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Sarah M. Rigney
Inextricably Intertwined: An
Exploration of Identity
Development in Adults with
a Disabled Sibling

ABSTRACT

This study sought to answer the question “What is the long-term impact on the identity formation of adults who grew up with a disabled sibling?” The bulk of literature exploring the impact of a sibling’s disability on his/her non-disabled sibling focuses primarily on children. With so few studies asking non-disabled adult siblings about their experience, however, the research examining this unique relationship lacks depth and scope. In exploring this relationship through an adult lens, there were two primary hypotheses: 1) non-disabled siblings would report having an experience that was rich with both rewards and challenges, and 2) this relationship would have indelibly shaped their self concept and their identity.

The study took a qualitative, exploratory approach. The researcher interviewed twelve participants, two men and ten women between the ages of 21 and 58. Their sibling’s disabilities covered a range of diagnoses from autism to Down Syndrome to spina bifida. Seven of the participant’s siblings were identified as being significantly to severely disabled and four of the DS were identified as being moderately disabled.

There were several findings of the study which were divided into eight major categories. Some of these categories touched on how and when participants obtained knowledge of their sibling’s disability and the relevance of this knowledge. It also explored each participant’s perception of how their sibling’s disability shaped their sense

of self, others, and the world. These findings highlighted the formative nature of this relationship and the role of disability therein, on adult siblings' identities.

INEXTRICABLY INTERTWINED: AN EXPLORATION OF IDENTITY
DEVELOPMENT IN ADULTS WITH A DISABLED SIBLING

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

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2009

ACKNOWLEDGEMENTS

This thesis could not have been completed without the help of several people whose contributions I gratefully acknowledge. Thank you to my participants: your stories were rich with love, hardship and brilliance. To Dana: for your keen insight, critical thinking, and positive attitude. To Lindsay: for your constant support, patience, cheerleading, and coffee-making over the course of this year. And to my family: I am who I am because of you.

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CHAPTER I

INTRODUCTION

Within the family system, the sibling relationship is inimitable; it is “unique among close human relationships by virtue of its long duration and also because participants share a common genetic and social heritage, a common cultural milieu, and common early experiences with family” (Goetting, 2008, p. 703). Studies examining siblingship have explored how rivalry, age difference, gender, and birth order alter sibling dynamics and, therefore, a child’s burgeoning sense of self. But what happens when this relationship is altered by the presence of disability?

There has been an increasing amount of information generated over the last two decades which examines this exact question. Initially, most research focused on the disabled child. Consequently, a substantial literature base exists around specific disabilities, community resources, risk and protective factors, school-based support, effective parenting techniques and more. It was not until later that researchers considered the impact of disability on the non-disabled child (NDC).^{*} Early research that examined how a sibling’s disability affected the NDC hypothesized that it had a negative impact, and subsequent studies seemed to “prove” that NDC were a population at risk for pathological depression and anxiety (Grissom & Borkowski, 2002).

^{*} Throughout this paper, NDC (non-disabled child[ren]) will automatically represent that child in the sibling dyad who is not disabled. DS (disabled sibling) will refer to the disabled child with whom the NDC interacts.

In their article entitled “Invisible children? The need for support groups for siblings of disabled children,” Naylor and Prescott (2004) describe how these early research efforts identified the ways in which both disabled children and their non-disabled siblings were socially marginalized, the former by non-inclusive social policies, and the latter through the lack of resources that understood and supported all members of a family in which one person was disabled - particularly the non-disabled, or “well” sibling. Implicit within that framework was the idea that the siblings of disabled children grow up unseen by those around them, lost within family, school, and community systems as a result of stresses induced by their sibling’s special needs.

The focus of research has shifted, however. In the last two decades studies began to counter the assumption that a sibling’s disability automatically negatively impacted the NDC by exploring the ways in which NDC have a “both-and” experience where they encounter challenges related specifically to their sibling’s disability and how they make positive meaning of the unique qualities of this relationship. What the literature has failed to capture in greater depth is how this complex relationship shapes the NDCs identity and self-concept. Moreover, the majority of research has looked the child’s experience but not the adult’s, missing subsequent personal emotional and cognitive growth, and developmental change. While some studies on adults have begun to consider the latter, few also include and discuss the additional developmental tasks faced in supporting and helping the non-disabled sibling in adulthood, nor have they looked at the particular lens non-disabled siblings develop when their existence is so closely tied to another’s whose ability to be in or understand the world is different. Subsequently, the aim of this

qualitative study is to explore this topic using the question: "What is the long-term impact on the identity formation of adults who grew up with a disabled sibling?"

The sample for this study consisted of a total of twelve participants made up of adult men and women over the age of 18 who had a disabled sibling who was within 10 years of their age and with whom they had spent a minimum of 10 years growing up. Participants were interviewed about how the experience of growing up with a disabled sibling impacted their identity, including when and how they first knew their sibling was disabled; how their understanding of the disability and its effect on them changed over the course of time; the role their parents played while growing up, and if /how this also impacted the NDCs identity and self concept; how living with a disabled sibling shaped their view of the world, their relationships with others, and their view of themselves; the role, if any, of therapy in helping them sort out the ways in which this relationship affected them.

For the purposes of this study, "identity" refers to an individual's extrinsic experience of oneself as seen through one's views of the world and of others, and consisting of a person's subjective, anecdotal experience in one's familial and social environment. "Self-concept" is a more specific term that refers to the intrapsychic dimensions of an individual as seen in one's views, values, and beliefs about oneself as expressed explicitly through 1) self-ascribed roles; 2) occupation choice; and 3) self-description. These definitions were developed by the researcher and were not formulated using a specific theoretical lens. Finally, there exist several definitions for the term "disabled." In this study, a combination of the United States Congress' Developmental Disabilities Assistance and Bill of Rights Act (42 U.S.C. 6000 et seq.) definition of

disability and the United Nation's definition of the term "handicap" were used in order to screen participants and to create a common definition of "disability" that took into account degree of impairment. Within this definition cognitive impairments as well as psychiatric disabilities are included. However, for this study only participants whose siblings had cognitive but not psychiatric disabilities were included. This differentiation was made due to the limited scope of the study and the nature of psychiatric disabilities - i.e. they may go undiagnosed until late adolescence or early adulthood (Dew, Balandin, & Llewellyn, 2008). In addition, some studies suggest that there are pertinent differences between mental illness and physical or cognitive disabilities that may differently affect non-disabled siblings. For instance, in a study comparing mental illness to mental retardation Seltzer, Greenberg, Krauss, Gordon, & Judge (1997) found that adults of siblings suffering from mental illness had more negative experiences overall as a function of having to adapt to their sibling's mental health crises later in life as opposed to those siblings who grew up with a disabled brother or sister (cited in Dew et al., 2008). For these reasons, having a sibling with a psychiatric disability may result in a significantly different experience than those NDC whose siblings have cognitive or physical disabilities.

Going into this study, there were several hypotheses: 1) An exploration of this relationship from an adult's perspective would yield results that highlighted that which was challenging *and* rewarding about this unique sibling relationship, as opposed to one or the other. 2) NDC would describe the tendency to put others' needs before their own in both their personal and professional lives; 3) NDC would perceive themselves to embody the following characteristics: caring or sensitive, organized or controlled, high-

functioning - a “doer” who is used to doing well, and highly responsible, especially in their relationships with others; and 4) participants would describe experiencing higher-than-average stress, anger, frustration and/or resentment. These hypotheses are pertinent to the larger question being asked as they explore the ways in which one’s identity is formed and expressed.

Despite increasing attention given to NDC in recent years, few studies have explored how growing up with a disabled sibling impacts the long-term development and identity formation of the NDC. As a result, this study lends itself to various audiences: families, individuals (children and adults) who have a disabled sibling, family therapists, social workers/community mental health workers, and special education teachers. Within the field of social work, this topic and the populations it affects are entirely relevant, for the presence of a disabled family member affects the family unit as a whole, altering the nature and degree of interrelatedness between each member. The subsequent impact of this on one’s relationship to oneself - personally, emotionally, psychically – and to the world, cannot be ignored. Therefore, within the field of mental health, it behooves professionals to know about the various ways in which this relationship impacts non-disabled siblings in the moment and over time.

The question of “What is the long-term impact on the identity formation of adults who grew up with a disabled sibling?” will be examined in the context of the existing literature, with particular attention to: the language of disability; the nature of the sibling relationship, especially that between NDC-DS, and its evolution over time; the family and social dynamics that impact NDC; theories which explore the concept of identity formation; and, finally, practice interventions used to support NDC and their families.

The methodology chapter will outline the study design and methods for data collection and analysis, and will provide an overview of the study sample. The fourth chapter will share major findings of the study, and the fifth and final chapter will discuss these findings relative to each other and to the literature; it will also note limitations and implications of the study.

CHAPTER II

LITERATURE REVIEW

This study sought to answer the question: What is the long-term impact on the identity formation of adults who grew up with a disabled sibling? Early research on the “well” siblings of disabled children assumed that having a disabled sibling (DS) led to maladjustment in the non-disabled child (NDC); thus research focused on measuring the degree of degree of anxiety and depression experienced by NDC (Grissom & Borkowski, 2002; Levy-Wasser & Katz, 2004). Appropriately named the “maladjustment view” by Glidden (1993) (as cited by Grissom & Borkowski, 2002; Levy-Wasser & Katz, 2004), this assumption pathologized the family members of individuals with disabilities, “lead[ing] researchers in this field to design and utilize measures of psychopathology without recognition or measurement of potential benefits” in this singular sibling relationship (Grissom & Borkowski, 2002, p. 79). This spurred a new series of research that not only examined the potential positive effects of growing up with a disabled sibling but also explored how different variables altered this experience. Subsequent studies sought to answer the following questions: How did disability affect family dynamics, and therefore, how did it impact individual family members? Did gender, birth order, and age affect the NDC’s adjustment? How did family patterns or parenting styles indicate better or poorer adjustment? Did type or degree of disability alter the NDCs experience?

Intermittently, studies also took into account social factors such as socioeconomic status and, on the rare occasion, race and ethnicity.

Separating out any number of dependent variables has resulted in conflicting and obfuscating results. Non-disabled siblings of handicapped children are still perceived to be at greater risk for having significant adjustment difficulties (Fisman, Ellison, Gillis, Freeman, & Wolf, 1996; Giallo & Gavidia-Payne, 2006; Naylor & Prescott, 2004; Opperman & Alant, 2003; Rossiter & Sharpe, 2002; Sharpe & Rossiter, 2001;), however more studies recognize and account for the possibility that this particular sibling relationship may also have positive attributes. Thus, this research is not for naught; disability, as one of many factors, is a pertinent, influential factor in shaping the life of a family and its individual members. The variability of the literature in fact highlights the range of experiences that NDC have and the incredibly complexity that disability brings to a family's dynamic.

NDC, in particular, as a result of their proximity to their disabled sibling and because of the nature of the sibling relationship, experience disability in ways formative to their development. While most of the research on NDC supports the notion that having a disabled sibling alters the experience of the NDC in both positive and negative ways and that there are several variables at play, most only hint at potential rather than explicit long-term effects of growing up with a disabled sibling (Fisman et al., 1996; Giallo & Gavidia-Payne, 2006; Lobato, Kao, & Plante, 2005; Naylor & Prescott, 2004; Opperman & Alant, 2003; Sharpe & Rossiter, 2001). Similarly, few studies exist that ask adults about this formative experience, and this represents a significant gap in the literature. A recent review by Dew, Balandin, & Llewellyn (2008), in which the authors

investigated 21 empirical studies that discussed the psychosocial impact on siblings of people with lifelong physical disabilities, found that only four of twenty-one focused on adults (defined as those 19 years old and over) – and only after researchers expanded their definition of disability in order to account for an adult population at all. “This overrepresentation of studies with children highlights a lack of knowledge about the experiences of adult siblings . . . and includes a lack of information on how the psychosocial impact of disability in childhood affects the adult sibling relationship” (Dew et al., 2008, p.495). Researchers clearly agree that having a disabled sibling is an important factor in the lives of non-disabled siblings. However, there is a shocking dearth of information about the actual long-term effects of growing up with a disabled sibling.

Research that does study the adult population explores a range of topics: why NDC tend to go into helping fields (Marks, Matson, & Barraza, 2005) or how this relationship is different from other sibling relationships (Begun, 1989). Some have even sought to measure ways in which the non-disabled sibling’s self-esteem has been affected (Burton & Parks, 1994). However, few have asked about and examined the ways in which adult non-disabled siblings identity is effectively shaped within the context of this relationship, and what this process may look like over time. This study will explore these facets and, subsequently, the impact of this relationship on one’s relationship to oneself - personally, emotionally, psychically – and to the world.

This literature review attempts to flesh out the various aspects of the question being asked, namely: 1) what is meant by the term “disability,” how and why it is important to understand it in a social context, and how it affects the family system; 2) the

unique nature of the sibling relationship and its relevance to identity formation; 3) the importance of interviewing an adult population; 4) how identity can be understood from both a theoretical and clinical perspective; 5) how and why therapeutic interventions are pertinent for this population.

Disability

Disability was a concept loosely defined in many of the studies cited herein. It is a term with multiple definitions and social meanings. A “disability” can take many forms and have different etiologies: congenital birth defects of unknown origin and effect; cognitive, sensory and physical disabilities; learning challenges; emotional disturbances; chronic illnesses; and behavioral disorders. In each of these categories, the degree of impairment can vary from mild to severe. Surprisingly, some of the research included here named the types of disabilities studied but did not consider or account for the potential differences between them, for example how cerebral palsy manifests differently than Down syndrome (Caro & Derevensky, 1997; Dodd, 2004; Dyson, 1999; Giallo & Gavidia-Payne, 2008; Grissom & Borkowski, 2002). Still others accounted for differences between types of disability, but they did not take into consideration the degree of impairment within a type of disability, i.e. mild versus severe autism (Dew et al., 2008; Flaton, 2006; Giallo & Gavidia-Payne, 2006; Naylor & Prescott, 2004). Only a few studies noted and accounted for both of these factors (Davis & Salkin, 2005; Fisman, Wolf, Ellison, & Freeman, 2000; Rossiter & Sharpe, 2001; Sharpe & Rossiter, 2002). Part of the disagreement between studies has to do with conflicting data about whether these variables are of any significance, with some arguing that the presence of *any* disability is disruptive to the family system, and type and degree of disability are

secondary considerations (Dodd, 2004; Giallo & Gavidia-Payne, 2008; Orsmond & Seltzer, 2007). In their respective reviews of siblings of individuals with mental retardation and lifelong physical disabilities, Rossiter & Sharpe (2001) and Dew et al. (2008) also note this discrepancy in studies but explicitly state that both degree and type need to be further studied in order to better understand how they may affect interpersonal dynamics.

