so, I know that growing up she wouldn’t have been as much a part of my life as she is now... ‘Cause she would have been off to college when I’m still in elementary school or something like that. So, you know, I always feel happy that it is the way it is.

Jeff also expressed the idea that, despite the challenges related to his brother’s disability, he wouldn’t necessarily change things:

I would say [pause] it was different and looking back on it, I could say it was harder, I guess, it’s just, while it was happening or, I just never, I didn’t know anything else. It was just what was, you know, it’s just how it was....it was different, I wouldn’t say I would like, didn’t like it or I didn’t really think there was a time when I was like, “Oh, I wish it was this way.” There were times when I, when I wished it was like, “Oh, I wish my brother could, you know, talk to me and we could have a conversation about this, this, and this.” But, I learned that I could still talk to him, he responds to what I’m saying and whether like, doctor says “Oh, he’s just, you know, responding to your voice.” It like, doesn’t really matter for me. I just believe that, like he knows, you know, what I’m saying when I talk to him...I don’t think I regret anything, I just, it was just something that you got used and you, you got through it.

Identifying as a Sibling

There was a range in the importance students placed on their sibling identity. For many participants, being a sibling was such a key part of them that they wrote about it in their college admission essays. Jeff was one of several students who included their sibling in their essays, and he went even further by writing what he called a supplemental essay that he included with his college applications:

And just ‘cause I thought, like, that was a side of me that was different from everyone else and it was a side of me that I’m proud of and you know, I love him so much that I want to put it out there because it’s a big part of me.

Jeff also talked about the importance of both his brother and his sister in an activity that was part of his RA selection process. At the same time, he, like many of the other participants, felt that being a sibling wasn’t the only, or most important, part of himself: “I would probably say like family is bigger than sibling, but sibling’s a part of that. I would say probably that’s like the biggest. Or just like, community in general would be the biggest influence.”

Hannah also saw sibling as part of her identity; she had completed a project on siblings in 8th grade, and felt that this identity has grown stronger in some ways since she started college:

I guess maybe in the sense that now it’s an identity that I choose to have, ‘cause like I said it’s not so obvious that I have a brother with a disability when I’m here, so it’s instead of just being identity that I have it’s something I choose to have.

While participating in an identity-related exercise on campus Aurora focused on her family:

There was an “other” category so it was kind of like, anything you wanted to put in there and what I put in there and what I put in there was like, my relationship with my family, I guess. More of like, my mother, which has to deal with my sister, like the way, you know, how she always has to take care of her, so that was

my most important part...of me. So, I feel like having her as a sister is my most important identity element or [laughs].

Other participants didn't strongly relate to a sibling identity. Sarah didn't view sibling as an identity and said that "it's normal for me":

I mean I don't think it's an identity. I don't think it describes, I think it has a lot to do with, I think that my sister's disability has influenced me in a way. I don't think it describes who I am though because I am a totally different, I'm not her. You know?...I don't think it's, it's affected who I've become but not in a negative way by any means...Saying it identifies me or describes me is kind of it could go either way. I mean I could say it describes me in a sense that it has influenced me but it doesn't describe who I am. I don't dwell on the fact that my sister has a disability by any means. She's got disabilities and that's that....Informally I'm, you know, more like my personality and all that other stuff which I think is influenced by family in general, not just my sister. It's my family in general has influenced who I have become. The whole family unit thing.

At the end of her last interview I asked Sarah if there was anything about having a sibling with a disability that she hadn't thought about prior to the interviews. Part of her response reinforced the notion that sibling wasn't an identity for her and that she didn't view her experience as truly different from her college peers: "I never thought of myself as a college student with a sibling with a disability." This rejection of sibling as an identity can be connected to the overall core category of *My College Experience is the Same and Different*. Not identifying as a sibling ties into the idea that in a general sense, siblings are not really that different from other students.

Deanna didn't see sibling as a direct piece of her identity: "but more indirectly, with the certain things that's attributed to my personality, like the patience and the...caringness and stuff like that." Jane's view of herself as a sibling was more related to all of her siblings or, as she laughingly described it, as "a sibling times five." When asked about specifically being someone with a sibling with a disability, she said:

I think sometimes, I think it depends, if you ask me, then yes [laughs] but it's not always on the forefront of my mind but then you know as you start to, to get into, as I said, like when someone asks you "oh do you have any brothers and sisters, you know, tell me about them all" and you know, that's when, that comes up usually.

James also generally viewed his sibling identity within the context of his entire family but did feel that his specific experiences with his siblings with disabilities mattered greatly: "I'm my parents' son and a member of our family and a sibling and all of these things matter and probably especially matter to me because losing some of my siblings was something that I went through with my surviving siblings." Later in the same interview James commented that it was "more a part of who I am than what I do."

For some participants, it seemed difficult to separate family identity from sibling identity, which connected to the times when participants couldn't distinguish what was an influence from their sibling and what was an influence from their family as a whole. This issue seemed further complicated for participants from larger families, as the participants sometimes mentioned the influence of coming from a larger family.

Summary

Through the data analysis process, it became clear that for each participant, having a sibling with a disability influenced one's college experience. The specific areas and extent of the influence varied with each person, but nobody was untouched by growing up with a sibling with a disability. When asked initially about their experiences, participants gave a wide variety of responses, ranging from pride to frustration, often in the same interview. Additionally, several aspects of students' experiences in college were not connected to having a sibling with a disability, such as some college choices related to the college selection process and participation in study abroad. Importantly, students

generally didn't feel pressure from their family to go against their desired college choice and didn't report many guilty or conflicted feelings about going away to college. For many, these interviews were the first time that they had extensively reflected on themselves as siblings. Although participants identified specific difficulties related to their sibling, the overall picture was largely a positive assessment of the sibling experience with little negative impact. Some participants expressed appreciation and gratitude for their sibling and described the experience as rewarding or a blessing. At the same time, they also recognized their losses and acknowledged frustration and sadness. Having a sibling is "normal" for them, they are "used to" it, and "can't picture it any other way." Participants readily identified the lessons they have learned and the things they have gained through their sibling.

Although a formal identity as a "sibling" wasn't relevant to all of the participants, it was a substantial part of their lives, illustrated in several ways, including the fact that most wrote about their sibling in their college admissions essays. For example, in talking about the role his brother may have played in his college selection process, Jeff said that "it's become so much a part of me, and shaped who I am." It seemed that the sibling aspect of participants' identity wasn't always something they thought about daily, although it seemed more present on an everyday basis for the two participants who were pursuing special education degrees. Having a sibling with a disability was often more of a global influence on their personalities and this aspect of themselves served as a backdrop for their lives as college students. Their identity as a sibling was sometimes moved to the forefront when they heard negative comments on campus or were involved in conversations about families that required them to make a decision about disclosing

information about their sibling with a disability. Answering questions accurately about their families sometimes required lengthy explanations to routine questions and highlighted differences between participants and their classmates/friends. There was sometimes sadness or frustration about these and other differences but these differences were also seen as advantages or positive aspects of participants' lives. Some participants liked having an experience that set them apart from others and appreciated how growing up with their sibling helped shape their outlook on life and personalities. Participants often acknowledged that their family was indeed different but for them personally it didn't feel different – it was simply their family and that was what they knew so it wasn't different for them.

Family life was important to participants in the study, and at times it was difficult to separate sibling influences from overall family influences. Their close relationship with their families was another way that some students felt different from their peers but, again, participants generally viewed this in a positive light. Participants were aware of some issues associated with their sibling's future care, and some were aware of possible difficult choices ahead. Thoughts of the future didn't weigh particularly heavy on most of them but, at the same time, most had thought about living close to their families in the future. Some participants connected this explicitly to their siblings with a disability.

The core category of *My Experience is the Same and Different* contained the essence of participants' experiences. The specific influences on participants' lives as college students were represented in the five key categories: *Lessons Learned from Siblings*, *Having a Sibling Shapes My Personal Traits*, *Having a Sibling Plays a Role in*

*My College Choices, Having a Sibling Contributes to My Academic Experiences, and
Being a Sibling in My Social Interactions.*

CHAPTER V

DISCUSSION

Overview of the Findings

This study used constructivist grounded theory to examine the college experiences of college students with a sibling with a developmental disability. Data from interviews and written materials provided by the participants were the basis of the emergent theory. The core category in this theory, which encompassed participants' experiences, was *My Experience in College is the Same and Different*. This core category described the paradox that was their experience in college. Although they identified many specific aspects of their time in college that were different from their peers who did not have a sibling with a disability, overall participants felt that their college experience was the same. There were five key categories related to the core category: *Lessons Learned from Siblings*, *Having a Sibling Shapes My Personal Traits*, *Having a Sibling Plays a Role in My College Choices*, *Having a Sibling Contributes to My Academic Experiences*, and *Being a Sibling in My Social Interactions*.

The key categories were ways in which having a sibling with a disability affected participants' experiences in college. The five key categories were put into two groups, based on the timing of the influence. Two key categories were considered to be aspects of participants' Pre-College Experiences: *Lessons Learned from Siblings* and *Having a Sibling Shapes My Personal Traits*. Three key categories were parts of participants' College Experiences: *Having a Sibling Plays a Role in My College Choices*, *Having a Sibling Contributes to My Academic Experiences*, and *Being a Sibling in My Social Interactions*. All five key categories connected to the core category and were specific

ways that having a sibling with a developmental disability influenced participants' experiences in college. Additionally, there was a relationship between the Pre-College Experiences key categories and the College Experiences key categories. The Pre-College Experiences described in *Lessons Learned from Siblings* and *Having a Sibling Shapes My Personal Traits* often influenced participants' specific College Experiences.

The key category *Lessons Learned from Sibling* contained five subcategories, each one was a lesson that participants had learned from growing up with a sibling with a disability and had influenced their college experience in some way. The five subcategories were: Valuing What You Have, Appreciating Differences and Being Nonjudgmental, No Self-Pity, Never Give Up, and Having Hope and Faith.

Having a Sibling Shapes My Personal Traits consisted of three subcategories describing different qualities that evolved through their experiences with their siblings. The three subcategories were: Having Patience, Understanding Others, and Being Mature and Responsible.

The key category *Having a Sibling Plays a Role in My College Choices* represented the different college-related choices that participants made and this category had five subcategories. Some subcategories were more influenced by having a sibling with a developmental disability and others were minimally affected. The five subcategories were: Choosing a College, Choosing a Major, Career Plans, Participation in Out-of-Class Activities, and Planning for the Future.

Having a Sibling Contributes to My Academic Experiences was comprised of four subcategories, all related to the influence of participants' siblings on their academic and learning experiences. The four subcategories were Papers and Projects, Personal and

Academic Benefits, Classroom Discussions, and Hearing Inappropriate Language in Academic Settings.

The last key category, *Being a Sibling in My Social Interactions*, had five subcategories and described the ways in which participants' relationships, interactions, and behaviors in social settings were affected by growing up with a sibling with a disability. The five subcategories were: Transitioning to College, Friendships, Dating and Relationships, Talking about Siblings, and Hearing Derogatory Language in Social Settings.