For the purposes of this study, “disability” is clearly defined using language from both the United Nations’ Human Rights Act (2007) and the United States Congress’ Developmental Disability and Bill of Rights Act (2003). It speaks to both type and degree of disability and is as follows:

[Disability refers to a severe, chronic condition present in (USC, 2003)] an individual 5 years of age or older that prevents said individual from performing an activity in the manner or within the range considered normal for that person, depending on age, sex, social and cultural factors (UN, 2007); such limitations are

- A. Attributable to a mental or physical impairment or combination of mental and physical impairments;
- B. Manifested before the individual attains age 22;
- C. Likely to continue indefinitely;
- D. Result in substantial functional limitations in three or more of the following areas of major life activity
 - a. Self-care;
 - b. Receptive and expressive language;
 - c. Learning;
 - d. Mobility;
 - e. Self-direction;
 - f. Capacity for independent living;
 - g. Economic self-sufficiency; and
- E. Reflect the individual's need for a combination and sequence of special, interdisciplinary, or generic services, supports, or other assistance that is of lifelong or extended duration and is individually planned and coordinated, except that such term, when applied to infants and young children means individuals from birth to age 5, inclusive, who have substantial developmental delay or specific congenital or acquired conditions with a high probability of resulting in developmental

disabilities if services are not provided. 42 United States Code §6001(8) (USC, 2003)

Of note in this definition is the use of the phrase “limits or prevents the fulfillment of a role that is normal, depending on age, sex, social and cultural factors,” taken from the United Nations definition of “handicap” (UN, 2007). The UN utilizes what is known as the social disability model, in which disability is seen not as a medical abnormality, pathological problem, or a character deficit but as a problem “result[ing from] the interaction between a person and his or her environment” (UN, 2007). By including this in its definition, the UN recognizes the prejudices and stereotypes associated with “disability,” which assume that there is a so-called “norm” against which one’s disability is “ab-normal” (Kaplan, 1998).

A norm, however, is a socially constructed notion. In most contexts, the terms “abnormal”, “dis-“ or “less-abled” are deficit-oriented and have pejorative connotations. In models such as the “medical model,” the disabled individual is “sick” and does not fit into society as it exists for the majority, who are able-bodied (Kaplan, 1998). Thus, to be *disabled* reflects a society in which environmental or attitudinal barriers exist that makes the individual who is differently-able “defective” (UN, 2007). In reality there exists in any given society a spectrum of people who are differently able. However, it is not within the scope of this thesis to address the Disability Movement, or how and why disability can be understood to be a social construction.

It is relevant, however, to note the way social attitudes about disability may affect the research used here, which appears to reflect a broader bias of disabilities being understood, perceived and treated as something negative or the disabled person as

deficient. This can be seen, for example, in how researchers first studying the NDC-DS relationship presumed it had a negative impact on the NDC. They looked for how NDC were “maladjusted” and “found” that NDC experienced guilt, isolation and resentment as a result of having a disabled sibling (Dodd, 2004; Grissom & Borkowski, 2002; Rossiter & Sharpe, 2001). It should be noted that, to date, only one of the studies utilized in this research mentions, let alone discusses, disability within a larger sociocultural framework (Davis & Salkin, 2005).

On a similar note, only one article of twenty-four mentions the need for studies to reflect more racial diversity in their study samples, noting that the impact of a sibling’s disability is “multifactorially determined” and that the familial and cultural significance placed on the sibling relationship could significantly alter the experience of the disability (Lobato et al., 2005, p. 627). The intersection of race and disability further illustrates why the latter must be kept in mind. Both are social constructs and have been imbued with the power to keep certain people separate from the larger population. Bank and Kahn (2007) cite Franklin, Franklin & Draper’s (2002) research which reported that higher numbers of African American and Latino children (versus European American children) are placed in special education classes, the former as a result of labeling, racism and poverty-related issues, and the latter due to language and cultural differences. When what is perceived to be a “disability” depends on the color of one’s skin and/or whether one is able to do things the same as the next person, then how society defines “disabled” must be reconsidered within the larger framework of how society is structured to better meet the needs of the status quo, as opposed to the diverse abilities of all people.

Social Stressors and Family Dynamics

While the focus of this study is on the sibling relationship, the latter does not exist in a vacuum. Just as there are a multiplicity of factors *within* the relationship that one must attend to in order to understand the influence of siblings on one another, so there are larger family dynamics and social stressors that impact how and why siblings interact and relate as they do. While a study attempting to capture all of these dynamics would be too unwieldy, it is important to understand the larger forces at play that may affect this relationship. Sibling relationships are important in influencing the emotional and social context in which a child grows up, and these skills are translatable to many different social situations throughout a person's life (Bank & Kahn, 2007; Brody, 1998; Cicirelli, 1995; Moser, Jones, Zaorski, Mirsalimi, & Luchner, 2005; Seligman & Darling, 2007). However, the family and how it functions impacts sibling dynamics. As Brody (1998) stated, "family members are part of an interactive, interdependent network in which behavior in one individual or subsystem affects the others" (p. 3).

What family factors mitigate or exacerbate the NDCs experience of growing up with a disabled sibling? Boyce et al. (1983), Fiese & Wamboldt (2000), and Turnbull & Ruef (1996) conducted studies that showed having a family routine is associated with stability and predicts healthy behavioral, social and academic outcomes in children (cited in Giallo & Gavidia-Payne, 2006). Families who know how to problem-solve and who also have clear, consistent communication also better manage the stress that accompanies having a disabled child (Giallo & Gavidia-Payne, 2006; Levy-Wasser & Katz, 2004; Opperman & Alant, 2003; Seligman & Darling, 2007). In addition, in families where parents discuss with their NDC the name, nature, etiology and communicability of the

disability affecting the NDCs sibling, NDC show more positive adjustment (Giallo & Gavidia-Payne, 2006; Opperman and Alant, 2003; Seligman & Darling, 2007). How parents interact with their children is also key: even-handed and conscientious parenting, especially of sibling disputes, improves the parent-child as well as the sibling relationship and promotes better adjustment (Giallo & Gavidia-Payne, 2006; Richmond, Stocker, & Rienks, 2005). Finally, the utilization of or engagement with “natural” support systems, e.g. immediate and extended family, peers, and social groups (such as religious communities), promotes better adjustment and a positive coping responses for adolescents with DSs (Opperman and Alant, 2003; Seligman & Darling, 2007).

Not surprisingly, families in which NDC demonstrate “negative adjustment” – i.e., higher anxiety, depression, acting out behaviors, social isolation, feelings of guilt and shame, low-self-esteem - often struggle with many of the above-stated qualities: the family lacks cohesion as a result of poor communication skills and problem-solving abilities, they have fewer internal and external resources upon which they can draw, and these families have more superficial knowledge of their sibling’s disability (Giallo & Gavidia-Payne, 2006; Opperman & Alant, 2003; Seligman & Darling, 2007). In addition, several studies have found that children, in general, have a more difficult time adjusting when they receive differential treatment, or they perceive that their parent favors one child over another. These dynamics contribute to feelings of difference, increased isolation and poorer peer relationships both in childhood and adolescence (Brody & Stoneman, 1994; Naylor & Prescott, 2004; Opperman & Alant, 2003; Richmond et al., 2005). Also, NDC have higher sensitivity to and lower thresholds for managing discord in families where parents experience higher marital tension and

personal stress (Dodd, 2004; Fisman et al., 2000; Giallo & Gavidia-Payne, 2003; Seligman & Darling, 2000). These facets are important to consider because, as Brody (1998) stated, the various dyads that exist within a family impact one another. Brody, Stoneman & McCoy (1992) reported that the positive or negative behavior between parents and their NDC tend to be replicated between the NDC and his or her DS (cited in Brody & Stoneman, 1994). They also went on to share that inter-parental conflict is positively linked to family conflict as well as to unequal, or differential, sibling treatment (as cited by Brody & Stoneman, 1994). Differential treatment by parents is connected to more negative externalizing behaviors and depression in children who receive less positive attention (Richmond et al., 2005).

The complicated interrelationships indicated herein highlight the challenges and limitations to studying the sibling relationship within the family system – there are simply too many factors to consider at once, any of which may have a significant (mediating or exacerbating) effect on the sibling relationship. This is also why caution must be taken when assuming, as initial studies did, that the NDC-DS relationship automatically results in negative adjustment of the NDC. No causal relationship between disability and poor adjustment has been demonstrated (Rossiter & Sharpe, 2001). Other limitations in the examination of the NDC-DS relationships can be found in the studies themselves. In addition to the limitations mentioned earlier, i.e. research that did not account for type or degree of disability, the studies included in this review are dominated by quantitative research that uses a variety of quantitative measures, varies in the collection and reporting of pertinent demographic data, and does not take into account sociocultural factors.

Flaton (2006), in his phenomenological study, was the only researcher to contest the overuse of quantitative studies to measure what is acknowledged to be a complex, individually subjective experience. As he wrote, “When investigators employ qualitative methods, inconsistencies [like those present in quantitative studies] need not be explained but, rather, are understood as part of the complexity of the individual subjective experience...” (p. 135). Flaton further cited Ellis and Flaherty (1992) who stated, “The aim of all qualitative researchers is exploration in order to understand, not solution or truth” (p. 136). Of the fourteen child and adolescent studies used in this literature review, nine were comprised of quantitative studies, two were analyses of the literature (one of which performed a quantitative integration of the literature), and three utilized a qualitative approach. In comparison, of the eight articles and three books on adult NDS, only two of these were strictly quantitative in nature whereas two involved mixed methods, and six involved extensive interviews (usually more than one), and one was a review of the literature.

Dew et al. (2008) and Rossiter and Sharpe (2001) noted in their respective literature reviews that using different measures in quantitative studies to assess the NDCs adjustment contributes to the variability of results in the field. Several studies also inconsistently included sibling dependent variables such as gender, birth order, age difference, and family size which clouds the available data in the field and prevents studies from being compiled and analyzed for these factors independently (Dew et al., 2008; Rossiter & Sharpe, 2002). Neither in the literature reviews nor in the majority of studies did researchers consider the relevance of developmental stage of their participants. In fact, of the twenty five studies examined, only four accounted for this as

a potential factor in the NDCs experience (Fisman et al., 2000; Grissom & Borkowski, 2002; Grossman, 1972; Opperman & Alant, 2003). Two more conducted longitudinal studies, thus considering the role of time as an influential factor in the NDCs experience (Begun, 1989; Caro & Derevensky, 1997), and one noted that, with age, NDC may have greater ability to reflect positively on their experiences growing up (Dew et al., 2008). Failure to consider time, developmental stage, gender, birth order, etc. as factors presumes that the sibling's disability is the primary reasons behind the NDC's positive or negative adjustment, as opposed to other factors.

Finally, who participates in these studies must be considered. One of the studies cited here used parents and teachers as the primary reporters to assess NDCs behaviors and emotions (Fisman et al., 2000) and many more use them as supplementary informers (Dodd, 2004; Giallo & Gavidia-Payne, 2006, 2008; Naylor & Prescott, 2004). As Dew et al. (2008) and Rossiter and Sharpe (2002) noted, however, parents – mothers, in particular - demonstrate a negative bias¹ in studies where they are asked to report their observations of their NDC. This contrasts sharply with those studies that do solicit information directly (and solely) from NDC and which indicate that NDC have much more positive experiences than reported by their parents (Burton & Parks, 1994; Caro & Derevensky, 2007; Grossman, 1972). In addition, one must consider that those families who participate in these and similar studies may do so because they have concerns about their child's adjustment (Giallo & Gavidia-Payne, 2006). They also have time to complete these studies and may have access to agencies or organizations that typically

¹ These studies hypothesize that parents experience significant feelings of guilt about having a disabled child, and that these feelings are then displaced onto the NDC and measured as internalized anxiety and depression, or externalized acting-out behaviors (Fisman et al., 2000).

connect researchers to participants. In other words, some families and agencies may have more resources in terms of money, access to programs and/or research capabilities than others which will produce a non-representative sample.

The lattermost point speaks to the fact that disability is just one of many factors that impact a family; there are several larger societal factors, such as socioeconomic status (SES), race and ethnicity, which can also significantly affect a family. While SES was inconsistently accounted for, when it was captured, families with lower SES regularly predicted poorer adjustment in NDC (Opperman & Alant, 2003; Seligman & Darling, 2007) except when mediated by positive family factors like cohesion, communication, structure and use of communal supports (Giallo & Gavidia-Payne, 2006). This must be studied further, however, as most of the participants in the studies cited came from primarily middle and upper class backgrounds. Regarding race, in the studies examined for this literature review only seven of twenty-five accounted for race in the study's demographics; of those who had actual participants of color (only six of the seven studies had at least one participant of color), the latter constituted 20% or less of those studied. None discussed the relationship between race and SES and, subsequently, to disability.

Park, Turnbull & Turnbull (2002) reported that 28% of children with disabilities live in families whose incomes fall below the federal poverty line (as cited in Seligman & Darling, 2007, p. 63). Edelman (1985) reported that 1 in 2 of those who live in poverty is African American compared to 1 in 5 European Americans living in poverty (as cited in Seligman & Darling, 2007, p.68). Poverty leads to poor prenatal care, malnutrition and, subsequently, higher rates of disability (Seligman & Darling, 2007). These are elements

that also heavily impact mothers' and fathers' ability to parent well, and a family's ability to access medical care, information, and community supports (Lobato, 1995; Seligman & Darling, 2007). Not only do *these* factors then mediate or exacerbate parental stress and NDCs adjustment, but they are factors that also impact an individual's sense of efficacy and personal identity (Bronfenbrenner, 1997, as cited by Rossiter & Sharpe, 2002; Miller & Garran, 2008). That these populations are significantly underrepresented in the literature only perpetuates the racism and labeling that leave them unaccounted for when discussing the role of disability within the family.