The core category, *My Experience in College is the Same and Different*, was made up of three subcategories: Uniqueness of the Sibling Experience, This is All I Know, and Identifying as a Sibling. The first subcategory, Uniqueness of the Sibling Experience, was further divided into three parts: Positive and Negative Aspects of Being a Sibling, Sibling Relationships, and Daily Realities. Positive and Negative Aspects of Being a Sibling offered a general overview of participants' lives as siblings. Sibling Relationships described the benefits and challenges of their relationships with their sibling with a disability. Daily Realities included the logistical and day-to-day concerns connected to their sibling's disability. The second subcategory, This is All I Know, addressed the idea that for many participants, their lives as siblings didn't seem different to them because they had never really known life without their sibling and while their experiences may appear out of the ordinary to outsiders, it was normal to them. The third subcategory, Identifying as a Sibling, explored the different ways that participants viewed a sibling identity.

Relationship to Research Questions and Literature

The research question that guided this study was intentionally broad: How do college students with a sibling with a developmental disability experience college? This broad focus resulted from two important ideas. The first was based on the review of previous sibling literature. There was no prior research that used a holistic approach to studying the college experiences of siblings so it was difficult to choose a single aspect of the college experience and explore only that dimension. It seemed more appropriate to cast a wide net and see what parts of the college experience were connected to being a sibling or were deemed relevant by the college student siblings themselves. The second reason for such a broad focus was related to methodology. I would be unable to determine what specific aspects of college were influenced by having a sibling until the participants in the study shared that information with me. In order to have a theory that was truly grounded in the data I had to ask participants about their time in college overall and then work from their descriptions of their experiences. This was accomplished by asking questions about their time in college as a whole as well as the specific parts of their lives as college students that they felt related to having a sibling with a developmental disability. There were also discussions about the aspects of college that are often common across many students, such as selecting a college, choosing a major, participating in activities, and so forth (Miller, 2006). This exploration revealed what parts of the college experience were influenced and to what degree, what parts of the college experience weren't influenced, how students viewed themselves in comparison to their peers, and what it was like for them as college student siblings.

Although this study used qualitative methodology, the grounded theory developed in this study has some similarity to Astin's (1993) input-environment-outcome (I-E-O) model, which is generally associated with quantitative research. Like the I-E-O model, the results of this study acknowledge that students enter college with specific experiences and characteristics that can interact with both their environment and specific outcomes. Having a sibling with a developmental disability would be considered an input and could have an effect on some of the outcomes noted by Astin, such as personality, values, and career development. Outcomes are also affected by environmental variables, such as institutional characteristics and peer groups (Astin); sibling as an input variable could interact with these aspects of the college environment and influence specific outcomes.

The results of this research do not directly relate to many of the studies discussed in Chapter II because of the research question addressed. Much of the prior research on siblings has focused on specific outcomes (e.g., Burton & Parks, 1994; Dyson & Fewell, 1989; Hannah & Midlarsky, 1999) and often compared siblings to a control group of participants who had siblings without disabilities (e.g., Bischoff & Tingstrom, 1991; McHale & Gamble, 1989; O'Kane Grissom & Borkowski, 2002). The qualitative approach in this study was consistent with the type of research question being asked and allowed for a more holistic and comprehensive examination of siblings' experiences in college.

Many of the themes present in the core category and key categories were reflected in the literature. The core category of *My Experience in College is the Same and Different* was present in other research and there were also connections to the five key categories,

particularly *Lessons Learned from Siblings, Having a Sibling Shapes My Personal Traits,* and *Having a Sibling Plays a Role in My College Choices.*

Core Category: My Experience in College is the Same and Different

The core category of *My Experience in College is the Same and Different* was supported in several ways by previous research on siblings. The themes described in *My Experience in College is the Same and Different* related to the findings of another qualitative study on siblings (Wilkerson, 2001). Wilkerson's phenomenological study of nine adolescents with a sibling with Down syndrome resulted in nine essential themes of the sibling experience, as well as variations of those themes. The core category in this study, *My Experience in College is the Same and Different*, was specifically reflected in the Wilkerson study:

The participants believed that their experiences were not that different from others their age with siblings without Down syndrome. They compared their experiences to those of their friends. They believed their experiences were mostly similar to their peers and stressed this aspect of the experience. However, they were aware of the differences in their experience. (p. 127)

One of the subcategories of *My Experience in College is the Same and Different*, This is All I Know, could also be seen in Wilkerson's study, which included the idea that having a sibling was "all I have ever known" (p. 125).

In addition to identifying nine essential themes, Wilkerson (2001) also examined influences on participants' experiences as siblings and discussed five common influences: perception of sibling's level of functioning, sibling's mood swings, difficult communication with sibling, spirituality, and family. Several of these influences are reflected in the core category of *My Experience in College is the Same and Different*, specifically the subcategories Positive and Negative Aspects of Being a Sibling and

Sibling Relationships. Although Wilkerson's study was specific to having a sibling with Down syndrome and in the current study I looked more broadly at developmental disabilities, there seemed to be similarities with some of these influences on the sibling experience. Several participants struggled with the unpredictability of their sibling's moods and challenges in communication with their sibling.

The core category of *My Experience in College is the Same and Different* was echoed in another study on families with children with disabilities; Scorgie and Sobsey (2000) interviewed parents of children with disabilities and found that, "They intimated that although the experience of parenting children with disabilities is in many ways similar to parenting their children who do not have disabilities, it is significantly different, and even life-changing, in other ways" (p. 204).

Within the subcategory Positive and Negative Aspects of Being a Sibling, participants expressed a sense of gratitude for their sibling's presence in their lives and the experience of growing up with their sibling. A couple of participants used "blessed" or "a blessing" to describe the experience. Similar language was used in another study (Johnson, 2005). In Johnson's study of 30 adults who had participated in a sibling support group as a child the participants were given a list of 20 feelings and asked to select "the five most accurate feelings that they had regarding their sibling both when they were an elementary school child and as an adult" (Johnson, 2005, p. 29). "Blessed" was the 6th most frequently selected feeling and was chosen by 12 of the adults (Johnson).

Another aspect of the core category, closeness to family, was also reflected in the literature. Some participants discussed their close relationship with their families and the

importance of family in their lives. Lobato (1990) reported closeness to family as a “potential positive effect” (p. 17). In another study, parents with a child with a disability felt their families had become closer and stronger (Abbott & Meredith, 1986).

Identifying as a Sibling, one of the subcategories of the core category, was also related to the literature. Participants varied in their identification as siblings; some saw it as an important part of their identity and for others it was less significant as a formal identity. Additionally, for some of the participants with larger families, a sibling identity wasn't necessarily specific to having a sibling with a disability. The variability in identifying as a sibling is consistent with the model of multiple dimensions of identity presented by Jones and McEwen (2000). The model of multiple dimensions of identity was based on interviews with 10 undergraduate women, and the data were analyzed using grounded theory methodology (Jones & McEwen). The resulting model offered a more flexible view of identity development:

The model reflects an acknowledgment that different dimensions of identity will be more or less important for each individual given a range of contextual influences. It also presents identity development as a fluid and dynamic process rather than a more linear and static stage model. (Jones & McEwen, p. 411)

Jones and McEwen's model of multiple dimensions of identity included a core identity, identity dimensions such as race, gender, and sexual orientation (represented by intersecting circles), and contextual influences. Participants seemed to fit into this model in different ways. For some, their identity as someone with a sibling with a disability was one of the intersecting circles, along with dimensions such as gender, sexual orientation, race, and religion. Other participants seemed to view the sibling role as part of their core identity, sometimes indirectly via their sibling's influence on aspects of their personality. Finally, other participants' experiences seemed more consistent with the expected way

that a sibling identity would fit into the model, as family background, a contextual influence. Other contextual influences from the model, such as life experiences and sociocultural conditions, could also be involved. Even for those who didn't strongly identify as a sibling, certain contextual influences sometimes made that aspect of their identity more salient; this could include discussions or questions about family, incidents of ableism, or negative language in academic or social settings. For example, as described in the core category, Jane didn't see her identity as a sibling as something that was "on the forefront of my mind." She viewed it as context specific, such as when she was asked questions about her siblings. Additionally, in Jeff's first interview, when asked how his daily life as a college student had been influenced by having a sibling with a disability, Jeff said "it's one of those things that's like, in the background" and discussed how he was affected when he heard people use the word "retard."

The idea that the components of identity can shift over time seems relevant to the sibling experience. Researchers have noted the importance of studying siblings throughout their lifespan (Hodapp et al., 2005; Stoneman, 1993). Although this was not suggested by the results of the current study, it is possible that participants might find that their identity as a sibling will wax and wane throughout their lives. For example, the role of a sibling may become more salient as parents age and future care responsibilities for their siblings become more pressing. It is possible that for many siblings, the sibling dimension of their identity is not as salient during college. This may be particularly true for siblings like the ones in this study, who do not live at home while attending college. When students with a sibling with a developmental disability are at college, they may not be immersed in their family life and may experience some emotional distance from the

impact of their sibling on the household; on a daily basis they remain busy at school with academics, activities, jobs, and their social life.

Another aspect of the sibling identity relates to visibility. As some participants noted, sibling is not a visible identity so other people don't automatically know that one may have a sibling with a disability. In this aspect, a sibling identity is similar to other invisible identities such as disabilities (Brown, Connors, & Stern, 2000), learning disabilities (Troiano, 2003), religion (Clair, Beatty, & Maclean, 2005), and sexual orientation (Clair et al.).

Key Categories

Lessons Learned from Siblings and Having a Sibling Shapes My Personal Traits

The key categories related to pre-college experiences, *Lessons Learned from Siblings* and *Having a Sibling Shapes My Personal Traits*, are consistent with recent trends in disability research. The participants acknowledged the difficulties they have encountered as siblings and sometimes keenly felt the loss of a "typical" sibling relationship. However, the overall impression was that they felt they had gained many things from having a sibling with a disability and they appreciated those benefits. A study of adults who had participated in a sibling support group as children is consistent with this impression: "Most respondents did not say that their sibling had a negative impact on their lives" (Johnson, 2005, p. 33).

Many of the specific benefits described by the participants in the current research reinforced the findings from the clinical and research literature. Participants in this study described a variety of ways in which growing up with a sibling with a disability positively influenced their lives. Some of the qualities described in *Lessons Learned from*

Siblings had been previously identified in the sibling literature, including understanding and acceptance of difference (Stainton & Besser, 1998; Wilkerson, 2001), tolerance (Lobato, 1990; Meyer & Vadasy, 1994; Stainton & Besser; Wilkerson), and appreciation (Meyer & Vadasy). Collectively, *Lessons Learned from Siblings* related to how participants viewed the world. Meyer and Vadasy have discussed how one's outlook on life can be affected by having a sibling with a disability. All three of the subcategories within *Having a Sibling Shapes My Personal Traits*, Having Patience, Understanding Others, and Being Mature and Responsible, were represented in previous studies. Wilkerson found that adolescents with a sibling with Down syndrome felt their experiences helped them become patient and have compassion. Maturity and responsibility were also described in the sibling literature (Lobato; Meyer & Vadasy; Simeonsson & McHale, 1981). Other studies are also consistent with both *Lessons Learned from Siblings* and *Having a Sibling Shapes My Personal Traits*. For example, Dykens (2006) reviewed similar outcomes in a discussion of a paper by McMillian and Swenson: "Siblings note that having a brother or sister with disabilities teaches them patience, tolerance, empathy, a sense of social justice and advocacy, acceptance of difference, and a 'common humanity' with others" (as cited in Dykens, p. 187). *Lessons Learned from Siblings* also connected to one of the influences Wilkerson described, spirituality. Spirituality and faith were discussed by several participants in the current study; some drew comfort from their faith or felt it helped them understand why their sibling had a disability. Wilkerson found a similar belief:

The participants described depending on God to assist them in their journeys, particularly the challenges. Their faith had gotten them through difficult times and would continue to help them. Some participants felt that it was God's will for their sibling to have Down syndrome and that belief gave them peace. They felt

that God had a purpose and that was enough for them to accept the situation. Their faith and beliefs had much influence on their experience. (pp. 141-142)

There was also a connection between Hodapp and Urbano's (2006) survey of adult siblings and subcategories in *Lessons Learned from Siblings* and *Having a Sibling Shapes My Personal Traits*. Hodapp and Urbano found that over 80% of the respondents felt that growing up with a sibling with a disability gave them more empathy and understanding of differences. There have also been related findings in research on parents of children with disabilities. Parents in a study by Abbott and Meredith (1986) reported that they personally "had a greater appreciation for the small and simple things of life" (p. 374). The parents in the Abbott and Meredith study also noted that their families had developed more patience, compassion, and unselfishness.

Lessons Learned from Siblings and *Having a Sibling Shapes My Personal Traits* were also consistent with findings from Flaton's (2006) qualitative study. Just as participants talked about developing compassion and learning about diversity, similar findings were reported by a 35-year-old woman with a brother with Down syndrome who was the focus of a phenomenological case study (Flaton). She felt that because of her brother she learned about diversity, compassion, and empathy (Flaton).

The themes included within *Lessons Learned from Siblings* and *Having a Sibling Shapes My Personal Traits* are supported by research on parents conducted by Behr (1989). Behr used grounded theory to develop the item pool for an initial version of the Positive Contributions Survey (PCS). The PCS was then administered to parents who had children with and without disabilities. Using exploratory factor analysis, Behr identified five factors that made up parents' positive perceptions of their children: source of happiness and love, source of family strength, source of personal growth and maturity,

source of help and motivation, and source of knowledge about and compassion for special problems in life. Behr also compared the parents of children with disabilities to those with children without disabilities and found that three factors discriminated between the two groups. In increasing order of the ability to discriminate between the two groups, these factors were source of happiness and love, source of family strength, and source of knowledge about and compassion for special problems in life (Behr). The more detailed descriptions of the factors in Behr's study showed great similarity to the positive aspects of sibship described by the participants in the current study. These positive aspects included appreciation for the little things in life, family closeness, patience, responsibility, career development, understanding about special problems in life, and compassion for others (Behr).

Elements from *Lessons Learned from Siblings* and *Having a Sibling Shapes My Personal Traits* can also be seen in Taunt and Hastings' (2002) study of parents with a child with a disability, which included several categories of positive aspects of having a child with a disability. Some parents felt that the impact of their child on their life included a changed perspective on life and increased sensitivity, which they defined as "increased tolerance, awareness of others, improved sensitivity to child as a parent, increased patience, thoughtfulness, compassion" (Taunt & Hastings, p. 415). These positive influences expressed by parents are similar to some of the reflections offered by the participants in the current study; participants felt that growing up with a sibling with a disability affected their outlook on life and provided them with increased patience, tolerance, and compassion, and sensitivity towards others. Taunt and Hastings also asked parents about the impact of the child with a disability on other children in the family and

a similar connection between their study and the current study existed. Although their study did not use self-reported data from siblings, some of the findings are consistent with the results of the current research:

Respondents...identified that children with disabilities had a positive impact on siblings and on the extended family. Similar effects were reported, and these focused on increased sensitivity and caring on the part of siblings and other relatives (especially grandparents), things that relatives have learnt as a result of their contact with a child who has disabilities, and increased closeness and support in the extended family. Siblings in particular were singled out as having developed greater maturity and a greater sense of responsibility. (Taunt & Hastings, pp. 413-14)

Scorgie and Sobsey (2000) also found that parents reported positive outcomes similar to those discussed by the participants in the current study. These included compassion, perseverance, perspective on life, and “an ability to be comfortable around people who are different” (Scorgie & Sobsey, p. 203).

The themes in *Lessons Learned from Siblings* and *Having a Sibling Shapes My Personal Traits* were generally considered to be beneficial by participants and the idea of positive outcomes is consistent with the more current trend in the literature to explore the positive effects of having a child in the family with a disability. Although there were some early studies that focused on the positive aspects of having a child with a disability in the family (Abbott & Meredith, 1986; Behr, 1989), many clinicians and researchers have observed that for many years the disability literature has traditionally assumed negative outcomes for both parents and siblings (e.g., Hodapp et al., 2005; Stoneman, 2005). The idea that families may have a positive view towards having a family member with a disability is becoming more common in the literature (Dykens, 2005). Dykens (2006) goes beyond the idea of positive outcomes for families and advocates for the abandonment of the pathological approach to people with mental retardation and the use

of a positive psychology approach when studying people with disabilities. Much of the newer literature with a positive lens focuses on parents but siblings are beginning to be addressed either directly or indirectly (Scorgie & Sobsey, 2000; Stainton & Besser, 1998; Taunt & Hastings, 2002).

The recognition that having a sibling with a disability can be positive has been reflected in more recent quantitative studies. As reviewed in Chapter II, prior research on sibling outcomes varied widely (Cuskelly, 1999), with some studies finding no differences between siblings and control groups (e.g., Bischoff & Tingstrom, 1991; Dyson, 1999), some finding negative outcomes for siblings (e.g., McHale & Gamble, 1989; Nastasi, 1997), and a meta-analysis of empirical research on siblings revealing a “small negative effect” (Rossiter & Sharpe, 2001, p. 76).

Some of the more recent research on siblings’ adjustment seems to be supporting the view that having a sibling with a disability doesn’t automatically cause negative outcomes; two studies found that, compared to control groups, siblings exhibited no differences in adjustment or had higher scores on adjustment measures (Cuskelly & Gunn, 2006; Fahey, 2005). Cuskelly (1999) has written extensively on the methodology of sibling studies. A recent study of the adjustment of siblings aged 7 – 14 attempted to address some of these methodological drawbacks (Cuskelly & Gunn). Cuskelly and Gunn compared children with a sibling with a disability and children with a sibling with no disability and found no significant differences between them on internalizing and externalizing behaviors, competence, and self-concept. Fahey compared adults with a sibling with mental retardation to a control group of adults with siblings without mental retardation. The adults with a sibling with mental retardation had significantly lower

levels of depression and anxiety and were less likely to use negative coping skills. These more recent studies are promising, particularly those that attempt to address methodological challenges (Cuskelly & Gunn). The current study didn't explicitly examine specific outcomes such as internalizing and externalizing behaviors or depression. However, there is the general connection of siblings reporting generally positive experiences.

Chapter I included several first-person and clinical accounts of adult siblings discussing their college experience. Some adults recalled feelings of guilt about leaving home for college along with a desire to escape (Hart, 1989; McHugh, 2003b). There seemed to be few similarities between the experiences of the siblings in the current study and those described in Chapter I. Although most of the participants in this study carefully considered the issue of distance from home, they were not conflicted about going away because of their sibling. Participants did not report feeling guilty and stated that their parents clearly wanted them to have a "traditional" college experience. This contrast seems consistent with the positive trends in the literature as well as generational differences. Several of the first-person excerpts were from adult siblings who grew up and attended college during an era when the climate for disabilities was much different; attitudes towards people with disabilities were more negative and services and educational and occupational opportunities were less common.

Just as the participants in the current study didn't uniformly report positive sibling experiences, the more recent focus on positive outcomes doesn't dismiss or ignore the challenges often involved with disabilities. However, these newer studies are an important shift away from assuming that siblings will have negative outcomes or

problems with adjustment. Powell and Gallagher (1993) framed sibling outcomes as a continuum from negative to positive, with many mediating factors playing a role in siblings' location on the continuum. The idea of a continuum informed the current study and the results of this study support the notion of viewing the influence of having a sibling with a disability on a continuum. For participants in this study, different aspects of the college experience were influenced in a variety of ways. Powell and Gallagher also noted the dynamic aspect of having a sibling with a disability:

It is important to remember that this continuum of outcomes for siblings is not static. Simply because a sibling seems to have a very healthy, positive relationship at one time does not mean that, at another time, the same sibling may not express some very negative behaviors and feelings. (p. 48)

Dykens (2005) also reminds researchers that family members can experience both positive and negative outcomes, often simultaneously, and that the influence of a family member with a disability can differ based on developmental stages. Dykens recommended that future research take a balanced approach:

One can easily imagine cases in which a sibling uses her relationship with a brother or sister with disabilities to cultivate strengths in the areas of humanity, kindness, love, and social justice. Such strengths may not necessarily protect this same sibling from also having negative feelings, perhaps being angry at their sibling or embarrassed by his or her appearance or behavior. Such positive and negative reactions are fully expected and fall within the realm of healthy emotional experiences. (pp. 362-363)

This dynamic can be seen in the experiences of the siblings in this study; many expressed gratitude for the presence of their sibling in their life but were saddened by aspects of their relationship with their sibling with a disability. On campus, some participants felt their sibling status enhanced their academic life or provided them with a unique outlook on life while at the same time they felt different from their friends when the topic of

families came up or dealt with uncomfortable and unpleasant feelings when they heard peers calling someone a “retard.”

Having a Sibling Plays a Role in My College Choices

Another key category reflected in the literature was *Having a Sibling Plays a Role in My College Choices*. There were some overall similarities between this category and a phenomenological case study of Anna, a 35-year-old woman with a brother with Down syndrome (Flaton, 2006). Anna felt that her brother had a substantial influence on the choices she made and that if he wasn't in her life: “[I would have] had a very different life in terms of my career choice, where I live, and what I studied in school” (Flaton, p. 141). There were also two subcategories that were supported by previous research: Career Plans and Planning for the Future.

Career plans. For several participants, growing up with a sibling with a disability influenced their career choice in some way. These influences included not choosing a medical career because of overexposure to hospitals and doctors during childhood, choosing a helping profession, and selecting a career that directly involved people with disabilities. This finding relates to prior research on career development among college students in general as well as siblings. Both quantitative and qualitative studies have examined the relationship between family and college students' career decision-making process (Brown, 2004; Hargrove, Creagh, & Burgess, 2002). Hargrove et al. used a quantitative approach to examine the career decision self-efficacy of undergraduate students and determined that different family variables “may play small, yet significant roles in college students' confidence in engaging in developmentally appropriate career planning activities and ability to formulate clear and stable career goals” (p. 197).