Latino families face similar sociocultural problems such as lower SES, but they also more often contend with immigration status and language barriers that contribute to disproportionate rates of poverty, lower educational and occupational achievement, as well as poorer and limited access to health care (Lobato, 2005). Latino families also encounter higher rates of chronic illness and disability as compared to European Americans (Lobato, 2005).

In both Latino and African American families we see the impact that social constructions of race have on families and how this is both a source of the problem and a barrier to its solution. African American and Latino families have developed unique and resilient family and community cultures that emphasizes collectivism (or group responsibility for the individual), mutual-help patterns, and strong family ties that include relying on extended family and/or "fictive" kin (Boyd-Franklin, 2003; Lobato et al., 2005; Seligman & Darling, 2007). These relationships embody the concept of reciprocity, or "the process of helping each other and exchanging and sharing support as well as goods and services" (Boyd-Franklin, 2003). As a function of this, these families

may not seek outside help unless they are cut-off from their support system.

Simultaneously, the emphasis on the needs of the group de-emphasizes the individual needs of group members. Lobato (2005) states that “collectivism is associated with high levels of empathy and willingness to make personal sacrifices for the welfare of the group” (p. 625). In this atmosphere, it is likely that the experience of the NDC - not only of his sibling but also of *himself* - may, in fact, be very different as a function of his or her familial and ethnic culture.

The professional community’s lack of attention to and consideration of race and ethnicity as a potentially major variable in the NDC-DS relationship also highlights a major gap in the literature. The failure to consider, for instance, that Latino families emphasize sibling interdependence (versus autonomy, which is more typical in European American families), or that older siblings are expected to take care of younger siblings, and, socially, siblings are expected to be close companions (Lobato et al., 2005), suggests that the current studies are not completely accurate – *especially* when they stress the importance of mediating family factors. Within this cultural context, siblingship takes on different meanings, responsibilities, joys and, perhaps, burdens, but further research, that specifically explores the rich and varied life of families of color, is necessary to more fully understand this.

Siblingship

When first examining disability within the context of the family, Bank and Kahn (1986) initially focused primarily on the mother-disabled child relationship and Bowerman & Dobash (1974) looked at its impact on the marital relationship (both cited in Goetting, 1986). However, families are comprised of complex interpersonal processes

and characterized by different dyadic relationships, or subsystems, that affect one another (Brody 1998; Cicirelli, 1991). Just as family dynamics as a whole are important to consider when conceptualizing identity formation, the sibling relationship is also paramount when considering how and why people develop and are shaped.

Sibling relationships are often thought about in terms of rivalry (Cicirelli, 1991). However, they are also a source of pro-social interactions with the balance of both positive and conflictual relations serving to “create experiences that are most likely to nurture children’s social, cognitive and psychosocial development” as well as their personalities, and personal adjustment (Brody, 1998; Brody & Stoneman, 1992). This is due, in part, to the unique nature of the sibling relationship. It is typically the longest lasting relationship people experience over the course of their lifetime (Bank & Kahn, 1982; Brody, 1998; Cicirelli, 1991, 1995; Goetting, 1986; Richmond et al., 2005), with one study by Fitzpatrick and Badzinski (1994) estimating that 80% of individuals spend at least one-third of their lifetime with their siblings (cited in Rittenour et al., 2007). The sibling relationship is also characterized by a shared genetic heritage and a common cultural, social and emotional milieu (Bank & Kahn, 1997; Brody, 1998; Cicirelli, 1991, 1995; Goetting, 1986; Rittenour et al., 2007), even if the siblings do not share the same experiences within this milieu. Although the level of closeness between siblings can vary for different reasons and tends to fluctuate with major life events, it is important to note that studies prove that this relationship is unvaryingly and voluntarily maintained albeit it in looser form throughout adulthood (Bank & Kahn, 1997; Cicirelli, 1991, 1995; Goetting, 1986; Rittenour et al., 2007).

Can the same be said of the NDC-DS relationship? It is commonly accepted that the presence of disability in a family creates a unique stress on the family and its individual members. Within the family system, NDC are more likely to encounter the following situations than their peers who have healthy siblings: limited time and attention from parents, increased stress at home, social concerns (bringing friends home or being out in the community with their DS), restrictions on family activities, guilt about getting angry at their DS, feelings of protectiveness about their sibling, and concerns about the future (Dew et al., 2008; Dodd, 2004; Lobato, 1990; Rossiter & Sharpe, 2001; Sharpe & Rossiter, 2002). It is therefore reasonable to assume that the relationship between a disabled child and his or her sister or brother does not subscribe to some of the “norms” of a sibling relationship in which both people are not disabled, as described above.

Rittenour et al. (2007) posit that “sibling relationships focus on their shared family background and their allegiance to each other instead of psychological closeness, acceptance, and approval” (p.177), suggesting that the biological bond connecting siblings takes precedence over personal feelings or attitudes toward one another. Therefore, regardless of whether NDC have positive or negative feelings about their DS, they likely still feel connected to them. But are closeness, love, and intimacy the same and are they related? Lee, Mancini, & Maxwell (1990) examined the emotional closeness occurring in typical sibling relationships, defining “emotional closeness” as a “sense of shared experiences, trust, concern, and enjoyment of the relationship” (as cited by Rittenour et al., 2007, p. 172) and grown out of “participating in family functions, enduring family hardships, having common interests and experiencing age-related issues” (Rittenour et al., 2007, p. 172). This contrasts with Begun’s study (1989) in which she

determined that NDC feel close but not intimate with their DS, and that the relationship is different in terms of nurturance, admiration, and domination patterns. Dew, Balandin, Llewellyn (2008), Dew, Llewellyn, Balandin (2004), Grossman (1972), Orsmond & Seltzer (2007), Safer (2002), and Strohm (2005) further highlight that the *nature* of the NDC-DS relationship is different primarily because it is not reciprocal. The shared experiences, common interests and mutual enjoyment that Lee et al. (1990) and Rittenour et al. (2007) describe are not, in fact, part of the NDCs experience because the disability inhibits the kind of intimacy in which one feels deeply known.

The NDC-DS relationship also differs in that NDC often face developmental tasks that other sibling dyads do not. Opperman and Alant (2003) suggest how, in addition to the stress of the separating and individuating, adolescents are faced with the task of negotiating how their sibling's disability affects them in the social arena, and this can cause increased feelings of anxiety and elicit feelings of embarrassment, shame, and/or guilt. Davis & Salkin (2005), Safer (2002), and Strohm (2005) all share personal and collected stories of how NDC must also navigate stigma and social anxiety when out with their DS – a particularly stressful experience as an adolescent when one is especially concerned about peer perception, and when a DS is having an epileptic seizure or a behavioral outburst. Safer (2002) and Strohm (2005) share how this process for adolescents also elicited questions or concerns that they, too, would be perceived as being disabled or “different.” It is also typical that at this stage NDC may also be asked to take on additional caretaking roles such as babysitting their DS, an interesting dynamic when the NDC is close to or even younger than one's DS (Opperman & Alant, 2003).

Having a DS also affects one's interpersonal relationships and how one approaches major life cycle events beyond adolescence and into adulthood. The main participant of Flaton's study (2006), Anna, shared how a serious consideration in whether she could be in a long-term relationship with a man was whether or not he was prepared to have her brother, Danny, who had Down syndrome, be a fixture in their life together. In families where there are only two children, the NDC and the DS, the former usually takes care of aging parents alone and with no other siblings with whom they can commiserate (Goetting, 1986; Strohm, 2005). When their parents die, many NDC also have to take into consideration what is to become of their DS, oftentimes becoming the primary caretakers or guardians of their DS in place of their parents – a circumstance particular to the NDC-DS relationship (Davis & Salkin, 2005; Dew et al., 2004; Safer, 2002; Strohm, 2005). As the literature indicates, not only does siblingship in the NDC-DS dyad *feel* different, it has different characteristics by virtue of the tasks and experiences resulting from the disability – the long-term impact of which might be understood better from an adult perspective.

Adults

The bulk of these studies focus on the NDC-DS relationship in children, raise concerns, and discuss interventions, but what happens once these children grow up? How do they make meaning of this relationship and its impact on them? What these studies teach us is that there are a multitude of social, familial and interpersonal factors that affect this relationship and the NDC. They also suggest that this relationship is formative, but in what ways and how does one measure this?

Rossiter & Sharpe (2002) strongly emphasize and call for increased study of the adult population, stating that more positive experiences and psychological functioning may be found in adults siblings, which “would provide a more balanced perspective to the literature and some comfort to the parents of siblings of children with mental retardation” (p. 78). Dew et al. (2008) echoed this after their review of the literature found only four studies on adults, even after they altered their definition of disability to include autism, Down syndrome, and mental illness. They stated that the “overrepresentation of studies with children highlights a lack of knowledge about the experiences of adult siblings of people with...disability. This includes a lack of information on how the psychosocial impact of disability in childhood affects the adult sibling relationship” (Dew et al., 2008, p.495).

Even if the results of childhood studies have produced varied results, what is consistent in the literature is the search to better understand the importance of this particular relationship on the behavioral, emotional, social, and psychological development of the NDC. That there are too few studies asking children about their experiences firsthand or interviewing adults to reflect on both their childhood and adult experience of this relationship highlights a gap in the literature. Certainly, more studies focusing on the child’s *in vivo* experience will help researchers better understand the variables at play. However, studying adults allows for a more comprehensive, in-depth understanding of this relationship. As Flaton (2006) wrote:

In examining the experience from an adult sibling’ perspective, we might gain insight into the effect on an individual’s entire life, not only their childhood. Because adults generally possess greater self-knowledge, skills and abilities than do children or adolescents, they are often able to reflect upon formative experiences with a fuller understanding of how having a sibling with [a disability]

influenced and had an impact upon the context of their own development throughout childhood and adulthood (p.136).

So what *do* studies in which the adult population is interviewed or assessed tell us about the nature and impact of this relationship on the non-disabled sisters and brothers of individuals with disabilities?

Adult participants provide a wide range of experiences that can be described as positive and negative, rewarding and challenging. What stands out is that, as adults, the accounts that are “negative” are those they ascribe to the past, when they were younger. In contrast, qualitative and quantitative studies indicate that adult participants, in describing how this relationship *currently* affects them, talk about what they took from the experience and speak of these attributes in positive terms (Dew et al., 2008). For example, an early study by Grossman (1972) in which college students were interviewed, reported that participants felt they had greater understanding of people, more tolerance and compassion towards people in general, a heightened awareness of the consequences of prejudice, an appreciation of their own good health and intelligence, and a feeling that the experience had resulted in closer family ties. A later study by Burton & Parks (1994) also looked at college-aged siblings of disabled individuals but examined self-esteem, locus of control and career aspirations, specifically. They reported similar results as Grossman (1972), adding that participants stated that their (disabled) siblings helped them to “be more responsible, be more tolerant, better able to see the good in others, develop a better sense of humor, and be more flexible” (p. 182). Having used a control group in their study, Burton & Parks (1994) also identified that there was no difference in self-esteem between those who grew up with or without a DS. The participants with

disabled siblings did, however, exhibit a significantly higher internal locus of control, with researchers suggesting a possible connection between psychological strength and having grown up with a DS. In addition, in Burton and Park's study (1994) as well as that by Marks et al. (2005), a higher proportion of NDC went into helping professions, signifying how influential this relationship was in their own lives. Finally, a longitudinal study by Begun (1989) captured sibling relationships that spanned a lifetime (46 participants were between 12-69 years of age) and measured the qualitative aspects of their relationship: nurturance, competition, intimacy and satisfaction. Overall, participants again reported having positive relationships although Begun (1989) noted that the relationships described were non-intimate and less competitive.

These adult studies reveal that the nature of this relationship is different from siblings relationships in which both people are not disabled. At the same time, these differences do not produce a polarized experience of *either* good *or* bad, but have the potential to be both and everything in between. It is more accurate to say that growing up with a disabled sibling often entails dealing with feelings that exist on a spectrum ranging from painful to frustrating, embarrassing, funny, joyful, and blessed, and the context of these experiences is heavily impacted by the presence of disability. How this then impacts the NDC, particularly his/her identity, may be better understood from the theoretical standpoint of attachment.

Contemporary Relational and Identity Theory

What can be difficult to articulate, let alone categorize and generalize in the form of empirical data, is how one's relationship to another shapes one's identity. Child-focused studies primarily focused on quantitatively measuring the positive or negative

adjustment of NDC, but for what purpose? The unspoken premise underscoring these studies is that these able-bodied, able-minded children will be forever impacted by this relationship over the course of their life. In other words, *who* they are and *how* they enact this sense of identity through their behaviors, emotional expression, relationships, and career choices will be informed by having a disabled brother or sister.

The literature base around the nature and characteristics of the sibling relationship is expanding, however there is little in the way of theory that offers explanations as to *why* this relationship has the potential to have such a powerful impact on oneself and one's identity formation. What is undeniable, however, is that this relationship *is* different from others both as a function of time and by its nature. It was the hypothesis of this study that, by virtue of these characteristics, siblingship is formative to one's identity. The NDC-DS relationship, a type of sibling relationship with its own particular characteristics, is similarly influential but in ways that reflect the dynamic of disability.

One's context, one's world is in part constructed by and through one's relationship with others such that one's view of another is integrated into one's identity, and certain pieces are "inextricably intertwined" (Seligman & Shanok, 1995); in this case, we are discussing a specific "other": one's sibling. Siblings play a multiplicity of roles in each other's lives (Coles, 1998). Brothers and sisters are both caretakers and peers, playmates and companions, confidantes and rivals, people from whom one attempts to differentiate and, simultaneously, uses as a model for socialization.

Cicirelli (1995) also emphasized the relational security and support afforded by siblings throughout the lifespan. The nature of the sibling relationship – the proximity of siblings in the shared family environment, the longevity of the relationship, the nature of

the interactions typically experienced by and between siblings from an early age up until one's death – suggest that the circumstances are ripe for one sibling to significantly influence the other's identity and self-concept as they have been defined in this study. Indeed, Kahn (1988) describes siblings' tendency to “carry frozen impressions of each other throughout life; [these] simplifications and representations of one another as ‘good,’ ‘bad,’ ‘unreliable,’ ‘loyal,’ ‘fair,’ and so on and so forth, are often psychological mooring points against which each child forms his or her own self-representations” (cited in Moser, Jones, Zaorski, Mirsalimi, & Luchner, 2005, p. 10). Such representations – of the self and another – are not the result of just any relationship; they are only formed in the context of the closest and most substantive relationships.