In the current study there was also a relationship between family and career development. Having a sibling with a developmental disability influenced career choice directly and indirectly, via the categories related to participants' experiences prior to entering college: *Lessons Learned from Siblings* and *Having a Sibling Shapes My Personal Traits*. Many students in the current study felt that their precollege experience of growing up with a sibling with a disability affected their career choice in some way; Brown (2004), in his study of students' career decision-making, included a comparable element. Using a qualitative approach and a framework of wisdom development, Brown examined career decision-making in 18 women who had recently graduated from college. Within a wisdom development framework, the four major elements that influenced postcollege decision-making were Orientation to Learning, Experiences, Interactions with Others, and Environment. One aspect of Orientation to Learning was precollege biographies/values, which seemed similar to the views expressed by some of the participants in the current study: "Some students cited one precollege experience that had an enduring impact on their biographies and values. Other students reflected on the general influence of their family background on their values and life priorities" (Brown, p. 378).

Several studies have examined siblings' career choices, with varying results (Burton & Parks, 1994; Konstam et al., 1993; Marks, Matson, & Barraza, 2005). Two of these were quantitative studies that compared siblings' professional aspirations and choices to people without a sibling with a disability (Burton & Parks; Konstam et al.). Burton and Parks measured career aspirations by classifying students' majors as "a helping or nonhelping profession" (¶27) and found no significant difference between the

30 undergraduate siblings and 30 undergraduate non-siblings. Konstam et al. also examined helping and nonhelping professions, comparing 27 adult siblings to 27 graduate students, and found no significant difference between the two groups. Konstam et al. measured career choices as current and prior employment of the participants and used a broader definition of helping professions than the Burton and Parks study. Burton and Parks' choice to measure career aspirations by major seems somewhat limiting, both by making assumptions about the direct relationship between major and career and excluding those pursuing medical careers. For example, in the current study Hannah's major was anthropology, which would have been classified as a nonhelping profession. Yet Hannah was planning to become a doctor, a career considered a helping profession by both Hannah and the Konstam et al. study. Burton and Parks' measure for career aspirations eliminated undergraduates interested in medical careers who had more traditional pre-medical majors such as biology or chemistry.

Having a Sibling Plays a Role in My College Choices, and more specifically, the subcategory Career Plans, was also supported by a study conducted by Marks, Matson, and Barraza (2005). In the current study, all of the students who were pursuing either helping careers or careers directly related to disabilities felt that growing up with their sibling had influenced their career choices. The participants in the Marks et al. study expressed similar feelings: "All of our participants felt in some way that it was through their life experience of having a sibling with a disability that led them down their career path" (p. 211). Marks et al. used a qualitative approach and, rather than compare career choices of siblings to non-siblings, they focused exclusively on siblings who had chosen careers in special education and considered "the potential impact that being a sibling of a

brother or sister with a disability has had on them” (p. 206). Using a combination of focus groups and individual interviews, they studied seven siblings who were either undergraduate students majoring in special education or had completed an undergraduate or graduate degree in special education (Marks et al.). There were some other commonalities between participants in both studies. Like Deanna in this study, one participant in the Marks et al. study felt that his brother had helped him in his career by offering him “a unique perspective on the various individual needs of people” (p. 211). Another participant in the Marks et al. study echoed the concerns about language use on campus and advocated for “more sensitivity towards individuals with disabilities was needed, particularly in how individuals with disabilities are portrayed in class lectures (i.e., not using “person-first language”)” (p. 211). Although the focus of the Marks et al. study was on the influence of having with a sibling with a disability on careers, they found influences on other aspects of life that were consistent with the current study. These included participants’ being close to their families and influencing relationships with others (Marks et al.).

Planning for the future. Participants’ involvement in future planning for their sibling with a disability seems consistent with some of the literature. Participants had all thought about their siblings’ future to varying degrees. Adolescents in Wilkerson’s (2001) study reported being aware of the role that their sibling would play in their lives in the future.

Some participants in the current study had spoken with their parents about the future and even discussed preferences but none had developed concrete plans. The process of developing a future plan for people with disabilities, sometimes called

permanency planning, is complicated (Kaufman, Adams Jr., & Campbell, 1991). Research on parents' permanency planning has shown that many parents of adults with disabilities haven't developed a concrete plan (Freedman, Krauss, & Seltzer, 1997; Heller & Factor, 1991; Kaufman et al.). Additionally, parents who anticipate that another child will take their place in caring for their child with a disability do not always explicitly communicate this wish to the sibling (Bigby, 1996; Kaufman et al.). Given the limited planning from older adults with adult children, the level of planning found among participants' families is not surprising. The demographic variables of the families of participants in the current study were generally different from the families in the research discussed above; specifically, the majority of the participants' siblings were under 25, with many still in their teen years, and several families had other children without disabilities still living at home and going to school. Viewed within the context of family life cycles, the minimal focus on future planning is understandable. Turnbull, Summers, and Brotherson (1986) discussed seven stages in a family's life cycle: "couple, childbearing, school age, adolescence, launching, postparental, and aging" (1986, p. 53). They also identified specific stressors often associated with each developmental stage. Participants in the current study represented families in three developmental stages: school age, adolescence, and launching, with some families spanning several stages. Turnbull et al. noted that "the presence of a mentally retarded member creates additional responsibilities for families at every developmental stage beginning with childbearing" (p. 55). Tasks related to future planning issues, such as guardianship, financial planning, and residency, are primarily considered to be tasks for the launching, postparental, and aging stages of the family life cycle. Based on this model of the family life cycle and the

participants' families' current stages within that life cycle, it is not unexpected that future planning was not a major concern among siblings.

Another aspect of planning for the future, thinking about having children, was not explicitly explored in the study. It was not a topic that I specifically brought up when asking about participants' future plans and they did not discuss future children in anything beyond general terms. This was somewhat surprising as clinicians and professionals who have worked with siblings have noted that it is not uncommon for siblings to have thoughts and questions about their potential future children, including the genetic aspect of some disabilities (Harris & Glasberg, 2003; Meyer & Vadasy, 1994; Strohm, 2002).

Having a Sibling Contributes to My Academic Experiences and Being a Sibling in My Social Interactions

In the current study participants often discussed their responses when they heard language that they considered inappropriate or derogatory, this was included in two categories, *Having a Sibling Contributes to My Academic Experiences* and *Being a Sibling in My Social Interactions*. The specific subcategories were Hearing Inappropriate Language in Academic Settings and Hearing Derogatory Language in Social Settings. Similar to those subcategories, Wilkerson (2001) noted that participants in her study often mentioned a dislike of phrases such as "mentally retarded" and "retard." One university has recognized the effects of such language and taken a proactive approach to educating students through a program called More Than Words (Campbell, 2007).

Campbell described the influence of language on campus:

"Don't be retarded." My friend tenses up every time someone says the word *retarded*. Her brother is disabled and the word stirs up feelings that most people

rarely consider. How many times a day do the sentences “That’s gay” and “You’re so retarded” come out of people’s mouths? Through overuse, are they now becoming a part of everyday language? While many people may not realize that the words they speak may offend, carelessly used words can indeed lead to hurt, discrimination, and on occasion, violence. (p. 19)

Participants in the current study struggled with similar issues related to hearing such language on campus, including the realization that such words and phrases seem to be an accepted part of speech.

The key category *Being a Sibling in My Social Interactions* was connected to the literature in another way. In two of the subcategories of *Being a Sibling in My Social Interactions*, participants discussed the influence of their sibling on their romantic relationships and friendships. The phenomenological case study of Anna, a 35-year-old woman with a brother with Down syndrome, revealed some similar themes (Flaton, 2006). Just as many participants in the current study reported that their significant others would have to be accepting of their sibling, Anna was clear with her future husband that her brother’s approval was essential in order for their romantic relationship to continue (Flaton). Anna also noted that other social relationships were also influenced by her brother: “The significant relationships that were not thrust upon me, the ones that I chose, those are all directly related to him” (Flaton, p. 141)

Limitations of the Study

There were several limitations of the current study. Despite efforts to recruit a diverse sample, there was minimal diversity among participants. Most participants were White, Catholic, and heterosexual and most were female. Many were from larger families and most identified their family’s socio-economic status as middle-class or upper middle-class. Many of the previous studies on siblings have been similarly limited by

homogeneous samples (Boyce & Barnett, 1993; Hodapp et al., 2005; Mary, 1990; Rogers-Dulan & Blacher, 1995).

The amount of time that lapsed between completing an interview and participants receiving the transcript to review was also a limitation. Some of the delays in completing transcriptions were beyond my control, such as work and family obligations. Although this was not ideal, the interviews with participants did not seem to be negatively affected by the delay.

An additional limitation, and one that is perhaps unusual among contemporary college students, was that all of participants' parents were still married. Two students had a parent who had been married and divorced before they were born. It is possible that college student siblings whose original family unit was not intact could have a different experience.

Other limitations were related to institutional type and students' residential status. All of the participants attended private, four-year institutions. Additionally, none of the students in the study lived at home and commuted to school. All but one of the participants attended a school that was at least several hours away from their families. The experiences of siblings who attend different types of institutions and/or who do not go away for college may be different from those who participated in this study. Research has shown that institutional type and size, as well as residential status, can affect students' college experiences and outcomes (Astin, 1993; Pascarella & Terenzini, 1991). Additionally, enrollment in four-year colleges has been connected to family social capital (Sandefur, Meier, & Campbell, 2006), raising the possibility that participants' enrollment

at private, four-year institutions may reflect a difference between their experiences and those of other siblings.

Self-selection of the sample must also be considered. Participants who expressed interest in the study may have felt more comfortable discussing their experiences as siblings. Siblings with more negative or mixed feeling about their sibling with a disability or the experience of growing up with a sibling with a disability may be more hesitant to express those thoughts to a researcher and as a result might not respond to postings about sibling research. One clinician, in conducting research for a book about being a “normal” sibling, described her difficulties in finding siblings to talk to: “I discovered that problem siblings are no more popular to talk about than to write about or think about; even the most forthcoming self-aware people become disturbed, dense, and defensive” (Safer, 2002, p. 35). I had a similar experience during the recruitment process, a co-worker knew someone with a sibling with a disability and offered to pass along information about my study. That person’s relationship with the individual’s sibling was apparently difficult, and the person didn’t want to discuss it. Although my co-worker had explained to him that no judgments would be made about him and that I wanted to interview people with a range of sibling experiences, he was not interested in participating because of his negative experiences with his sibling.

Sibling researchers have emphasized the importance of examining mediating influences, such as gender, birth order, and type of disability on people who have a sibling with a disability (Hodapp et al., 2005; Stoneman, 2005). The small sample in this study made it difficult to find patterns related to these mediating influences, a challenge that was not unique to the current study. There did seem to be a trend for participants

from larger families to be less likely to identify specifically as a sibling. Stoneman has acknowledged that the intricacies of families and disabilities can make it difficult to understand how specific factors influence siblings and called for a specific way to address these issues: “Answers to important questions relating to child characteristics and sibling developmental trajectories will only be possible when large multi-site studies of siblings provide sufficient statistical power to begin to address these complex, but important questions” (p. 344). Stoneman’s suggestion for addressing these issues involves a quantitative approach to studying siblings and perhaps a combination of her recommendation along with additional qualitative research could provide a holistic understanding of different mediating influences. The large multi-site studies recommended by Stoneman may help identify mediating influences. Qualitative studies can complement that knowledge by providing a deep and rich understanding of how siblings view the different influences on their experiences. Additionally, quantitative studies using the I-E-O model (Astin, 1993) could include sibling as an input variable.