By viewing the sibling relationship through the lens of certain aspects of Erikson's identity concept as well as contemporary relational theory, we may better understand why this particular relationship has the potential to be so formative. In their article discussing these two theories, Seligman and Shanok (1995) interweave Erikson's lifespan perspective on development and considerations of sociocultural, or environmental influences, with relational theory's emphasis on the relationship between the “self and the other, the past and the present, internal and external processes and representation and ‘reality’” (p. 542). In doing so, they capture how personal experience, and the formation of one's identity, is “created and re-created at the threshold of the intrapsychic and the social, such that they are inextricable” (p. 537).

Identity Over Time

Erikson's theory incorporated two important ideas relevant to this study: 1) the individual's identity is not fixed in childhood but unfolds over the course of one's

lifespan and is informed by developmental tasks that characterize different life stages; 2) identity development is not solely an intrapsychic process but is fostered by one's social and cultural environment (Berzoff, Flanagan, & Hertz, 2004). Though not the first theorist to conceptualize development as a series of stages, Erikson was one of the first to recognize that people continue to grow, change, and develop past adolescence. "The Eight Ages of Man" (1950) outlines the eight major stages that people go through over the course of their lifespan, with each stage comprised of an age-specific crisis or concern which they must then navigate (Berzoff et al., 2004). In the process of doing so, they are engaged in an interaction that informs their intrapsychic experience. Erikson's conceptualization of time as both a mitigating factor and a catalyst for change in one's identity development parallels Goetting's (1986) later discussion of the developmental tasks of siblingship over the life cycle, although Goetting does not discuss her findings within a specific theoretical framework. Goetting (1986) recognizes the sibling relationship as one that is "unique and influential" (p.703) and, similar to Erikson, describes how siblings' interactions with one another have certain characteristics at given stages over the course of the life cycle.

Erikson also believed that the development of one's identity was not a solely an intrapsychic process, but that interactions with and exposure to factors external to oneself also inform one's identity; these "social relationships and social institutions foster or hinder ego development throughout [one's] life span" (Berzoff et al., 2002). Seligman and Shanok (1995) also iterate this by describing Erikson's identity concept as a process that was both synthetic and integrative in nature, for it combined that which happened "within the psyche and in the individual's relationship to "reality" and the social world"

(p. 540). Both of these concepts are supported by research exploring how different family dynamics can have mediating or exacerbating effects on the NDCs experience and subsequent development.

How then do these factors - time and the individual's relationships with others - then inform one's identity? Drawing on Benjamin (1988), Bollas (1987), Hegel (1907), Mitchell (1991), and Shanok (1981, 1987, 1983), Seligman and Shanok (1995) state that "the sense of self is inextricable from the awareness of the "otherness" of others; that is, it is not possible to experience individuality without a sense of the dialectical tension between separateness and connectedness" (p. 543). An individual's identity does not remain fixed and static throughout one's life, and it does not develop in a vacuum; rather, it grows, shifts and is shaped in relation to one's immediate world and relationships with important life figures.

The Individual in a Social Context: Self and Other

As defined by Seligman and Shanok (1995), identity is:

both a capacity to sustain and an experience of the simultaneity of separateness and relatedness as dynamically intertwined elements of intersubjective experience.... It is impossible to imagine an individual's self-experience without actual others in whose presence the self is experienced: who you are has to do with whom you are with. (p. 546-7)

The emphasis here is on the intimate connection that occurs between an individual and another, and how this connection informs one's self-concept as well as one's identity. It is in the context of intimate, substantive relationships that the individual begins to organize one's ideas about oneself and one's views of the world. Through a relationship one feels connected; this is the "mooring point" of which Kahn (1986) spoke and from which one is able to separate and individuate. The dynamic tension inherent in

separating out that which is “me” versus that which is “other” while simultaneously knowing that there is no “me” without “another” is what allows for the creation of identity.

As one’s relationship to another changes and grows over time, so then does one’s identity. The elements of time and intimacy, self and other are intertwined. It is through one’s relationship to another that one takes on and then re-enacts the more elemental expressions of identity: the roles one takes on; the feelings, values, and beliefs one expresses; and the ways in which one interacts with others. These patterns of relating are rooted in one’s initial relationships and then play out over time. The sibling relationship, with its’ “long duration, ...[shared] genetic and social heritage, common cultural milieu” (Goetting, 1986), is such a relationship. Within the unique context of the NDC-DS relationship, however, the literature has shown that some dynamics may warrant individuals wanting or needing therapeutic interventions to better understand the full impact of this relationship in their lives.

Interventions

The concern generated by studies indicating that NDC were a population at risk for maladjustment led to a flurry of studies that examined how therapeutic interventions might alleviate or diminish this maladjustment. Though the larger question of this thesis looks at an adult population, a literature search on interventions for adults produced no results. In the absence of these, articles on children may provide insight into what types of issues adult clients might face, which interventions are effective, and which modalities might be most conducive to understanding, healing and reparation.

Both Dodd's (2004) and Naylor & Prescott's (2004) results showed that NDC have both positive and negative feelings about their DS, ranging from NDC taking enjoyment in and expressing happiness about their disabled sibling, to feelings of increased responsibility, isolation and the recognition that they (the NDC) receive less attention than their disabled sibling. Naylor & Prescott (2004) state clearly, that these experiences lead to "a clear impact on that part of their identity concerning who they are in relation to their disabled sibling" (p. 202-204). Both studies found that one particular modality - group work - allowed these children to openly admit to and discuss these conflictual feelings. "Permission" to share these experiences and emotions promoted increased self-esteem, allowed for greater understanding about the DS (and therefore caused less stress), and facilitated better interactions with the disabled sibling at home (Dodd, 2004; Giallo and Gavidia-Payne, 2006; Naylor & Prescott, 2004).

Giallo & Gavidia-Payne (2008) discuss the findings of similar group studies but note several deficits to the group model, such as: its recreational model indirectly and incidentally provides psychoeducation about disability and illness; as many groups function as the coping mechanism, they fail to teach more individualized coping skills that can be carried outside of the group setting; and, finally, groups focus on the NDC but do not address larger, systemic (family) issues, which often directly influence the NDC's adjustment (Brody & Stoneman, 1994; Giallo & Gavidia-Payne, 2003; Levy-Wasser & Katz, 2004; Lobato, 2005; Opperman & Alant, 2003; Richmond et al., 2005). Based on this assessment, Giallo & Gavidia-Payne (2008) conducted a family-based psycho-educational intervention with some positive and notable results, suggesting that family interventions are effective. Fisman et al. (2000) also cited literature that related NDC

negative adjustment to lower family functioning and higher incidents of parental stress, suggesting that future interventions be addressed via the family or in its various dyadic compositions.

What might we anticipate of adult clients who grew up with a disabled sibling? Any sibling relationship has dynamics that may need to be worked out in therapy, as sibling's – regardless of whether they are disabled or not - are important characters in one's life story.

Brothers and sisters develop patterns of love and hate, care and abuse, and loyalty and betrayal. There are power struggles . . . interdependencies, role experiments, and divisions of emotional and instrumental labor. All of these will shape future adult functioning, perceptions, expectations, self-care, and self-worth (Moser et al., 2005, p. 267-8). In other words, here is where many people directly learn some of the basics about who they are – or dare not to be – as individuals, partners, parents, and peers. (Watanabe-Hammond, 1994, cited in Moser et al., 2005, p. 267-8)

As Moser et al. so aptly capture, the sibling relationship is rife with issues to be played out in an individual's emotions, behaviors, feelings of self efficacy, perceptions of self, and relationships with others. When disability figures into the sibling relationship, it, too, needs to be addressed. Kate Strohm (2005) recounts participating in years of therapy in which her relationship with her sister's disability – how it affected their relationship, how it altered her father and mother's ability to parent more or less equally to both children, how she took on particular roles as a way of “compensating” for her sister's disability - never came up. Thus she found herself continuing to struggle with thoughts and feelings about herself that she'd internalized as a result of this relationship and the role of disability in it.

Different modalities may be useful in different ways for adults. Because there is no literature on this topic, the forms therapy might take and the benefits adults of DS may glean from therapy are only speculative. Based on children's reports and anecdotal evidence, however, it seems clear that therapy as tool for making meaning of the NDC-DS relationship or better understanding one's identity in relation to one's sibling and, particularly, to the disability and its role in the family, would likely be very powerful. In future research, it will also be important to consider sociocultural and economic factors when exploring the types of interventions that are helpful for children and adults who have disabled siblings. As stated earlier, some people may prefer to use self-identified supports that are more culturally fitting. They may also come from support systems that do not necessarily welcome outside interventions or which emphasize utilizing religious or personal resources over professional ones (Bank & Kahn, 2007). Some adults may also face economic or language barriers that prohibit them from seeking the support that they need and want.

Summary

What is the long-term impact on the identity formation of adults who grew up with a disabled sibling? This literature review examined various aspects of this question by first outlining the background research on NDC, which initially defined the NDC-DS relationship as one that resulted in maladjustment on the part of the NDC. It then incorporated new literature that showed how NDC have a diversity of experiences with their DS, but then critiqued how this literature failed to explore the impact of this relationship on NDC through various stages of the NDCs growth and development. The review then looked at the language used in the question: "disability", "adult", "identity

formation” and considered what these terms mean in the context of the NDC-DS relationship, taking into account the myriad factors that also impact this relationship – e.g. family dynamics, race, class. Finally, it explored the theoretical tenets of identity formation from the perspective of Erikson’s identity concept and contemporary relational theories. Subsequent chapters will delve into the specifics of this study: the methodology and sample, findings, ending with a discussion of the results.

CHAPTER III

METHODOLOGY

This study was an attempt to answer the question: What is the long-term impact on the identity formation of adults who grew up with a disabled sibling? In order to explore in depth the phenomena of identity from the participants' point of view, a qualitative design was utilized and flexible methods employed (Anastas, 1999). Available theories and literature were used to create a qualitative interview tool, the first part of which consisted of a 15 point questionnaire that captured demographic information (SES, race, ethnicity, gender, etc.) (Appendix A). The second portion consisted of a semi-structured interview guide comprised of 21 open-ended questions (Appendix B). The latter allowed all twelve participants to share a range of experiences that, in their narrative form, were rich with each individual's unique perspective. The data derived from the open ended questions were coded and grouped into themes. The findings represent the major themes which emerged from the data.

Sample

This study used a non-probability sampling process in which participants were self selected through snowball sampling (Anastas, 1999). Participants were recruited using word of mouth and the internet. Specifically, friends, family members, and colleagues were approached and provided with the inclusion criteria for this study (listed below) in order to assist in recruitment. A posting (Appendix C) describing the study and listing the inclusion criteria was also placed on the SibNet website, a home-base for

people with disabled siblings to chat or identify local resources. Local agencies, identified by their work with disabled individuals and their families, were contacted via phone to ascertain their willingness to post recruitment flyers. After receiving agency consent, verbally or in writing (by email), a recruitment poster (Appendix D) with the study's information was sent to these agencies. Potential participants, who were self-selected, initiated phone or email contact with the researcher indicating their interest in participating in the study. Potential participants were screened over the phone or by email to ensure that they met the criteria for the study and to be informed of the purpose and nature of the study. Potential participants were informed of the minimal risks in taking part in the study, and, if eligible and interested, a mutually convenient time was arranged for the interview. Following this exchange, phone participants were sent a copy of the informed consent form via email. In-person participants received the informed consent prior to the interview.

Inclusion criteria for participants were: 1) Participants must speak English; 2) Participants must be full, biological siblings (not half or step-siblings) to their disabled sibling; 3) Participants must be within ten years of their DS's age; 4) Participants must have spent 10+ years growing up with their DS; 4) Participants must be 18 years of age or older; 5) Participants' siblings must also meet the aforementioned definition of "disability." There was minimal risk to participants taking part in this study.

The sample size for this study was twelve. All twelve participants identified as White, or Caucasian, and were of European descent. Two men and ten women between the ages of 21 and 58 participated in the study, with the median age being 32.5 years. One participant grew up in a lower-income family, seven in a middle-income family, and

four in an upper-middle income family. Five of the participants were both older than their DS and they were the oldest children in the family. Seven participants were younger than their DS and they were the youngest child in their household; there were no middle children in the study. Six of the participants had only one sibling, whereas the other six had two or more siblings. The age difference between the participants and their DS range from 1 to 9 years, the median being 2.875 years. In total, there were seven male disabled siblings and five female disabled siblings, five female-male sibling dyads, two male-male sibling dyads, and five female-female sibling dyads.

Three of the DS's had autism, and one had undiagnosed Asperger's, both of which are considered cognitive disabilities. Four DS had Down syndrome, one had trisomy p+14, one had Williams Syndrome, one had spina bifida, and one had traumatic brain injury, epilepsy and autism. As part of the demographic questionnaire, participants were asked to describe the degree of their sibling's disability using a likert scale. Seven of the DS were identified as being significantly to severely disabled, the latter of which was defined as being "entirely dependent on [the participant] and/or other family members for basic needs (eating, dressing, hygiene, etc.)." Four of the DS were identified as being moderately disabled, which was defined as "requir[ing] some assistance with day-to-day living activities but s/he was able to accomplish some things on her/his own." One of the DS was described as being mildly physically disabled, as defined as "he could do most things on his own and only required [the participant's] assistance as needed," but emotionally and socially was significantly disabled.

Data Collection

The original design for this study was approved by the Smith College School for Social Work Human Subjects Review Committee (Appendix E). A second submission was made in order to accommodate phone interviews and was also subsequently approved (Appendix F). Prior to the interview, phone participants were provided with the informed consent form (Appendix G), as well as the demographic questionnaire, via email to read, sign and date electronically. These forms were then sent back via email, along with a written statement confirming their willingness to participate in the study. Participants participating in an in-person interview were provided with a hard copy of the consent form to read, sign and date prior to filling out the demographic questionnaire and participating in the interview. The informed consent form outlined the purpose of this study, its risks and benefits, as well as inclusion criteria.