Strengths of the Study

This study was able to address some of the limitations of prior research by using a qualitative approach, avoiding the deficit perspective so common in sibling studies, and using data collected directly from siblings rather than relying on parent or teacher reports. It provided an in-depth look at a complex experience and allowed siblings’ voices to be heard. Using constructivist grounded theory, the study looked at the experiences of college student siblings and formulated an interpretative theory based on their unique perspectives. Consistent with Charmaz’s (2006) definition of interpretative theory, the theory that emerged from the data focused on understanding the experiences of college

student siblings. The current study added to knowledge about siblings during this stage of their life, which contributes to efforts to learn more about the sibling experience throughout the lifespan.

The current study offers a contemporary look at college student siblings as well as a holistic view of siblings' experiences in colleges. Many of the previous studies on college student siblings were based on research that was at least 10 years old (Burton & Parks, 1994; Grossman, 1972; Kibert, 1986). Compared to previous studies, the participants in this study grew up in a climate that was much different for people with disabilities. Boyce and Barnett (1993), in their review of 30 years of sibling research, pointed out that, since sibling research began, there have been changes in family size and structure, longer life expectancies for people with disabilities, a shift towards less institutionalization of people with mental retardation, and a change in society's view of people with disabilities. Additionally, legislation has increased the amount of educational and vocational options for people with disabilities (U. S. Department of Education, 2001; Young, 1997). There are new opportunities for people with disabilities, such as students with Down syndrome and other developmental disabilities who are attending college, sometimes living and learning with other college students without disabilities (Kaufman, 2006). Other services help people with autism, such as colleges and universities that have developed programs to support the needs of college students with disabilities on the autism spectrum (Moore, 2006). Another strength of this study was that, unlike many previous sibling studies that examined discrete aspects of siblings' functioning, this research was able to take a comprehensive view of siblings' lives as college students. This study revealed how these students viewed themselves and their identity as siblings

and explored what colleges and universities can do to support college student siblings and revealed how these students viewed themselves and their identity as siblings.

Additionally, the current study showed that there are aspects of the college experience that are influenced by having a sibling and highlighted some areas to examine in greater detail in future research.

In her discussion of the negative bias often found in sibling research, Stoneman (2005) noted that “having a sibling with a disability is viewed as a problem to be understood and then solved” (p. 347). This study explicitly attempted to avoid this approach towards siblings and held the assumption that having a sibling with a disability could influence students in both positive and negative ways. The use of a qualitative methodology allowed for Stoneman’s advice to be followed:

The challenge for researchers is to recognize our biases and set them aside. One way of working toward that outcome is to communicate with people who have disabilities about their sibling relationships and let their voices influence our research questions and how we interpret our findings. (p. 347)

Unlike many of the previous studies that relied on reports from parents and teachers or responses to quantifiable measures, the current research used a qualitative methodology in order to remain grounded in the siblings’ voices. Their experiences and perspectives served as the foundation for the resulting theory. As the results demonstrated, siblings’ experiences were multifaceted and a qualitative approach is well suited for examining complex themes (Marshall & Rossman, 1999; Strauss & Corbin, 1998).

Recommendations for Practice

The results of this study provide valuable information that can help support the needs of college student siblings and assist student affairs professionals, academic

advisors, other administrators, and faculty who work with college student siblings. Student affairs professionals could include staff members in areas such as counseling services, career services, disability services, residential life, student activities, and leadership programs; recommendations relevant to each of these functional areas are discussed below. The theory that emerged from this research could help all student affairs professionals to better understand what the college experience is like for these students. Student development theory can be used for program and policy development (Evans, 1996) as well as for helping “student affairs professionals be more proactive in anticipating issues and more responsive to, and understanding of, concerns that arise as they work with students” (Evans, p. 172).

In addition to contributing to the knowledge base on this population, there are several concrete steps that colleges and universities can take to support the needs of college student siblings. One recommendation for practice, grounded in the key category *Being a Sibling in My Social Interactions*, is to offer opportunities for college student siblings to support each other. One of the subcategories in *Being a Sibling in My Social Interactions*, Friendships, demonstrated the comfort, support, and connection that participants gained from talking to peers who had a family member with a disability. Disability and grief sometimes served as bonds between participants and their friends. The results of this research can assist with the creation of formal support services for college student siblings by providing research to justify the creation of these programs and the empirical foundation necessary for effective implementation.

The majority of participants were at least minimally interested in the idea of a group for college student siblings and many provided suggestions for specific goals and

activities. The idea of a formalized support group wasn't particularly appealing but most felt they would enjoy the opportunity to meet other siblings, hear their stories, or interact with other students who could understand what it's like to have a sibling with a disability. These aspects of a sibling group are consistent with several of the goals of Sibshops, a national model of sibling support groups. Sibshops were established 25 years ago (D. J. Meyer, personal communication, December 28, 2006) and are available in 39 states and 10 countries (The Sibling Support Project, 2007b). The goals of Sibshops are:

- Goal 1:* Sibshops will provide brothers and sisters of children with special needs an opportunity to meet other siblings in a relaxed, recreational setting.
- Goal 2:* Sibshops will provide brothers and sisters with opportunities to discuss common joys and concerns with other siblings of children with special needs.
- Goal 3:* Sibshops will provide brothers and sisters with an opportunity to learn how others handle situations commonly experienced by siblings of children with special needs.
- Goal 4:* Sibshops will provide siblings with an opportunity to learn more about the implications of their brothers' and sisters' special needs.
- Goal 5:* Sibshops will provide parents and other professionals with opportunities to learn more about the concerns and opportunities frequently experienced by brothers and sisters of people with special needs. (Meyer & Vadasy, 1994, pp. 4-5)

Other suggestions from participants included planning activities to raise awareness of disability issues on campus, providing opportunities to volunteer with children with disabilities, having a social group that involved the sibling with the disability, and offering resources for education majors who may have siblings in their future classrooms. The idea of support services for siblings was new to almost all of the participants. Only one participant was aware of sibling support services prior to the study, and none of the participants had ever attended any sibling workshops or support groups.

There have been a variety of support services designed for people with siblings with disabilities (e.g., Lobato, 1990; Lobato & Kao, 2002; Meyer & Vadasy, 1994). The

number of workshops are still very limited despite the great need for them: “although brothers and sisters have the longest-lasting relationship in the family, siblings (as we see again and again) have, compared to their parents, far fewer opportunities to gain access to programs, services, and professional support” (Meyer & Vadasy, p. 22). Most of the existing programs and information about these groups and programs are geared toward younger children (Cruz, Andron, & Sammons, 1984; Dyson; Lobato; Powell & Gallagher) although Meyer and Vadasy discussed the availability of a small number of programs geared toward adult siblings and Cramer et al. (1997) have developed a sibling program that serves children and adults. Don Meyer, the director of the Sibling Support Project, a national organization, noted that “the closest to a college-age Sibshop” is a social service club run by college student siblings at The University of Notre Dame, but it is designed to support younger children (D. J. Meyer, personal communication, January 3, 2007).

Research on sibling support programs in the United States and several other countries has been somewhat mixed. Not all groups have found differences related to participation but some programs have demonstrated clear positive outcomes for siblings who participate. These outcomes included increased sibling knowledge about disability/illness, decreased negative adjustment, improved sibling connectedness and sibling relationships, fewer internalizing and externalizing behaviors, improvements in self-concept and self-esteem, decreased sibling related stress, higher social support, and better socioemotional functioning (Evans, Jones, & Mansell, 2001; Lobato & Kao, 2002; Metzger, 2005; Phillips, 1999; Smith, 2000). Additionally, qualitative analysis of sibling support groups have revealed that both parents and children rated them highly and

children who participated enjoyed the opportunities and activities provided by the program (D'Arcy, Flynn, McCarthy, O'Connor, & Tierney, 2005; Dodd, 2004; Dyson, 1998; Naylor & Prescott, 2004; Rogers, 1999).

Johnson (2005) conducted the first research on long-term effects of participation in Sibshops. Johnson surveyed 30 adults, ranging in age from 18 – 34, who had participated in at least one Sibshop during childhood. The vast majority reported being satisfied by their participation in Sibshops and many felt it was helpful to them as children; specific benefits included interacting with other siblings, taking part in recreational activities, learning coping strategies, learning about disabilities, and having “a positive effect on their feelings toward their sibling” (Johnson, p. 31). Additionally, over 70% “said that Sibshops affected their adult life” and over 90% “would recommend the program to others” (Johnson, p. 31). Some respondents also expressed a wish for the Sibshops to have continued through adolescence (Johnson).

Overall, the research on the effectiveness of sibling support services suggests that these programs can be beneficial for college student siblings. Additional support for establishing sibling support groups on campus comes from research on support groups for other student populations. Evaluations of campus support groups for international students (Carr, Koyama, & Thiagarajan, 2003; Smith, Li-Chen, Inman, & Hudson Findling, 1999) and first-year students (Pratt et al., 2000) have been positive. One study of first-year students also showed higher scores of measures of adjustment to college (Pratt et al.).

One possible way to initially implement sibling support services on college campuses could be to address sibling issues as part of disability services, student groups

related to disabilities, or counseling services. Implementing organizations for siblings into existing departments might be an effective way of starting to increase awareness of siblings' needs without creating a new organization or requiring extensive campus resources, such as funding and staff time. If enough interest was generated through these efforts, new campus organizations or programs specifically geared toward college student siblings could be developed. This could particularly be useful on smaller campuses where the number of college student siblings may not be very large. Another possibility is seeking out partnerships with existing sibling services in the community, including Sibshops; this option may be particularly effective in a geographic area with several small colleges near each other.

Another way to support siblings on campus is through the use of Story Circles, a type of Intergroup Dialogue. In story circles small groups of people meet on a short-term basis:

To discuss, through the sharing of their autobiographical narratives, how they each conceptualize and experience the group identity they have in common (which is the focus of a given dialogue). Typically, a single facilitator, representing *the* identity group at focus in a given dialogue, facilitates. (Clark, 2003, pp. 31-32)

Story Circles have been used on the University of Maryland's campus for several groups of students, including men, women, multicultural individuals, and students with psychological disabilities (Office of Human Relations Programs, 2003, 2004). This approach is consistent with the type of support participants spoke about and avoids the idea of a formal or psychological support group, which was not appealing to many participants.

The results of this study are also applicable for high school students and their families and could easily be incorporated into existing sibling support programs. Some of the participants in this study suggested that high school siblings carefully consider the issue of distance when choosing a college and also urged parents to not pressure their children or hold them back. Sibling support groups with adolescent members could address this topic, including inviting current college student siblings to talk about their college experience. Discussion and activities related to college would allow high school students to consider their needs and prepare themselves and their families for the upcoming transition. Additionally, services for parents could provide information about college student siblings that would allow parents to be aware of relevant issues and concerns that their child may have during the college application process. An awareness of how college is experienced by students who have siblings with a developmental disability would enable both parents and school counselors to provide advice and support specific to these students' concerns.

The results of this study can also be used to increase awareness of faculty, staff, and administrators of the needs and concerns of college student siblings. For example, the theory described in this study could help student affairs professionals who work in career services and counseling services have a better understanding of college student siblings and how growing up with a sibling with a disability influences their experiences in college. By understanding the various ways that having a sibling with a disability affects students' time in college, student affairs professionals can offer help and guidance that is tailored toward their experience of feeling the same and different.