Data collection was accomplished in two parts: 1) through use of a short demographic questionnaire (Appendix A) that participants filled out after signing the informed consent form, and which inquired about a participant's age, race, and socioeconomic status, as well as the type and degree of disability of his/her sibling; 2) by participating in a semi-structured, one-on-one interview that lasted between 45-90 minutes (Appendix B). Half of the participants were interviewed in-person; the other half was interviewed over the phone. The latter approach was used in the hopes that it would allow for more diversity in the study. The primary difference noted between in-person and phone interviews was the presentation of subtle affect, e.g. when a participant became tearful or expressed sarcasm. These expressions were more noticeable in the in-person interviews where the researcher could both see and hear the affect, as opposed to

the phone interviews in which the researcher could only listen for explicit expressions of affect – i.e. laughter. Subsequently, it is likely that the researcher noticed and responded to these affective expressions in in-person interviews by asking follow-up questions. There were no noticeable differences noted by the researcher regarding length of phone vs. in-person interviews.

All interviews were audio taped in order to accurately capture the participant's words. They were then transcribed in full and coded for themes using content analysis. To increase reliability and validity, and to note any differences between interviewing participants in-person versus on the phone, the researcher intended to also make extensive field observations for the in-person interviews, which would have been cross-referenced with the participant's responses and would have served as additional data. Observations were to include non-verbal communication such as facial expressions, gestures, affect and tone of voice. Almost immediately this additional method was discarded as there was only one researcher conducting the study and she was unable to simultaneously conduct the interview, ask probing follow up questions, and take detailed notes on participants' nonverbal communications. Over the course of interviewing participants, however, the researcher did take into account and note emerging themes in participants' narrative responses. These were then incorporated into subsequent interviews in the form of questions, and they served as a platform for initially identifying and coding for particular themes during data analysis.

This research was conducted on the epistemological premise of fallibilistic realism, which, though rooted in the history of science, also recognizes that the researcher is shaped by her immediate historical and social context and her views, actions and

theoretical lenses influence the study, and the study's outcomes; thus the study is "social as well as material" (Anastas, 1999, p.18). It is for this reason that flexible methods were employed and the researcher's presentation and bias noted, i.e. the researcher's interpretation of the data collected - the quality and meaning of certain words, phrases or nonverbal communication styles or lack thereof - may reflect personal opinions or views that influences the final results of the study. However in an effort to monitor this, the researcher's biases and interpretations were recorded and discussed with a research advisor. In addition, this research advisor was used during the coding process to verify the reliability of the coding process and the identified themes.

Regarding the interview questions, there were two types of questions: demographic and qualitative. Fifteen demographic questions (Appendix A) identified the sample in terms of age, gender, race, ethnicity, socioeconomic status, etc., and they provided important contextual information that allowed the researcher to examine the "individual-in-context."

The qualitative portion the interview began with ascertaining broader, basic but contextual information by discussing the participant's family-of-origin's structure, style and dynamics. This established a frame for asking more specific questions that explored the NDC-DS relationship and related to the participant's sense of identity. The semi structured interview questions were designed to track the course of the relationship over time, and allow the participant to explore the evolution of how the NDC perceived him/herself, understood his/her role in the world, defined his/her goals and beliefs, and related to others. None of the questions used were derived directly from the literature, although they were developed with the literature in mind. Some questions sought to

verify that which was present in the literature (i.e. participant's feelings and reactions during childhood), whereas others explored what the literature did not cover (i.e. how participant's viewed themselves, and how that had been influenced by having a disabled sibling). Due to the flexible method, the interview guide was adapted throughout the data collection process.

Data Analysis

All interviews were transcribed in full by the researcher and the content analyzed for the purpose of identifying emerging themes. Codes grouped into major themes were identified throughout the transcriptions and marked by a different color highlighter. Subthemes, though grouped by color under their head theme, were identified on a per interview basis, organized in outline form under their major theme, and exemplified using participants' quotations. In addition, all major themes were analyzed for both content and process. Content referred to time and noted *when* participants came to an important piece of understanding. Process referred to *how* participants arrived at a particular level of understanding (i.e. if they were told about it or if they deduced it), *what* they understood, and the ways in which it impacted their sense of identity over time.

A second coder was used to improve the overall rigor of the study and to verify the reliability of the coding process with the identified themes. After these major themes were confirmed, all interviews were reviewed to ensure the major themes were accounted for in each interview and any unexpected responses (negative cases) were recorded. These major themes, which constitute the findings of this study, are illustrated by the direct quotations from participants' narratives. Quotations are given at some length in order to represent the themes and to enable the reader to draw his or her own conclusions

about the data. In these instances all identifying information was eliminated. In the event that a particular quotation referenced a person by name, the latter was assigned an alternative name which was used consistently throughout the Findings Chapter.

There were several limitations to this study. Transferability and generalizability outside of this study are limited due to the small number of participants. While using the internet as a recruitment source did allow for geographic diversity it did not yield the racial diversity hoped for. Also, in using two different methods (in person vs. phone interviews) the interaction between researcher and participant may have been affected. As stated earlier, the primary difference was in the researcher's ability to note and reflect on the presentation of affect, which was a limiting factor in the phone interviews. In addition, the presence of the phone may have acted as an invisible barrier to communicating, thus inhibiting interpersonal connection and contributing to the interviewer being less attuned to the meta-messages provided in the body language and facial expressions of participants. The presence of the latter in in-person interviews possible prompted more probing questions in which additional information was captured.

CHAPTER IV

FINDINGS

This study was an attempt to answer the question: what is the long-term impact on the identity formation of adults who grew up with a disabled sibling? This chapter will present the data collected from twelve interviews with 2 adult men and 10 women who grew up with a sibling who was moderately to severely disabled. These interviews were transcribed and, from them, eight major categories emerged that were relevant to the experience of NDC. These categories will be presented as follows: 1) knowledge of disability; 2) the relevance of this knowledge; 4) parents' management of the disability; 5) the range of feelings of NDC; 6) NDCs perception of a) one's self, b) others, and c) the world; 7) developmental stages and psychological tasks of NDC; 8) the role of therapy. (See p. 47 for Table 1, which details some of the demographics of the participants and their disabled siblings.)

Knowledge of Disability

"I was so young but I do know that he was different..."

All twelve participants cite having implicit knowledge that their sibling was "different" in some way, and at a relatively early age. Eleven of them noticed physical differences in how their sibling looked or behaved. One sister stated,

I think I always knew that Mark was "off" ... in comparison to what I saw around us, and I think I absorbed the self-consciousness that he seemed to lack, so that I became really protective and defensive about his small head, his rocking, his staring, his loud voice. P10

Table 1

Participant Demographics

Participant #	Age	Sex	Participant Birth Order	DS Older/Younger	Age Dif.	Sex of DS	Type of Disability	Degree of Disability	DS Pseudonym
1	37	M	1 st	Y	3	M	autism	4	Joseph
2	25	F	2 nd	O	2	F	trisomy p+14	4	Katie
3	21	F	6 th	O	5	F	Down syndr.	3	Chrissy
4	42	M	4 th	O	8	M	spina bifida	4	Ted
5	28	F	1 st	Y	5	M	autism	5	Michael
6	24	F	2 nd	O	1	F	Down syndr.	3	Megan
7	24	F	2 nd	O	1	M	autism	4-5	James
8	58	F	2 nd	O	1.5	F	Down syndr.	4	Kathy
9	47	F	1 st	Y	2.75	M	Asperger's	1 (phys), 4 (emot)	Tom
10	31	F	5 th	O	9	M	Williams syndr.	3	Mark
11	34	F	1 st	Y	2	F	autism, epilepsy, TBI	5	Kit
12	42	F	1 st	Y	4	M	Down syndr.	3	Mary

In addition, seven siblings noticed cognitive differences in their DS, most notably in their own or others' ability to pass them in the acquisition of basic skills, like reading. A common experience for ten of the twelve NDC was gaining understanding through peer interactions, in which their DS was indelibly labeled as "retarded," made fun of, or teased as a result of his or her disability. At this time and in these moments, the knowledge that their sibling was different elicited strong feelings of protection but was simultaneously imbued with negativity; to be "different" was bad. As one participant stated, "I remember at the time...[that] I felt like *I* was being made fun of... I wasn't retarded but I took that on because of Mark – I wanted to take up his cause or something" (P10). In contrast, another participant shared that,

I think when I was very young and I just knew that he was different but I didn't care about being different that was a different feeling, whereas I think I got older [and] in elementary school I kind of realized that being different kind of means being weird and I [didn't] know how I [felt] about that...I feel like a lot of childhood was grappling with that issue. P7

Seven of the participants also remembered events that signified that something was different in their family: stretches of time when grandparents stayed with them while their parents took their sibling to the hospital, special tests that were administered to their brother or sister, or when their parents introduced new language, e.g. "autism" or "syndrome," into the home.

Armed with these observations, it is no wonder that eight of twelve participants knew their sibling was disabled by the young age of six. Two others knew by the age of seven or eight. The remaining two were both older siblings to children diagnosed with disabilities on the autism spectrum – a sometimes difficult disease to diagnose until the

child is older. At a very early age, the knowledge that their sibling was disabled became an important aspect of the environment in which participants grew up. By virtue of this, it began to shape their understanding of others and their responses to the world. The relevance of having this knowledge can be further seen in the *kind* of knowledge participants had and how they began to make meaning of their sibling's disability with this knowledge.

Relevance of Knowledge

The importance of this knowledge – the name of the disability, how it affected one's sibling, where it came from - is immeasurable. In seven of twelve cases, NDC were told explicitly by their parents the name and nature of their sibling's disability. For three participants, in particular, it provided context around their sibling's aggressive, disruptive and sometimes violent behavior. One participant shared,

[O]ne of the early things was [that understanding the autism] provided a language around his behaviors and his temper tantrums, which were pretty explosive even prior to that period of time. But...it was the autism that made the temper tantrums happen and then maybe later you know it provided - I understood that he had to be schooled separately and then sometime around the age of 6 and 8 - it meant you know, that as a family there were certain things that we had to do to take care of him and ... that meant different roles for me as a brother. P1

Another stated that, "...it helps me to not take him personally or get frustrated if I know that he's not his behavior..." (P10).

Five of the twelve participants were not provided with explicit information about their siblings' disability by their parents as children, and all remarked, retrospectively, that having that knowledge would have made a difference to them. One participant stated,

...when I was younger and I would try to ask them something, they were very sort of evasive.... [W]hat I did know was piecemealed together from [a] college newspaper/magazine article [published about our family]....I think it would've been nice for me to know and understand it... I like to know what's going on and so for me it's very hard not to have a thorough understanding of this part of who she is. P2

Another participant echoed this sentiment, noting that it would have provided understanding for her around the protective measures taken regarding her sister's epilepsy. She also remarked that this was a conversation between parents and NDC that should be ongoing, highlighting the importance of time as a factor in the NDC's ability to understand and make sense of the disability:

I really wish it was explained to me, obviously on simpler terms, when I was young, you know? I think ...continuing to have that conversation is huge and on [the child's] level, obviously, [in order] to try to help them understand and absorb it. [Then, I'd have been able to understand and say], "Ok, I may not like it, but this is something that we're doing because she could hurt herself, you know?" P11

One participant, whose brother had spina bifida and who is now father to a child with autism, emphasized his decision to act differently than his parents,

It's sort of how my family operates; if you don't ask the question, they don't supply the answer. So the sad thing was, it wasn't really until the researcher came in [to interview our family about our experience, when I was 25]...that I understood the whole story.... [I]t definitely allowed me to see my parents in a different light.... [I]t was sort of an eye opener...I don't think it wasn't a case of I didn't care. I was assuming my parents would tell me when they felt the need to, and they were assuming that if "he ever has a desire to, he'll ask." With my daughter, I've talked to her about [my brother], I've talked to her about [her brother] - sort of taking the opposite approach. I won't wait for the question to be asked. P4

Finally, two sisters noted how talking about the disability in their respective families, as a means of trying to understand it better, was considered taboo because it infringed upon the parents' attempts to keep things together. Shared one,

P: [My parents] did try to create a sense of normalcy and at some points I think they could've addressed maybe there was something a little unconventional about what was happening in our house...

I: What might've that done for you – having more information?

P: (Laughs) I think – this is kind of a weird analogy, but I think in some ways [it's like your] parents never giving you the sex talk. But not having peers around you to inform you... if your folks don't give you the sex talk, in this day and age, kids can put it together... P2

This participant's analogy reflects that a conversation about the disability, like sex, is both basic and essential to life; what is unspoken is how she could not easily find this information out in mainstream society.

For some families, there were mitigating factors: the disability was rare, the medical establishment had little knowledge about the disability or had difficulty diagnosing it, there was social stigma attached to the disability, and/or there was little or no social acuity around it. Regardless of the circumstances, NDC felt the impact. One sister, who's brother has Asperger's, shared her experience of finally uncovering that which had plagued her brother - and, subsequently, her family - for so many years:

I remember it feeling, just like this huge relief. Not so much that we'd found the right label, but that maybe there were other people who were experiencing this and that clearly there were some people out in the world thinking about this and trying to capture what it was like and where the struggles were and what these people could do or couldn't do. Somebody was giving this some thought and was trying to untangle it and say, "Here's how we can help and support these people," because we had sort of thrown our hands up going, "We don't know what to do. We don't know where to find the help. We don't know what to call it." P9

Another sister shared what it was like to share with others about her brother's disability – and the difficulty that came when they did not know what she was talking about:

I definitely was embarrassed for a long time, when I was younger. I think part of it was the era and - 'cause I look around now and people really know what autism is and I think probably even now if you talk to kids they might even be more aware - but when I was growing up, you know I would say "my brother has

autism” and people didn’t know what that meant. So I think I always struggled with explaining it and explaining it well, and explaining it in a way that was not just negative. P7

Not only did explicit knowledge about the disability provide a context as well as a language for understanding and being able to talk about the disability, *not* knowing left three of the five participants (whose parents had not provided them with explicit information) confused about what was the disability and what was the person. One sibling described how her parents - in their grief over “losing” a perfectly healthy 3 year old to encephalitis that resulted in a traumatic brain injury, epilepsy, and autism - never fully explained what had happened or what her sibling’s diagnosis was. Subsequently, she understood only part of what was happening to her sister: “I understood the epilepsy piece but the autism...no, she was a person that, to me, in my eyes, she was a person that needed a lot of help. She was mean, and she made my life very inconvenient...” (P11). For another sibling, the inability to decipher what was wrong with her brother meant that his inability to pick up social cues or his struggle to communicate and temper his emotions became a character flaw as opposed to something over which he had no control:

[Now] I can know intellectually that this is a disability and this is what it’s called but it’s really hard to disentangle that from years of anger and resentment at Tom the person.... And it may be that had it been identified as a disability earlier on and given a name, both my parents and me, I’m thinking, maybe they could’ve helped me, I don’t know, separate out ... Tom the person from this thing he’s grappling with. P9

Regardless of whether they knew the name, characteristics, and course of their sibling’s disability, the majority of participants (n=9) sought out their own learning about their sibling’s disability. This knowledge played an important role in participants’ attempts to

make meaning of the disability and its' effects on their parents, the family as a whole, and themselves.

Parents' Management of the Disability

"I think they did the best that they could."

The environment created by family dynamics contributes significantly to the formulation of one's identity, for it is in this context that people learn to relate to others, understand the world, and, subsequently, begin to create a sense of self. The presence of disability in a family can have life-altering effects on a family's routine, members' roles, and ways of interacting. It can also change the relationships of the dyads therein: parents, parent-NDC, parent-DS, and NDC-DS. While the lattermost dyad is the one being studied, it's imperative to take into account how parents' parenting can affect the rest of the family system.

Bifurcation of Parental Roles

Ten of twelve participants in this study noted a significant bifurcation of parental roles when it came to managing the disabled sibling and his/her needs. In eight cases, the mother took on the primary caretaker role whereas the father took on a supportive, often financial, role. In seven cases, participants mentioned specifically that one or more of their parents became a vocal advocate for their disabled brother or sister; in four of these seven cases, mothers took on that role, three of whom did it in addition to being the primary caretaker. Two participants shared that the tension created by the separation of roles, and subsequent disagreements about how to manage the disabled child's needs, contributed to the eventual divorce of their parents. As one participant shared,

My mom ... had the hardest time. She is still really overprotective of Chrissy and my dad kind of wants her to do her own thing. [With my mom] whatever Chrissy wants to do, she can do. . . . [My dad is] trying to get her a home somewhere with her friends, 'cause she makes her own lunch, she goes to bed on time, she knows what she's got to do. She even does her workout regime, but my mom's very against Chrissy [going to a home], so it's a little fight right there. [My parents] ended up getting divorced right around the time I was born. I think part of it was 'cause [my mom] was so overprotective of Chrissy that it affected their relationship the wrong way... P3

Coping Mechanisms

In several instances, participants shared how their parents, or their family, coped. Subsequently, they learned to deal with what was oftentimes a difficult situation by accepting that it was an immutable fact of life. One sibling described the overwhelming nature of her brother's behavioral outbursts, and how she – and the entire family – coped with it by detaching themselves to a certain degree:

[As] Michael got older and the problems got bigger, it got to be more overwhelming and I – when he did have behavior problems I think I kind of went in a numbness to where I wasn't really dealing with it and I was just kind of – I mean that was the way that I coped, I just kind of went into that mode of “okay, we'll get through this. Whatever.” That's kind of how my parents were, too. I mean, we didn't really talk too much about – it was just something we knew that we'd have to deal with. I mean, if we went on a vacation, we figured that we might have a behavioral issue, or if we went out in public it wasn't uncommon that something was to happen and so it was kind of like part of our lives. P5

Another participant shared how her mother tended to normalize her sister's disability:

“[M]y mother's always been, “she's normal”, you know, or not that she's normal but she's Katie, she's doing what she's doing. We don't talk about her limitations. Not that we're not aware of her challenges and stuff...” (P2). But not everyone in a given family coped the same way, and for some participants, the family's way of managing the disability felt fragmented – and they felt lost, the boundaries between them and their parents blurred:

[We] were kind of always on guard because we never really knew what each day would be like or what each moment would be like or what each outing would be like, and so I think that we sort of lived in survival mode... I just felt like we were all sort of in our own process and I think that my parents assumed that I, we were sort of in a triangle – me and my mom and my dad – and they kind of assumed that I had the same feelings, experiences and made the same meaning out of it, without necessarily thinking that I wasn't or that maybe it was different because he was my sibling instead of my child. P5

One participant detailed how her mother's stress had a trickle-down effect:

I think my mom needed a lot of help in the house. She was home alone a lot with Kit and my dad went to work, or having to deal with stuff. I think it would've been great if there was- [if] she'd been able to get somebody in there to help support her... [Instead] she leaned heavily on me which I don't think creates a very healthy boundary with your child. I think it caused me to be even – you know, grow up even ...quicker. P11

This blurring of boundaries was also seen in how some participants saw and internalized the strain taken on by one or both of their parents, and then assumed supportive roles in response. Not only did this inform their behavior in childhood, but also as adults:

[G]rowing up I rarely... [My brother and sister]...we all – we all did pretty well. We complied, we did our chores, you know... we didn't rebel, so – very strange. And I was very quiet, very shy, and then I became very bonded to my mom because I saw she really wanted to know what was going on with us and so she would listen to me about my day or whatever and [she would] want to know what was going on. So that was nice, but I think, you know, emotionally we became dependent on each other...I saw her being upset or tired, or whatever, so I think I had sympathy for her. P11

And:

I: [How did being] the “Golden Child” or taking on your Mom's [perspective] on things - where else has that played out in your life aside from just [how you interact with your brother]?

P: Oh gosh, that's a big thing that's going on right now. I'm actually in the midst of conversations around separation around my husband, and I realize a lot of what's going on is [that] I'm right back in that role in my marriage, right now. That he suffers a lot from depression, and his dealing with it or not dealing with it to varying degrees over the years... I've created a nice, safe little protected haven and worked very hard to convince myself that, “Really this is okay. It's fine. I'll

be the primary wage-earner. That's okay because I'm the one who really likes and wants a career and you've never been interested in one, so this division of labor is fine with me. You're doing stuff with the kids and okay, I'm picking up a lot of the slack at home and doing other stuff, too, but really that's okay." And I'm just realizing how hard I've been working and say[ing], "Oh, this is really all ok?" and how not okay it's been with me! And that's all coming to a head right now, [now] that we're in the midst of trying to work out and untangle [it]. And he's been the one who's been saying, "You know, there's a lot of parallels. There's a lot of leftover stuff of your mom here," and I've been going, "This is not about Mom, this is about us." And as I talk about it more, [I've been saying to myself] "Oh, but there's echoes of Mom in here whether you like it or not. There's a lot of modeling here and roles that you're stepping into without necessarily realizing it." P9

One sibling describes how her mother coped with having a disabled child and how she drew on her mother's optimistic management of her sister's disability, but balanced it by also drawing on elements of her father's realism:

My mom tends to be very optimistic on the face of it and - I think that's a lot to counter my dad - [she] is definitely glass half full. If there was any doubt of half glass full from my mother or if she ever let that show through ... she could never let that happen. She never embraced that or chose to let that side prevail because I think then it'd be just a total mess because you can't have two people who are downers when it comes to my sister. Somebody's got to have upbeat stuff, you know. So I think I tend to adopt my mom's attitude. But I sometimes - the same way my dad probably gets sick of her being, like, really upbeat about it - I think I tend to be like, "Okay mom, let's get real. Let's grasp the levity of the situation." P2

One participant who is, herself, an art therapist who works with families, noted that coping by "getting over it" was not enough. The investment of parents in *both* children was something she and her DS needed from their parents - and she sees a clear impact of this in her work:

I really would've loved for my parents to have been able to be there for me, not so much in terms of time but to be able to - in the moments when they were with me - to be more present to the emotional stuff and not so much - "hey, get over it, we're fine." So if there was somebody who could've helped them with that as a family that would've been great. And it's so interesting with all these experiences ... doing therapy, [that they] led me to be an art therapist and I work with

families, and I see how that can have such an impact if the parents are involved, it really can change things for the kids. P12

Differential Treatment and Feelings of Ambivalence

All twelve participants acknowledged that they received less time, attention and/or they were treated differently by their parents relative to their disabled sibling. As one participant stated, “[A] good portion of the time...in therapy was around my feelings about my own identity, the things that happened in my family and... the things I felt were sort of lacking in terms of my own care and attention” (P1). Another said,

[A]s I got older and certainly when I was a teenager, there just wasn’t much space for [the emotional stuff] and I think partly because of my parents’ own limitations given who they are aside from any of the kids, but then having to devote so much time and energy to my brother and to my sister I mean I felt like my parents weren’t really able to see or support me in ways that I needed, yeah...P12

The disparate attention paid to NDC led to the development of coping mechanisms, which, for twelve of twelve participants, was expressed in at least one of three ways, “They did the best they could”, “that’s just the way/what it was”, and/or “we/I dealt with it.”

[It] was really hard to get any time when we weren’t all together because my mother ...didn’t want ...to leave Kathy alone. So ... there might’ve been ten times where I had [both my parents to] myself and a couple of those times [were] when Kathy was at camp.... I realized later that seemed unbalanced. But....that’s just what it was. P8

When explored further, these comments revealed mixed feelings, or ambivalence, as expressed by contradictory statements.

So I think there were times when I felt it was disruptive. Or, when I might’ve been resentful, but I think they were also really good about pushing her to keep up, like they were really active in the school system in advocating that she be mainstreamed in her education and that she be in the classroom as much as possible...And so I think it was less disruptive than it could’ve been, but there were still times when I was, I don’t know, I mean I’m sure – I *know*, I can remember one of the earliest instances of feeling jealous...P2

Some participants remarked that their age and lack of understanding contributed to such feelings – particularly when, as children, they were unable to make sense of the different kinds of attention they received. However, in the instance below, even time did not completely temper the sense that parents offered different attention, and that this elicited mixed feelings.

When I was a kid, there was always the issue of equality and who is getting more attention. When I was younger I was sensitive to that. I would go to visit friends and see that ... my friends' moms would just know everything about what was going on in school and would know all these little details that my mom just didn't quite know. Not that she wasn't involved, but it just takes so much time to care for James that knowing every intimate detail of my school curriculum might not necessarily happen. So I think sometimes that did bother me, because I would see "Well, the other moms can do it" but, in retrospect, I think, "Well, gosh, there was so much going on it would've been hard to be super-classroom mother or something." But I think also as part of that issue, [was] my parents would always, well, my mother in particular would be so aware of everything in my brother's life: his medication, school – all the minutiae of his life so well. And I would look and say, "Well, why don't you know the minutiae of my life like that?" And now I can see ... how it happens that way, but as a kid it bugged me. I also think there was definitely a difference in terms of how my dad was and how my mom was. I would say that my mom was the best at being James' advocate and my dad was the best at being my advocate. P7

Implicit and Explicit Expectations

As a function of their sibling's disability and its impact on the family, all participants (n=12) experienced feeling some kind of expectations. Very few (n=4) received explicit instructions as to what was expected of them. More frequently, and regardless of their parents' intentions, the NDC received implicit messages (n=7) or shared that they felt certain things were demanded of them (n=4).

[This project in high school] was something that I think sort of opened up a lot of things for me about how she'd impacted me and how I think at that point I resented the fact that I felt like I needed to stay close to her, physically close to her, so that I could provide for her needs, you know? ...I was sort of at the age, and I think a lot of that again was the expectations I pushed on myself, it wasn't

that my parents were asking me to step into that role. It was just something that I sort of felt like I ought to be doing... P2

One NDC shared that her parents' stoicism, though admirable, left no room for contradiction and this, in and of itself, set her up to doubt herself when she didn't feel the same way:

... I grew up kind of admiring my parents' ability to trudge on and have a positive mindset about all of it and at the same time I realized I resented that... because it made me feel like I didn't have permission to experience the range of emotions. It made me feel like to be angry about it was wrong and, you know, that would be a weakness on my part to feel anger or hurt or resentment. P5

As the following excerpt demonstrates, the expectations felt by this participant played a part in her taking on a role that she then assume as part of their identity:

P: I knew that because of her, like, I was definitely more of an overachiever... I guess I kind of wanted to make up for what she might be lacking in, in the eyes of my parents or something like that, like maybe get better grades and get the best grades and go to the best college – that sort of thing.

I: So, how did you get that message? Was that something you interpreted, was it something said explicitly to you?

P: It was probably something I misinterpreted. I'm pretty sure if you asked my parents ...they would not say that they expected me to make up for her deficits at all, but it was probably something I took upon myself. I mean my parents would expect the most out of both of us, anyway, ...but they would never say that I had to make up for her in any respect. P6

One participant noted that, even despite her family's overt statements that she not take on certain responsibilities, social dictates communicated otherwise:

...[W]e were raised together so, even though my parents and my uncle and other people said, "You're not going to be responsible for her..." - they didn't want that to make me make choices in my life -it [didn't] matter 'cause I would've. That's nice that they tell you that you don't need to be, but ... it's not how you're raised. P8

As seen in the previous example, expectations are not only communicated by ones parents, but by society – and, in this next instance - by other family members:

Now I don't remember my parents specifically – although, they probably did say that I needed to help them out more. I do remember my grandparents saying that I needed to be good and take care of Joseph, and take care of my mom and dad.
P1

Parental Expectations and the Assumption Guardianship

A handful of participants noted that their parents openly told them that they did not want the NDC to take on additional responsibilities:

[M]y parents have both been pretty good about...saying “You’ve got to do what’s right for you; you can’t think of yourself as the person who needs to watch out for Katie all the time....You don’t have to think ... that you’re bound to her. P2

The dynamics between a parent, his/her disabled child, and the NDC are complicated, however. One participant explicated the intersection of his parents increased attention on his disabled sibling, his own emotional response to it, his new perspective on the situation as an adult and, growing up, his mother’s statement of her hopes for the NDC:

I: [You’ve] mentioned “This was just the way it was and you deal with the card you’re dealt,” but at the same time it doesn’t mean you’re always happy with the card you’re dealt.