Another important aspect of this awareness relates to sensitivity to language, an issue that was prominent in two of the key categories, *Having a Sibling Contributes to My Academic Experiences* and *Being a Sibling in My Social Interactions*. Both of these key categories had subcategories pertaining to language: Hearing Inappropriate Language in Academic Settings and Hearing Derogatory Language in Social Settings respectively. The effects of inappropriate and derogatory language were clearly described by participants. Additionally, during the last interview participants were asked if they had any advice for faculty, staff, and administrators who work with college students with siblings with disabilities. Three participants made the same suggestion: increased sensitivity around terminology. This included both general language, such as not using sometimes colloquial expressions involving the word “retarded” as well as specific terminology related to disabilities. Terminology used, particularly in classroom settings, should be current and the use of People First language should be encouraged. People First language emphasizes the person over the disability by using phrases such as “person with a disability” instead of “disabled person.” Following the lead of one of the participants, informational campaigns on language could be implemented on campus. This type of initiative would be relevant to student affairs professionals working in residential life, student activities, and leadership programs. In addition to encouraging programming around language issues, student affairs professionals in those areas could help raise awareness about sensitivity to language among students in leadership, advisory positions as well as members of student organizations. Information about sensitivity to language could also be incorporated into a variety of educational opportunities: graduate programs

for student affairs administrators; professional development efforts; and orientation and training for administrators, staff, faculty, and student leaders.

Other efforts on campus could work on addressing the use of inappropriate and derogatory language among students. A program at Texas Christian University (TCU), *More Than Words*, has effectively tackled the issue of language on-campus and raised awareness of the effect that phrases such as “That’s retarded” can have on people (Campbell, 2007). This program is part of the university’s first-year experience program and focuses on many aspects of diversity, not just disability issues (Campbell). Additionally, TCU’s program demonstrates how something that affects siblings can be addressed as part of a larger diversity initiative. Similar efforts at other institutions would be an excellent way to improve the campus environment for college student siblings. Addressing language issues on campus goes beyond supporting siblings; it also helps combat ableism and promotes a shift in the way people with disabilities are viewed in society. For example, self-advocacy groups have noted the negative effects of words such as “retard” and “retarded” and are working to eliminate the use of such terminology (Self-Advocate Leadership Network, 2006).

Implications for Future Research

This study used grounded theory methodology to explore the college experiences of students who have a sibling with a developmental disability. The findings offer a model for these students’ experiences that illuminates the complexity of having a sibling with a disability. The existing literature on college student siblings is minimal, and this study provided important information about this population, including how college student siblings view themselves and what aspects of college are influenced by growing

up with a sibling with a disability. As noted earlier, the lack of diversity in the sample was a limitation of the study and is an important consideration for future research on college student siblings. Additional research on this population can address this limitation by including a more diverse group of students, particularly in terms of race, religion, sexual orientation, family size, parents' marital status, socio-economic status, social capital, institutional type, and residential status. Another mediating influence that should be explored in future sibling research is gender as some prior studies have revealed gender differences (e.g., Boyce & Barnett, 1993; Grossman, 1972; McHale & Gamble, 1989).

Clinical research has suggested that race and ethnicity may influence the sibling relationship (Welts, 1988). Other clinicians and researchers have examined racial and ethnic differences related to disability (e.g., Barnwell & Day, 1996; Mary, 1990; Siegel & Silverstein, 1994). The literature on both college student development and siblings notes the need for research on college students and siblings to include people from a variety of racial and ethnic backgrounds (Boyce & Barnett, 1993; Evans et al., 1998) and take cultural factors into account (Hodapp et al., 2005; Stoneman, 2005). For example, Boyce and Barnett noted that most of the available sibling literature focused on White samples and questioned the generalizability of those findings across racial and ethnic groups; they have advocated for more diverse samples in future research:

Cultural expectations for sibling interaction, roles, and responsibilities, as well as for coping with the presence of a disability in a family member, may differ markedly among different ethnic groups, and interventionists need to know how best to help families of each of these groups. (p.180)

Because previous research has shown that family functioning can affect sibling outcomes (Rivers & Stoneman, 2003; Rodrigue, Geffken, & Morgan, 1993), future

research should include siblings from a variety of family types, such as divorced, single-parent families, and same-sex couples. Some research has examined the relationship between family functioning and sibling outcomes. Stoneman (2005) noted that “well-functioning, healthy families help siblings to thrive” (p. 343). Rodrigue et al. (1993) found a correlation between self-esteem and marital satisfaction, such that “higher marital satisfaction among parents of children with autism was also associated with higher levels of self-esteem in siblings” (p. 672). Another study of children with siblings with autism found that higher levels of marital stress were a predictor of problematic sibling relationships (Rivers & Stoneman, 2003). Studies of college students in general, not specifically college student siblings, have examined family functioning, including the relationship between parental marital status and specific outcomes (Heyer & Nelson, 1993; Johnson & Nelson, 1998). Heyer and Nelson found that students with divorced parents scored significantly higher than students whose parents were not divorced on two-subscales of the Erwin Identity Scale, sexual identity and confidence. In Johnson and Nelson’s study parental marital status was a significant predictor of students’ development; students whose parents were divorced were found to have less intergenerational intimacy, less intergenerational individuation, less peer intimacy, and less peer individuation. Overall levels of family functioning were also related to specific developmental tasks such as intimacy and individuation with parents (Johnson & Nelson). Although an intact marriage does not automatically mean high marital satisfaction or low levels of marital stress, the research on family functioning when there is a child with a disability in the family suggests that family composition could have an

influence on sibling outcomes. Thus, samples with different types of families are important.

There are other topics related to siblings that were not explored in this study but could be of interest to future researchers. One issue is family response to disability; siblings' experiences could be influenced by how their family views disability. For example, in a qualitative study of siblings of deaf children, parents' anxiety about deafness was connected to the sibling relationship (Bat-Chava & Martin, 2002). Another topic relates to the language used in interviews; I generally used the word "sibling" rather than "brother" or "sister." Although "sibling" is common in the literature, it is not typically used conversationally. Using the word "sibling" during interviews could shape participants' responses.

Further research on siblings who are currently in college or recent graduates is warranted but additional information about persons with siblings could also be gained by talking to siblings at different stages of their lives. For example, studying siblings who have been out of college for longer periods of time, such as five or ten years after graduation, could add to knowledge of the experiences of siblings in college. Their views about the influence of having a sibling with a disability may shift after leaving college and potentially being out of their family home for a longer period of time. Being in a different life stage may allow them to offer another perspective on their time in college, and these additional reflections could reveal additional needs. Although the current study focused on traditionally aged college students, adult learners' presence on campus has increased (Snyder et al., 2006) and should not be neglected in future research on college student siblings.

This study specifically focused on having a sibling with a developmental disability, primarily autism and mental retardation. The sibling literature includes research on siblings of children with a variety of disabilities and medical conditions and it is important to consider potential differences related to type of disability (Stoneman, 2005). Future research should look at the experiences of college students with siblings with other types of diagnoses, including physical disabilities, learning disabilities, psychiatric disabilities, and chronic illnesses. Reviews of information about the needs of siblings often address disabilities and conditions from several categories (Lobato, 1990; Powell & Gallagher, 1993), suggesting that there are some common concerns.

Stoneman's (2005) call for innovation in future sibling research should also be heeded:

There has been a dramatic increase in the size of the sibling disability literature. Our conceptual frameworks and research methods, however, have tended to stay the same. Continuing to ask the same questions in the same way holds little promise for advancing our future understanding. (p. 343)

This study revealed the complexities inherent in the lives of college student siblings, particularly as shown in the paradoxical core category of *My Experience in College is the Same and Different*. One of the previously discussed limitations of prior research on siblings is the inconsistency of the results. Some of the difficulty in making conclusions about the effects of having a sibling with a disability is related to methodological weaknesses in some previous research (Crnic & Leconte, 1986; Cuskelly, 1999). The multi-faceted results of the current study and findings of previous research suggest that siblings' experiences are indeed complicated. Thus, the difficulty in drawing conclusions from existing studies may not be a limitation in the literature but a true reflection of siblings' experiences. This viewpoint should be considered for future research on

siblings. Both quantitative and qualitative approaches can help add to the knowledge base. Quantitative research conducted with an awareness of the methodological challenges associated with sibling research is valuable and, combined with additional qualitative research, can provide more information about the experiences and needs of college student siblings.

Another important consideration for future research is the idea of the sibling experience as positive. Much of the earlier research on siblings focused on negative aspects of having a sibling with a disability (e.g., Boyce & Barnett, 1993; Hannah & Midlarsky, 1985). This study demonstrated the many lessons and positive attributes that participants gained through growing up with a sibling with a disability. Future research can continue to expand on those experiences.

Conclusion

Society has no greater task than to provide for the healthy, positive development of children. As the field of disability sibling research matures, we will have increased knowledge about how to support children with disabilities and their siblings in ways that enhance their chances of growing into psychologically healthy adults, with firmly established, positive interpersonal relationships. The work involved in designing and implementing this research is difficult, but the benefits are great. (Stoneman, 2005, p. 347)

Stoneman's words emphasize the importance of sibling research, both current and future, and this study added to existing knowledge about siblings in support of the goals she advocates. Through multiple interviews, this study took an in-depth look at how college students who have a sibling with a developmental disability experience college and how their siblings have influenced their college experience. Written materials shared by some participants also provided additional data. The resulting conceptual model provided new information about college student siblings, a population that has been the

focus of few studies. In addition to expanding the knowledge base of both sibling research and college student development, this study offers valuable information on how colleges can support these students.

The current research helps to fill in some of the gaps in sibling research by offering a view of college student siblings that is more contemporary and holistic than existing research. It offers important recommendations for practice as well as future sibling research.

This study revealed the complexity of college student siblings' lives, as illustrated by the core category in the theory: *My Experience in College is the Same and Different*. The participants in this study described lives that are enriched and challenged by their sibling with disabilities. Importantly, the college student siblings who participated in this study seemed to have integrated both aspects of their lives: college students and siblings.

Information for Participant Recruitment

Participants Needed for Study

Does your sister or brother have a developmental disability?

Are you a college student or recent college graduate?

Would you like to contribute to new research about having a sibling with a developmental disability?

Please consider participating in a research project on the experiences of college students who have a sibling with a disability. This study involves interviewing people who meet the following qualifications:

- Have a sibling with a developmental sibling (including mental retardation and autism)
- Currently in college and completed at least 1 year OR graduated since May 2004
- Are between the ages of 18-24

Participation will involve 3 or 4 in-person interviews, 60 – 90 minutes each, that will be audio tape recorded. Interviews will be conducted at your convenience and all information will be kept confidential. At the completion of the interviews you will receive a \$30 gift certificate in appreciation of your participation. This study has been approved by the Institutional Review Board at the University of Maryland for research involving human subjects.

If you meet the qualifications for the study and are interested in participating or have any questions, please contact Jennifer Weisman at siblingstudy@gmail.com or 617-780-5136.