P: No, there’s definitely some resentment at times. I look at it now and say, “Okay, I was being selfish.” I don’t think I ever brought up [my resentments] but I thought, “Why are they spending so much time with him? Why are they not around?” There’s been a few times when my mother has said that they’ve worked pretty hard so that we don’t have to, so that our role is more of a brother to him rather than sort of a guardian. P4

Other participants shared similar examples, a common theme being parents’ attempts to relieve their NDC of future caretaking burdens:

[I had] this overwhelming sense of, “Thank god mom is dealing with that and I don’t have to deal with that.” And for years it was like, “Oh mom, I’m so sorry you have to deal with that, but better you than me.”And kind of a sense of guilt around that, like, “Wow. Dad’s out of the picture now. Maybe I should be helping her more, but ... ugh... too much resentment, too much messiness. I don’t want to go there. I’m just going to sort of avoid that and let poor mom deal with it....” And over the years I felt she was really good about saying, “No, that’s really kind of you [to offer to help]..., but this is not your issue to deal with. He’s

my son and I'm the mom. It's okay."And I remember just being so grateful that she was not putting me in the parent role to deal with it. P9

And another, who's brother will transition to a group home:

[Guardianship is] something that, actually, my parents and I talked about recently, because I've struggled with [the idea of being the primary caretaker..... [B]ut when I talk to my parents about it [they] said to me that their goal is that I don't ever have to do that, but I'll be involved and I'll make the decisions, but that ...we'll find a situation that makes sense for him. P7

The role of the parent in this situation is a complicated one. Though many participants expressed ambivalence or outright difficulty as a result of their parents management of their sibling's disability, more than half (n=7) remarked that their parents did well in managing what, as adults, they understood was a difficult job, and still others shared ways in which their parents tried to be attendant to their needs despite the time-consuming nature of their sibling's disability. What this data confirms is that growing up with a disabled sibling is not a clear-cut positive or negative experience, but that it has both its strengths and challenges. This is nowhere more apparent than in participants' expressions of the various feelings they experienced over the course of growing up.

Range of Feelings Experienced by NDC

Emotions are an entirely subjective experience. To express one's emotions is to communicate one's internal experience of an interaction or event. Simultaneously, it is a reflection of one's self – it is an internal process unique to the individual that has been formed, over time, by one's experience in and of the world. In this study, participants expressed a range of emotions, from anger to pride. As one stated, “[I was] angry about not having that basic need of feeling safe... having that not be guaranteed, something I could count on” (P5) This particular sibling had a brother who had autism and who could

be physically aggressive. Not all participants had this experience, but their emotions about their siblings, about the disability, and about the family dynamics that resulted from having a disabled sibling covered a wide range of emotions. Table 2 (p. 63) illustrates the range of emotions expressed by participants; those that are starred indicate actions or behaviors expressed by participants and interpreted by the researcher; those not denoted are the specific language used by the participants.

Repeatedly, NDC expressed feeling angry, frustrated, resentful and jealous. One participant described the relationship between feeling angry and taking on more adult responsibilities:

I think that I was angry early on and I never really understood it. And it wasn't until I was 14 and 15 and sort of asserting my independence that I became really aware of how much of my time was spent taking care of my brother, that ... where other kids in my school had had free time on the weekends, I was responsible for babysitting my brother when my parents were going out and...and that you know, that was a very sort of difficult point in my adolescence. So then there were lots of feelings of depression and anger and isolation and feeling abandoned by my parents and sort of, a lot of stuff that teens go through but a lot of how I went through it was informed with my relationship to my parents through how I had to take care of my brother. P1

Still others described the often complex nature of their emotions, and the difficulty that sometimes came with separating the person from the disability. As one participant said, when asked to describe how her sister's disability manifested, "it's sort of hard to attribute what is just Katie and what is due to the chromosomal anomaly" (P2). The duality of emotions many siblings experienced, sometimes led participants to express feelings of ambivalence or neutrality. After noting the conflicts present in one interview, the researcher asked the participant if he would categorize these often conflictual feelings

Table 2

Range of Emotions

	Participants												n =
	1	2	3	4	5	6	7	8	9	10	11	12	
Anger or frustration	X	-	-	-	x	-	x	x	x	x	x	x	8
Resentment	X	x	-	x	x	-	-	-	x	-	-	x	6
Envy/Jealousy or Unfairness	X	x	x	-	-	x	-	-	x	x	x	-	7
Sadness, grief, or hurt	-	x	x	-	x	-	x	-	x	-	x	x	7
Isolation, separateness, or difference*	x	-	-	x	-	x	x	-	x	-	-	x	6
Ambivalence, neutrality*	x	x	x	-	x	-	-	-	x	-	x	x	7
Pride or awe*	-	-	x	-	x	-	x	x	-	x	-	-	5
Strength, independence, or self-assuredness*	-	x	-	x	x	x	x	x	x	x	x	-	9
Open, accepting, tolerant, or aware	x	x	x	x	x	x	x	x	x	x	x	x	12
Depression	x	-	-	-	-	-	-	-	-	-	-	x	2
Confusion	x	-	-	-	-	-	-	-	x	-	x	-	3
Embarrassment or awkwardness	-	-	x	-	-	x	x	-	x	x	x	x	7
Guilt	x	-	-	x	-	-	-	-	x	x	-	x	5
Scared	-	-	-	-	x	-	-	-	x	-	x	x	4

as positive or negative, to which the participant responded,

...[There's] two parts of me – one part of me would say neutral. Everybody has to deal with the things that life hands them and the way that you cope with them is a valuable part of life. And the other part of me would say that it's a negative, that nobody should have to deal with a disability if they have a choice – which you don't, which is why you say it's neutral. P1

Another, whose brother had Williams Syndrome, a characteristic of which is a rocking motion, highlighted the tension in wanting to connect more deeply with her brother and, when unable to do so, wished he was “normal.”

I spent so much time with him that, you know, and I – I think I really envied him. I mean he had so much going on inside and for so much of my life I was so *out of focus* that I didn't have an inner metronome that made me rock. I think I was sort of jealous of whatever it was for him for awhile ... I was like, “God you're so ok in your idiosyncratic behavior. I can't even get into you and you're the closest thing to me and we can't really connect.” I really wanted a normal brother. I really wanted someone who was home and around who was like, showing me the ropes and looking out for me. Mark just...that wasn't his ride. P10

Participants cited the lack of reciprocity as the dominant dynamic missing in their relationships with their disabled siblings. One participant shared the same wish (for a “normal” sibling) but captured the tension in how this relationship had been formative in a positive way, and how, at the same time, that did not take away some of the loss she experienced in it:

I guess I would just say that even though it would be great if she wasn't disabled or whatever, I wouldn't change anything about who I am, so it would be hard to ask her to change. I think my parents and I just jokingly, at one point or another, we'd be like, “If Megan didn't have Down syndrome she'd be like this” or “Oh, I can totally tell that her personality would be like this” but, I mean, I like who I am and I like who she is. It'd be great - if anything, I'd just ask for a third sibling just so that I could have both worlds. P6

While having a disabled sibling did not mean there was not love or affection between siblings, it did significantly impact the nature of the relationship and many

siblings felt this to be a loss, for which they had to grieve. One sister, whose brother had Asperger's, said,

P: [T]here are so many ways in which he and I are so different personality-wise and because he was not a kid who plugged in socially I don't think of us having a long prior brother-sister history that I've lost. I'm not sure even know how much of that relationship is there. There were times in adolescence, teenage-hood where we connected – we have very similar sense of humor and we enjoy certain things very similarly.....

I: And so, at this point when you look at friends who have siblings...

P: Oh, I'm so jealous of them. Having a close brother or sister. <Becomes tearful.> Yeah, because it was never that.... Hence the wish for another sibling.... [There's] a few very close friends that I've adopted into that role.... But, yeah, that is a big sense of loss, not having that. P9

Another sibling noted that she had to take time in her life to grieve not only the “loss” of her sister, but also that of her parents:

Loss is a really hard thing for me to deal with. I mean, even breakups with boyfriends, I just...I was like, “I've got to figure this out. Loss is a really hard thing for me to deal with – I need to go back. I need to deal with the loss of Kit. I really need to go back and deal with the loss of my parents paying a lot of attention to Kit - my Dad, especially. My dad really has - he helped, he's always on the board of something to help disabled citizens, people. [So]...he seemed there for Kit but he wasn't there for us, or at least for me. I didn't feel like he was there for my brother.... So, yeah, I really had to grieve that. That my dad wasn't there. It was hard. P11

The knowledge that one's sibling was disabled left some feeling set apart, or different. One sibling shared, “I was very lonely in some ways, even though I had friends, I think there was a piece where I just felt very alone” (P12). Others shared how, often, others would not “get it” when they shared what it was like to grow up with a disabled sibling:

“OK, you understand what [autism] is but you don't get how I feel about it or what my experience is.” ...[People] don't realize what a big deal it is. I'll tell people now as an adult and they're like, “Oh, you know, that's really nice that your family...” It's almost... people are like...[they] don't know what else to say,

but to say “That’s great” or “That’s nice” even though it’s not I don’t know what the appropriate response is, but I don’t think it’s “Great” or “That’s nice,” but it’s not the kind of thing you say “Oh, I’m so sorry” about, either. [T]hey don’t get it. And I think it’s not getting it, in like, how much work it is. And just how hard it is. But also how enriching it is and how great it is – both ends of it.
P7

The duality of this experience can be captured in siblings’ self-ascribed independence. One participant - who called herself a Golden Child and whose independence was a hallmark of her success – shared how it was also isolating:

I don’t know if it was modeled for me, or if it’s just my personality or some combination of both, but this very independent streak of, “I can do it myself, thank you. I’ll go get help when I *really* need it.” But I have never been good at asking for help. And so it’s always been a very isolated road of, “I can be strong. I’m independent. I can do this. It’s okay. I can do this.” I can think of plenty of examples of Mom being like that, so whether Mom modeled that or I just inherited that personality trait or whatever the reason is there’s definitely a sense of, “Things aren’t so bad that I need to ask for help. You need to ask for help only when things get really, really bad.”.... I think my picture of what help is and who needs it didn’t mesh with me [because my brother needed a different kind of help]. P9

Another participant, when asked if it was easy for her to ask for help, replied (with a laugh):

No! Let me think about that. No! No. I have never thought about that in connection to Mark. I do most things on my own. I was just writing about that this morning - even this move. [My fiancée] and I are moving and, ahh... it would sure help if I could say “help!” I definitely take on way too much and it’s very hard for me to say...I don’t want to burden people, I really don’t. I feel – I struggle so much with feeling like a burden and to avoid that I try to do things by myself that I could probably use a hand with. Does that stem from Mark? That’s a great question. Probably. I mean, Mark, though, was one of many struggling siblings in my family and I just felt like, “Where the hell-?” I don’t...I can’t... I can’t burden... you know, my mom seemed so burdened already. By the time I was born, I was like, “Woman, you have to take a nap!” P10

Several siblings also conveyed pride they felt about their sibling. One sibling shared that every single member of her family – parents and siblings – has chosen an occupation in the helping field (as defined by any occupation in which one’s main job is

to help, teach, or heal others). In commenting on this commonality, she shared a value internalized from this experience – pride in helping others: “We were always a close family and Chrissy was included in everything. I really think she had a big impact on everyone’s life....[and] I think it’s awesome that we’re in those kinds of fields, helping people.” Another expressed her pride in her description of her brother’s unique ability to see through to the truth of things:

I just think that the paradox between “normal” and “handicapped/special/struggling/disabled” is really a funny one to me, because Mark often speaks like a – you know like the Greek chorus in an old drama. He will come out with these pronouncements....the clarity that he has...I have not often recognized that as being as powerful as it is.... [He] really gets to the heart of things. And very simply. There’s something so refreshing about how not-complicated his thinking is, sometimes. He can come out with these pithy statements that are like, “Wow.”[Throughout] his life, Mark has said things that are really simple but right-on...[Maybe] he’s lacking such-and-such skills but there is so much that’s in its place, you know, that wouldn’t I be the same person I am now if Mark hadn’t been handicapped. I know for sure I wouldn’t. I don’t know exactly how, but I don’t think I would be nearly as sensitive or open to other people and their quirks and styles and issues, and stuff. So...so, special is that term. The inner special, but I think it is true in the very simple definition of the term; Mark is that. It’s because he has Williams’ Syndrome that he’s special. There’s something about that that allows him to see things that I don’t necessarily see. And there’s a wisdom, there’s a wisdom that has come from his experience because of who he is, that I think sometimes – you know it’s easy to gloss over or to miss, but it’s a pretty awesome upside. P10

Perceptions of the NDC

The range and depth of experiences afforded participants also significantly impacted their perspectives. The following section is devoted to demonstrating how participants viewed 1) themselves, 2) others, and 3) the world. The first section, “Views of One’s Self” deals with self-concept, a term that refers to the intrapsychic dimensions of an individual’s identity, as exemplified through one’s views, values, and beliefs about

him/herself as expressed explicitly or through the sub-themes: a) self-ascribed roles; b) choice of occupation; c) self-description and d) general outlook.

View of One's Self

Roles.

“[She’s] just kind of made me the person who I am, you know? I’d be a completely different person otherwise.... It’s hard to describe because it’s like everything. “How am I the person who I am?” There’s not one thing I can pinpoint. I kind of look at everything with a different eye.” P6

All twelve participants - in the process of expressing their views, discussing roles they took on in relation – or reaction to – their sibling, sharing their motivations for going into their current field, or in describing themselves - demonstrated how their relationship to their sibling impacted their self-concept. Ten of twelve participants shared how their sense of who they were in their lives was inextricably connected to their sibling, and that their brother or sister’s disability, because it informed the sibling relationship, was a major factor in that. One sister described, “it feels like such a big part of me that it’s really hard to separate out. It’s hard to even imagine what it would be like to not have [a disabled sibling].” Another participant, who was one of a few participants who did not experience embarrassment at some point growing up due to her sibling’s disability, attributed this to having internalized her sister – and her sister’s disability: “It just – I never felt embarrassed or like I had to not say she wasn’t there, she was – this was part of who I [was].” Two siblings, over the course of growing up and realizing that their siblings were disabled, internalized the disability as a facet of their own identity, describing how they, too, were different - not only from their own, non-disabled peers, but also different from their siblings:

(P) I'm pretty sure I was aware of [the disability] pretty early on. We're really close in age and even though she's older, I mean, I walked first, I talked first and so as soon as I could walk and talk it was kind of like I was in charge. So, I mean I don't know if you had asked if I was 2 or 3 if I knew that she was disabled, I think I could tell you that something was different. And definitely by 5 or 6 I could put a name to it and I knew what it was....

(I) So, what effect did this knowledge have on you?