Appendix B

Recruitment Information for Gatekeepers

DATE

Dear NAME:

Thank you for your assistance in identifying potential participants for my research study on college students who have a sibling with a developmental disability. My name is Jennifer Weisman, and I am a doctoral candidate in the College Student Personnel program at the University of Maryland. In order to learn more about how college students who have a sibling with a disability experience college, I intend to conduct interviews with individuals who meet the follow requirements:

- Have a sibling with a developmental disability
- Be currently enrolled at a college/university and have completed one year *or* have graduated with an undergraduate degree since May 2004
- Are between the ages of 18-24

Involvement in the study includes 3 or 4 separate interviews of 60 – 90 minutes each, arranged at the participants' convenience. All interviews will be confidential and participants will be asked to choose a pseudonym for use in written materials. Participation in this study is completely voluntary, and there is the ability to withdraw at any point. Upon completion of the study participants will receive a \$30 gift certificate. This study has been approved by the Institutional Review Board at the University of Maryland for research involving human subjects.

I have enclosed several copies of a flyer with information for participants. I hope you will consider passing this information on to students in your classes and department. I believe it will add to the knowledge about siblings' experiences, particularly during college, and the results can be used to meet the needs of college student siblings. If you have any questions please feel free to contact me at siblingsstudy@gmail.com or 617-780-5136.

Sincerely,

Jennifer L. Weisman
Doctoral Candidate
College Student Personnel Program
University of Maryland, College Park

This research is being conducted under the supervision of:

Dr. Marylu McEwen, Associate Professor
Counseling and Personnel Services
3214 Benjamin Building
College Park, MD 20742

301-405-2871
mmcewen@umd.edu

Appendix C

Invitation Letter to Participants

DATE

Dear NAME:

Thank you for your interest in my research study on college students who have a sibling with a developmental disability. I would like to talk with you about your experiences as a sibling during college.

If you are interested in participating in this study, you should meet the following requirements:

- Have a sibling with a developmental disability
- Be currently enrolled at a college/university and have completed one year *or* have graduated with an undergraduate degree since May 2004
- Are between the ages of 18-24

Involvement in the study includes 3 or 4 separate interviews of 60 – 90 minutes each, arranged at your convenience. These interviews will be audio tape recorded, and you will be provided with a transcript of each interview. You may also be asked to share any materials you have written related to your sibling: admissions essays, class papers, etc. You are not required to share these materials as part of the study; if you choose to share these materials I will work with you to remove identifying information from them. All interviews and shared materials will be confidential, and you will be asked to choose a pseudonym for use in written materials. Your participation in this study is completely voluntary, and you can withdraw at any point. Upon completion of the study you will receive a \$30 gift certificate as a thank you for your participation.

I hope you will consider participating in this study. I believe it will add to the knowledge about siblings' experiences during college, and the results can be used to meet the needs of college student siblings.

If you are interested in participating in this study please review and sign the consent information, complete the enclosed information sheet and return it to me, using the pre-stamped envelope. Please contact me if you would like to receive a copy of this information sheet to complete electronically. Participants will be selected based on that information and then contacted to arrange the initial interview. It may not be possible for everyone who expresses interest in the study to participate and I will contact you to let you know if you are invited to participate in the study. If you are not invited initially, there may be an opportunity for you to participate later in the study. If you have any questions please feel free to contact me at siblingsstudy@gmail.com or 617-780-5136.

Sincerely,

Jennifer L. Weisman
Doctoral Candidate, College Student Personnel Program,
University of Maryland, College Park

Appendix D

Participant Information Sheet

If you are returning this form by mail, please use the enclosed addressed and stamped envelope. If you are returning this form electronically, please e-mail it back to me at siblingstudy@gmail.com and note in the e-mail that you have read the consent form and agree to the conditions of submitting this information. This information will help determine the selection of participant for the study. Thank you for your interest in this study! If you have any questions about this form please contact Jennifer Weisman at 617-780-5136 or siblingstudy@gmail.com

The purpose of this research project is to explore how college students who have a sibling with a developmental disability experience college. This information sheet will be used to assist in selecting participants for this research project. In order to preserve the confidentiality of the information on this form, completed information sheets will be stored separately from any data collected during interviews.

This research is being conducted by Jennifer Weisman, under the supervision of Dr. Marylu McEwen at the University of Maryland, College Park. If you have any questions about the research study itself, please contact Dr. Marylu McEwen at: Counseling and Personnel Services, 3214 Benjamin Building, College Park, MD 20742, 301-405-2871, mmcewen@umd.edu

If you have questions about your rights as a research subject or wish to report a research-related injury, please contact: **Institutional Review Board Office, University of Maryland, College Park, Maryland, 20742, (e-mail) irb@deans.umd.edu; (telephone) 301-405-0678**

This research has been reviewed according to the University of Maryland, College Park IRB procedures for research involving human subjects

Your signature indicates that:

you are at least 18 years of age;

you freely and voluntarily choose to complete this screening questionnaire

NAME: _____

SIGNATURE: _____ **DATE:** _____

Current Address: _____

Phone Number(s): _____

May I leave a message at this number? _____

E-mail Address: _____

Preferred way to contact you (please circle one): Phone E-mail

Age: _____ Gender: _____

Race: _____

Do you have any disabilities? If yes, please specify: _____

Please complete the following **information about your sibling(s) with a disability**.
Primary place of residence refers to where each sibling lives the majority of the time (at home, school, group home, residential placement, etc.). If you have more than 3 siblings with a disability, please provide the information at the bottom of this form.

<i>Age</i>	<i>Gender</i>	<i>Type of Disability</i>	<i>Is Disability Visible?</i>	<i>Primary Place of Residence</i>

Where (city, state) does your family live? _____

Name and Location (city, state) of your College/University: _____

When did you enroll? (semester and year): _____

Class Year or Month/Year of Graduation): _____

Your Current Residence (please check one):

On-Campus Residence Hall _____

Other On-Campus Housing
(Fraternity/Sorority Housing, etc.) _____

Off-Campus Housing
(not with family) _____

Living with Family _____

Other (please specify) _____

Please describe any preferences for meeting dates/times:

Appendix E

Informed Consent Form

Page 1 of 2

Initials _____ Date _____

<i>Project Title</i>	<i>A Grounded Theory Study of the Experiences of College Students Who Have a Sibling with a Developmental Disability</i>
Why is this research being done?	<i>This is a research project being conducted by Jennifer Weisman under the supervision of Dr. Marylu McEwen at the University of Maryland, College Park. We are inviting you to participate in this research project because you have a sibling with a developmental disability and are either currently enrolled in an undergraduate degree program or have graduated since May 2004. The purpose of this research project is to explore how college students who have a sibling with a developmental disability experience college.</i>
What will I be asked to do?	<i>Participating in this study involves 3 to 4 in-person interviews lasting 60-90 minutes each. Interviews will be scheduled at times and locations that are convenient for you. The interviews will take place over several months, and they will be recorded. You will be provided with transcripts of each interview to review and provide comments. You may also be asked to share any materials you have written relating to your sibling: admissions essays, class papers, etc. You are not required to share these materials as part of the study. After completing the final interview you will be compensated with a \$30.00 gift card.</i>
What about confidentiality?	<p><i>We will do our best to keep your personal information confidential. To help protect your confidentiality: (1) your name will not be included on the audio files of the interviews, transcripts, or on any shared written materials (2) a pseudonym selected by you will be placed on the audio files of the interviews, transcripts, shared written material, and other collected data; (3) Identifying information will be removed from copies of written materials given to the researcher; (4) through the use of an identification key, the researcher will be able to link your interview data to your identity; and (5) only the researcher will have access to the identification key. If we write a report or article about this research project, your identity will be protected to the maximum extent possible.</i></p> <p><i>Your information may be shared with representatives of the University of Maryland, College Park or governmental authorities if you or someone else is in danger or if we are required to do so by law.</i></p> <p><i>This research project involves making a recording of the interviews using a digital voice recorder. The interviews are recorded and then transcribed in order to allow a detailed examination of the contents of the interviews. After each interview the recording will be transferred to a personal computer and the file will be erased from the digital voice recorder. The audio files of the interviews will be stored on a personal computer in a password protected folder. Back-up copies of the interviews will be stored as password protected files on CDs and a portable jump drive and kept in a locked private residence. All audio files and the CDs will be labeled only with your code/pseudonym.</i></p> <p><input type="checkbox"/> <i>I agree to have my interviews in this study recorded with a digital voice recorder</i></p> <p><input type="checkbox"/> <i>I do not agree to have my interviews in this study recorded with a digital voice recorder</i></p>

CONSENT FORM

Page 2 of 2

Initials _____ Date _____

Project Title	<i>A Grounded Theory Study of the Experiences of College Students Who Have a Sibling with a Developmental Disability</i>
What are the risks of this research?	<i>The interviews may include discussion of topics that may make you feel uncomfortable. There is a risk of inadvertent disclosure of interview content. However, every effort will be made to avoid this risk but participants inadvertently may be recognized from their verbatim quotations.</i>
What are the benefits of this research?	<i>This research is not designed to help you personally, but the results may help the investigator learn more about the experiences and development of college students who have a sibling with a developmental disability. You may have increased awareness of yourself as a sibling. All participants will be given a list of resources that may be useful for siblings.</i>
Do I have to be in this research? May I stop participating at any time?	<i>Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized. The compensation in the form of a \$30 gift card will only be given to participants who complete the interviews.</i>
What if I have questions?	<i>This research is being conducted by Jennifer Weisman, under the supervision of Dr. Marylu McEwen at the University of Maryland, College Park. If you have any questions about the research study itself, please contact Dr. Marylu McEwen at: Counseling and Personnel Services, 3214 Benjamin Building College Park, MD 20742, 301-405-2871, mmcewen@umd.edu If you have questions about your rights as a research subject or wish to report a research-related injury, please contact: Institutional Review Board Office, University of Maryland, College Park, Maryland, 20742; (e-mail) irb@deans.umd.edu; (telephone) 301-405-0678 This research has been reviewed according to the University of Maryland, College Park IRB procedures for research involving human subjects.</i>
Statement of Age of Subject and Consent	<i>Your signature indicates that: you are at least 18 years of age; the research has been explained to you; your questions have been fully answered; and you freely and voluntarily choose to participate in this research project.</i>
Signature and Date	NAME OF PARTICIPANT: _____ SIGNATURE OF PARTICIPANT: _____ DATE: _____

Appendix F

Interview Question Guide

First Interview

Starting with some more general questions to learn more about you and then we'll talk about your experiences as a sibling. Some of these initial questions are going to be relatively basic, like your major, and others cover broader topics, such as your family. Please let me know if you feel uncomfortable discussing something I ask about. Just to start...

1. Please tell me about yourself and why you were interested in being a part of this study.

- Tell me about family/family members (including any siblings w/o disability - age, gender, where they live, what they do, etc.)
- What do your parent(s) do? What was their highest level of education?
- Sibling with disability (what's he/she like, functioning, any medical issues, etc)
- Have you ever had any medical issues?
- Tell me a little bit about where you grew up.
 - If applicable, how far are you from home (driving/flying)
- Tell me about your life right now
 - major/intended major
 - any activities/jobs
 - dating life (sexual orientation, in a relationship)
 - religious affiliation/identity, level of observance at school and at home
 - important pieces of you as a college student

2. What has it been like for you to have a sibling with a developmental disability [name of their sibling's disability will be used during the interviews]?

Possible sub-questions:

- What are some of your feelings about having a sibling with a developmental disability?
- What stands out for you about having a sibling with a disability?

3. There are a lot of things I'm interested in related to your college experience, including how you chose which school to attend.

Starting with the process of deciding to go to college and selecting a college - did having a sibling with a developmental disability play a part in that process? If so, how?

Possible sub-questions:

- Were your family's expectations about where you should go to college the

same as yours? If not, how were they different? What were your thoughts and feelings about that difference?

- Are you attending the college you wanted to attend? If no, why not?
- Where else (if applicable) did you apply? What factors contributed to your decision to go here?
- What made you want to go away to school/live at home for school? What factors influenced that decision (as appropriate) **ADDED 1/22/06**

4. When you began college, what was the transition like for you? What was it like to be away at school?

- What did you like? Dislike? Your experience, families, sibling's experiences.
- What do you like about the school you chose? **ADDED 2/25/06**

5. Has your daily life as a college student been influenced by having a sibling with a developmental disability? If so, how? Can you give an example of....

Possible sub-questions:

- Have any academic aspects been influenced? If so, in what ways?
- Has there been anything classmates or professors have said or done in class that has affected you, either by hurting you or affirming you? If so, in what ways?
- Has your involvement in any out-of-class activities been influenced? If so, how?
- Have there been any shifts in your responsibilities with your family? If so, describe how your responsibilities have shifted.

6. Have you ever done any projects/papers etc. related to your sibling or disabilities? Did you write at all about your sibling in your application essay(s)? If so, what did you talk about? For classes, have you ever done any presentations? If so, what was the reaction like from classmates or professors? **ADDED 2/25/06**

7. Do you talk about your sibling with your friends or classmates? Why/Why not?

Possible sub-questions:

- How do you decide when/if you talk about your sibling?
- How do you view yourself in comparison to your friends and classmates?
- Have any friends or classmates reacted in a way that stands out for you? What kinds of reactions have they had? How do their reactions affect you?
- Do you know any other siblings on your campus? If yes, what is it like to know another sibling on your campus?

8. Does the fact that you have a sibling with a disability influence your dating life? If so, how?
9. Have you ever participated in any sibling support activities? Why/Why not? If so, what were they like? Have you ever heard of SibNet (if 1st interview). Prior to receiving the resource sheet, had you ever heard of SibNet? Have you ever subscribed and/or participated in the listserv? **ADDED 2/25/06**

Second, Third, and Possible Fourth Interviews

1. Was there anything on the transcript of the last interview that stuck out for you?
2. Is there anything you want to add to or change?
3. Since the last interview, are there any additional thoughts or ideas about what we talked about?

Potential Questions:

- *1. When you began college, what was the adjustment/transition like for your family (including sibling)?

Possible sub-questions:

- Since you began college, what has your relationship with your family been like? Have any of your thoughts or feelings about your sibling or family changed since you began college? Has there been any shift in how you view your sibling or family?
 - Have there been any changes have occurred since you began college?
 - Have there been any aspects of your college experience that have caused any conflict with your family?
2. Were there ever any financial stressors related to your sibling? **Added 11/17/05**
 - *If so, did this impact your life in any way? (Things you couldn't do, etc.)
 - * Any influence on college selection process? Did any financial constraints related to sibling restrict the amount of money your parents could contribute to college?
 3. How do you look at college? What is the purpose of going? What do you want to get out of it/think you should get out of it? What kind of experience do you think it should be/want it to be? Is it meeting your expectations so far? Is there anything you wanted to do in college that you haven't done yet? If so, why? **ADDED 2/25/06**
 4. How does having a sibling with a disability influence how you think about your future?

Possible topics for probes:

- Career
- Personal life
- Where you live
- What your life is like?

Have you talked with your parents about the future/plans for sibling's care? Do any of those plans influence you now, in college? How you think/plan for the future? **ADDED 2/25/06**

5. When you think about your identity, is being a sibling part of how you view yourself?

Possible sub-questions:

- Do you consider being a sibling part of your identity? If so, tell me about it.
- How does it compare to other aspects of your identity (gender, race, etc.)?
- How has this changed since you were younger?
- How has this changed since you started college?
- Have a sibling VS. Being a sibling?

6. Are there any aspects of your college experience that might be different if you didn't have a sibling with a developmental disability? If so, what aspects and how do you think they might be different?

Are there any aspects that might be the same? If so, what aspects?

7. How would you compare you compare your college experience to your friends/classmates who don't have a sibling with a disability? Do you feel that having a sibling makes your college experience unique in any way? **Added 4/19/06**

*8. Do you have any advice that you would give to high schools students or other college students with a sibling with a disability?

How about any advice for the parents of a high school or college students with a sibling with a disability?

Alternate question for students who have already graduated:

- Do you have any advice that you would you give to college students with a sibling with a disability?
- Now that you have been out of school for a little while, do you have any advice for graduating seniors with a sibling with a disability, advice that may be useful for the transition out of college?

9. Is there anything that you would like to change about your college experience as a sibling?

10. If there were any services or groups for siblings would you participate? Why/why not?

Possible sub-questions:

- What should be a part of those services or groups?
- What should the people on campus (faculty, administrative staff, coaches, etc.) know about siblings?
- What do you think siblings in college need?

*11. Is there anything about having a sibling with a disability that you might not have thought about prior to this interview process? **Added 4/20/06**

*12. Is there anything else you think I should know to better understand your experience of having a sibling with a disability or about you as college student? **Added 4/20/06**

13. Is there anything you wanted to discuss that we haven't talked about or anything you wanted to share that I didn't ask about? Anything you expected to discuss that we didn't? **Added 4/20/06**

*14. Is there anything you would like to ask me? **Added 4/20/06**

* Questions were adapted from Charmaz (2002).

Appendix G

List of Focused Codes

Academic work (papers & projects)
Academics and Learning
Academics/Classes influencing self in positive way
Accepting sib's differences/Accepting reality of sibship
Achieving what sib can't
Admissions Essays
Advice
Alcohol/Drugs/Partying
All that I know
Always in the background
Appreciation
Awareness of others' needs
Being away gives new perspective on family
Being different
Being Responsible/Being the helper
Career – Helping People/Advocating for People
Caretaking responsibilities
Choosing friends who are accepting
Close to family
Closer to family than peers
College Selection Process: General
College Selection: Distance as a factor
College Selection: Influence of family and sibling
College Selection: Minimal pressure from parents
Communication with family & sibling
Compassion/Understanding/Sympathetic/Caring
Confronting others about language use
Dating/Relationships
Disappointing Sib/"Leaving them behind"
Diversity/Tolerance/Understanding of differences
Down Syndrome and standards of normality
Everyone has family/sib issues
Feelings about sibling/sibship
Friendships
Hope & Faith
How college would be different without sib – Friendships

I didn't know anything else
Influence on career
Influence on major
Influencing out of class activities
Inverted birth order
Job/Activity related to disability
Lessons Learned
Liking being different
Logistical & Family life limitations
Maturity
Missing traditional aspects of sibship/Things lost
Money not an influence
Negative/Difficult aspects of sibship
No influence on career
No influence on major
No influence on study abroad
No sibling related disagreements with parents while in college
No whining
Not being different
Others learn lessons in different ways
Outlook on life
Patience
Perseverance
Positive aspects of sibship
Reactions to words like "retard"
Relationship/Closeness with sibling
Religion/Faith/Spirituality
Sib upset by discussions of college/future
Sib's understanding of college/Having to explain college
Sibling as identity
Sibling support services [more for implications for practice]
Sibship an advantage in career
Sibship an advantage in classes/major
Sibship helps classmates
Social life at school
Talk to other siblings (within family)
Talking to other siblings/Disability as a connection
Talking/sharing about sibling (Disclosure)
Thoughts about future planning
Time in hospitals

Transition to college (for family)
Transition to college (for self)
Understand or see family/sib in a better or new way
Visits from family
Visits home
Wouldn't change anything

Appendix H
Inquiry Auditor Letter

Jennifer Weisman
78-2 Lyman Street
Waltham, MA 02452

March 14, 2007

Dear Jennifer:

It was a pleasure to be able to serve as the auditor to your doctoral research study. Having read your participants' transcripts; reviewed your core category, key categories and the relationships among the categories; and reviewed your grounded theory model, I can attest that your theory is based on the narratives of your participants, as they shared their stories with you during their interviews. Your theory gives a voice to students who have siblings with developmental disabilities and sheds light on how their experiences and development are influenced by their unique situation, especially during college. You should be extremely proud of your work and the contribution it will make to literature and the field. Congratulations on an outstanding project!

Best Regards,

Zaneeta E. Daver
James E Scott National Academy for Leadership and Executive Effectiveness

Appendix I

Resource List for Siblings

Online Resources

The Sibling Support Project of the Arc of the United States

<http://www.thearc.org/siblingsupport/>

SibNet, an online listserv for people with siblings with special needs. Direct link to sign-up for SibNet:

<http://www.thearc.org/siblingsupport/sibnet-listserv>

Family Village, A global community of disability-related resources

<http://www.familyvillage.wisc.edu/index.htmlx>

Rehabilitation Research and Training Center on Aging with Developmental Disabilities, University of Illinois at Chicago, offers resources and publications on family planning for caregiving

<http://www.uic.edu/orgs/rrtcamr/>

A bibliography of information related to siblings of people with disabilities, from the Center for Disability Information and Referral (CeDIR), Indiana Institute on Disability and Community, *Indiana's University Center for Excellence on Disabilities*

<http://www.iidc.indiana.edu/cedir/sibbib.html>

Books

Karasik, P., & Karasik, J. (2003). *The ride together: A brother and sister's memoir of autism in the family*. New York: Washington Square Press.

Meyer, D. J. (Ed.). (2005). *The sibling slam book: What it's really like to have a brother or sister with special needs*. Bethesda, MD: Woodbine.

McHugh, M. (2003). *Special siblings: Growing up with someone with a disability* (revised ed.). Baltimore: Paul H. Brookes.

Safer, J. (2002). *The normal one: Life with a difficult or damaged sibling*. New York: Free Press.

Simon, R. (2002). *Riding the bus with my sister: A true life journey*. New York: Houghton Mifflin.

Strohm, K. (2005). *Being the other one: Growing up with a brother or sister who has special needs*. Boston: Shambhala.

Local Resources

The Arc of Massachusetts, A state-wide organization representing the needs of individuals with developmental disabilities. Includes an extensive list of resources for individuals with developmental disabilities and their families as well as links to local chapters of Arc for support and advocacy resources.

<http://www.arcmass.org/index.htm>

New England Information on Disabilities Exchange, a comprehensive index of information helpful for people with disabilities and their families. The site also contains fact sheets and links to a variety of services and programs.

<http://www.disabilityinfo.org/>

Autism Resource Center of Central Massachusetts, Offers services for parents & siblings

<http://www.communitygateway.org/local/autism.htm>

For additional resources or questions, please contact Jennifer Weisman at siblingstudy@gmail.com or 617-780-5136.

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