(P) I could tell it set me apart from my peers. I could tell, I mean – she didn't go to the same school as me ever. It was, kind of like, not really a secret sometimes, but everybody else's siblings went to the same school and so it just, I knew something was – I was different. It also made me kind of more protective of her because I knew more about it, that sort of thing. P6

This participant simultaneously captured her initial awareness of her sister's disability, how she understood it in relation to herself and how, even at the very early age of 5 or 6, this elicited in her a sense of needing to look after her sister specifically because of the latter's disability. Despite being the younger of the two, this participant stepped into the role of older sister and protector. Taking on the role of older sister or brother was a common response amongst participants. All twelve, regardless of birth order, felt older than their disabled sibling and assigned certain attributes to this position: caretaking, responsible, protective, nurturing. (See Table 3, p. 70, for further details.)

How does one take on a role? As this next participant describes, there was an implicit need for support that she felt from her parents, as well as an unspoken expectation that she step up and into the role of older sister:

I think it sort of happened that I took on, that I sort of became the older sister and I think that's something [my parents] definitely permitted to happen... I think having an extra set of hands around was probably not a bad thing when it came to having Katie.... I think I was always on the look out for her. I was always – you know, we walked to school. So, instead of my sister being in charge of us walking to school, I was the one who was like, "Double check and look both ways before you cross." I was... I think I sort of stepped up into that role of big sibling, big sister, and I think part of it was the expectations. P2

Table 3

Roles

	Participants												n=
	1	2	3	4	5	6	7	8	9	10	11	12	
Older/oldest sibling Δ	x*	x	x	X	x*	x	x	x	X*	x	x*	x*	12
Caretaker	x	-	x	-	x	-	-	x	X	-	-	x	6
Responsible	x	x	-	X	x	x	x	x	x	-	x	x	10
Protective	-	x	x	X	x	x	x	x	x	x	x	x	11
Nurturing	-	x	-	-	x	-	-	-	-	-	-	-	2
Independent; leader	-	x	-	-	x	-	-	-	x	x	x	-	5
Golden Child; high achiever	-	x	-	-	-	x	-	x	x	x	x	x	7
Caretaker of Parent(s)	x	x	-	-	x	-	-	-	x	x	x	x	7
Advocate	-	x	x	x	-	-	x	x	x	x	x	x	9
Helper (to parent)	x	x	-	x	x	x	-	x	x	x	x	x	10
Peacemaker/mediator	-	-	-	-	-	x	x	-	x	-	-	x	4
Self-sacrificing/don't rock the boat	x	(x ^o)	-	-	x	(x ^o)	x	-	x	x	x	x	9

* These siblings were both the older child in the relationship, and the oldest child in the family.

^o These siblings paired the term “Golden Child” or “achiever” to descriptions of not wanting to “rock the boat” or engaging in self-sacrificing behavior.

Δ Those who described themselves as the older sibling in the relationship – regardless of whether they were or not – also commonly used the terms “caretaker”, “responsible”, “protective”, and “nurturing” in conjunction with this role, thus the reason for why these terms, and no others, are indented.

Despite having taken on this role under these circumstances, this same participant also described how telling others that she was the younger of the two children in her family eventually felt incongruous in terms of how she saw and thought of herself:

[It] was always sort of funny being the younger sibling because, people meet us and they always think I'm the big sister - probably because I'm that much taller, but [also because] I've always taken on what might be the big sibling, nurturer role just because of growing up with her... P2

While some participants associated caretaking with taking on an older sibling role, many also described it as a role in and of itself. In this role growing up they not only took care of their siblings, but also their parents, and, in the absence of their parents, of themselves. Two participants talked about the positive self-esteem and confidence they developed as a result of taking care of their sibling. One sister shared, “[It] was a very kind of positive thing that I shared with my family and it made me feel important because I was kind of able to do the caretaking and be more like an adult in the family” (P5).

Three participants stated explicitly that they felt the need to care for their parents; others alluded to doing so by way of “not rocking the boat” or by being good. This differs from those who described themselves as their parents’ helper – a specific role in which they aligned themselves with the parent to then help the latter with their DS. One participant, who described a scene in which his grandparents charged him with caring for his parents, shared exactly how he did that. Then he describes how, when making the decision to go away to college, the degree to which he felt he took care of his parents influenced his decision to go far away:

[Later] on in my childhood - I understood that my parents had spent a lot of time

in their advocacy for my brother and working with the schools and even on up to the state government in providing the right kind of education and care for him. And then my role in that was to really stay out of my parents' hair and to some extent take care of my brother.

And later:

[It] was really important for me to go out of state to be away from my family and I did go to college out of state. [At this time] I decided that I didn't ever want to live at home again and I haven't. And that has been the right decision for me. Because I just ... I can't.... be there for my parents the way that I had been as a child continuously for my whole life. P1

For this next participant, taking care of others and "keeping the peace" was a role she continued to take on with friends and significant others:

(I) So even as the... older sister, even though you're the younger sister... how have you seen [these different responsibilities or caretaking roles] play out in other parts of your life...?

(P) [Definitely] with friends. I [am] inclined to be the one who [finds] common ground among friends and will kind of stop disagreements and help people understand different points of view... I just was kind of more the peacekeeper among friends, which I think is maybe a role I play in the family is peacekeeper.... Even in romantic relationships, like, taking care of that person and making sure they have what they need; I just default to that. And not voice what I need as much, which is the same role I would play in the family of like not wanting to shake the boat, not wanting to make [things] harder than they are, being aware that, you know, if I complain about this it's going to make it that much harder for mom and dad and kind of having that same instinct in relationships and biting my tongue a little bit. Which has evolved, it's not as much as I've become aware of it, but it's still kind of the default setting for me. P7

The tendency to squelch one's own needs, or even to find them through being one's own caretaker, was not unusual. Another participant described how, in the face of her parents' distractions in dealing with one physically and cognitively disabled brother, another mentally ill brother, and also as a result of being the youngest of several children, she coped by becoming independent, depending on herself and taking on more adult roles at home:

You know, I've definitely spent a fair amount of time trying to figure out why [I took on these roles] and what I can come up with is that I had a lot of time to raise myself because my mom and dad were so busy with their own lives by the time I was born, that I think I created a sort of inner dictator in my own head that really prevented me from – it was sort of a coping mechanism to get through, it was like: “Here’s a caretaker. It’s going to be in my head.” It wasn’t nearly this clear cut, but I’ve sort of come about to this place of trying to understand how I got to be this way and I think part of it is that I didn’t really have strong parental figures in the sense of - dear God forgive me - I mean they were, they are wonderful people, absolutely, but they didn’t really raise me. I would say [my friend’s] mom and some of the babysitters I had were the strongest mother-figures in my life because my mom wasn’t around very much. So I think I just sort of got that way because I was like, “I have to get it together here because if I don’t, there’s not a whole lot of options.” But you know... [I know] there was a lot of love...but in terms of me being a separate kid growing up in that house, there wasn’t really room for that because the other kids took up so much time. Even if they were absent, that absence took up a lot of time for my mom. And then she was also busy getting her degree, going back to school, finally living her life after having birthed six kids.... [So] that’s one of my hypotheses as to how I sort of took on that role. I think I also had an aptitude for helping and being more adult than I was in years from an early age. P10

Seven participants described themselves as either high-achievers or as a “Golden Child” – the child who can do no wrong. For some, this was a way of taking care of their parents. For one participant, it was a way of defining herself as separate from her brother, whose behaviors she did not understand. While proud of her accomplishments, they – and the positive response she got from her father – also elicited discomfort:

(P) [There] was a lot tension and stress around [Tom’s behaviors], between mom and dad trying to sort out what it [was] and mom trying to support Tom, and Dad struggling with Tom and that causing tension between the two of them. [With] all the upset around Tom getting in trouble in school, I remember feeling like, “I’m the golden child in the family. I’m the eldest. I’m the high achiever. Everything has come easily to me.” It’s sort of like the good cop, the bad cop. I was the good kid, Tom was the bad kid. And that’s kind of how it felt to me. I can’t say for sure whether my parents felt that way. I’ve gotten hints and comments from my dad that lead me to believe he kind of saw it that way. I remember that leaving me feeling horribly, horribly uncomfortable...I kind of wanted to say, “It’s not that black and white, Dad. Don’t paint me into being the perfect, good kid who you can pin all your hopes on and everything’s going to be great, and of course she’ll do this and she’ll exceed in this and she’ll excel in that.”

(I) How much of [being the Golden Child] did you fall into, how much of you felt compelled ... or pressured to be that - or was it all of those [things]?

(P)I think I fell into it because in some ways a lot of that was coming easily: school was easy, friends were easy, college was successful, graduate school was successful. Got married, had kids, good job. Things did tend to fall into place and work for me easily, so in that sense I didn't mind that life was basically being good to me. And it's actually only now with issues coming up around me and my husband that I'm really starting to take a hard look at that again and realize how much of mom's role I am stepping into without realizing it: "Ok, I'll hold down the fort. I'll take care of everybody. I'll be the golden adult, now, or the golden parent for everybody and do it all." And what that's taking out of me, and that I have to say, "I can't do that anymore and I don't *want* to do that anymore. That is not my role." P9

For siblings who took on caretaking or Golden Child roles, the struggle as adults is learning to recognize the tendency to slip into these roles and taking steps to prevent it. As one participant stated, "When I am in relationships [I] just kind of automatically help, and make sure that person's needs are being met. So something I have to make sure I do is that I don't get so swept up in taking care of other people that I don't take care of myself" (P7). Another shared how therapy helped him recognize this very subtle tendency to always put others first at the expense of himself – and the anger that underscored it:

[Talking] about those things in therapy helped to concretize and understand some of my difficulties around taking care of my own feelings and making time to recognize what's going on in my own internal life instead of always others instead of me... I was angry without even knowing it, and it was really in that period of time that I got to sort of unwrap my anger and live with it and not be angry anymore. P1

With regard to roles, one unexpected finding was the significant number of siblings who were vociferous advocates of their sibling being able to live independent from the family (at this point in time, the parents), usually in a group home. Four participants' siblings already lived in such homes. Six other siblings noted their parents'

reticence around permitting this but expressed their belief that this was best for their sibling; three also said they thought it would be healthy for their parents.

Regarding gender-typical roles, findings were scattered. Three participants believed gender was a matter of importance between them and their parents, i.e. they perceived that one of their parents would have liked for them to be a different sex seemingly in order to fulfill the specific needs of that parent. As one participant shared,

I think my mother always wanted to have a daughter, and I think my father did, too. I think my mother wanted someone to sort of commiserate with. That sort of ended up being me partly because by the time [my older brothers] were independent, it was Tim and me. P4

And another:

I feel like I was really raised androgynously and fell into that so much because the other brothers...weren't showing up as the son that [my father] wanted. One was absent, the other one had a mental breakdown and was always mentally a little weaker than my father wanted him to be and emotionally more female, and then Mark, and for whatever reason I do think that I knew that. I do think that my father was longing for more of a son, not that he wasn't *delighted* for me to be born. He was - and we have an amazing relationship but I think I put on myself a kind of "be-both son and daughter to them, trouble free and take care of everything. Don't, don't, don't be a problem, don't be a kid." I think gender was in there. P10

In only one instance, in a family of two children, the participant shared her belief that her father's wish that she was a boy was directly correlated to her brother's disability. Only two participants shared the belief that the fact that they were women contributed to taking on gender-stereotyped roles (caretaker, nurturer). The remaining participants expressed difficulty with the question, as they could not imagine how the dynamic may have been different.

Occupations.

“If she wasn’t who she is, I don’t know what I would’ve done. I don’t know what career I would’ve picked....I can’t imagine not seeing the world the way I see it.” P8

In this study, ten of twelve participants entered fields characterized by helping, teaching, caring for, or healing others: three taught, three were in nursing/medicine, two practiced clinical psychotherapy, and two were mezzo-level social workers. Some participants indicated that their career is an expression of who they are. For many of these participants, going into a helping profession highlighted natural skills that they had developed over the course of their lifetime.

[Even] though I talk about wanting to have an identity separate from [my brother and his disability], I definitely recognized [my interest in social work was] because I had my brother. It’s made me aware of the social services world at a young age. It’s made me want to help other families cope with whatever their issue is, and recognizing that it’s not just disability but different families have different issues that impact that family, and wanting to be a part of facilitating that. But I’ve always just assumed, like, that’s – what else would I do? [To] me it just seemed like everything else didn’t feel like enough. You know sometimes, I was - I went through a phase of being interested in history and I like environmental science and I just felt like I wasn’t getting to the theme in my life, and that everything would feel just more peripheral and, for whatever reason, the stuff of social work is so relevant to me it’s just –how could I not do it? P7

Another sibling also noted the same proclivity, but remarked that, after doing some direct care work, she had to be careful about maintaining her boundaries.

I will tell you that I’ve done my best to steer clear of working with any sort of disabilities.... But ...I got laid off from [my job] and so I defaulted to admin work for a year and then I was like, “Ok, I can’t do this forever. I have to be in social work. It’s my passion. I can’t sit here and just do admin work when I know that there are more serious issues and things that can be helped. [...Doing] admin work, people don’t realize – they become petty over these stupid small things. And I’m like, “To people who really have a big picture of what the world is like, these things aren’t that big of a deal.” I actually really think it’s one of my better fits, being in social work. I don’t do direct care.... [and] it’s a really good use of my time and interests. P11

For a third participant, when asked about her motivation for becoming an art therapist, she replied:

(P) I think it was a number of things. The biggest one, though, was really seeking as many ways as I could to understand myself, in the end. You know there was certainly the desire to help others, and that was a role I naturally have had throughout my life, so [There's] sort of some natural level of – skill isn't the word I'm looking for – but I guess tendencies or ways that I am that lent to that kind of work. A lot of it was really just wanting to understand better and therapy helped me to do that. But from studying and doing all the coursework and the experiential work I just found that I was learning more, and then working with clients I was still just learning more. So there was a big piece that was healing myself as much as it was helping other people. P12

Self-description and general outlook.

A key question for participants was, “How would a friend describe you?” and “How would you describe yourself?” In addition to listing these primary responses, the researcher also noted other, spontaneous moments where participants described themselves. Participant responses are listed in Table 4 (p. 78); these are attributes participants provided, verbatim.

In addition to all twelve participants feeling as if they were more open and accepting, several spoke directly to the way in which their relationship with their disabled sibling influenced the way they, as individuals, approached life.

I guess in terms of changing the way I see things... more recently I called it the Zen of Kathy – ‘cause Kathy is always in the moment...and it really has helped me in the past couple years to think, “Is it worth getting nuts about or should I just relax?” And I think, “What would Kathy do?” “Oh, this really isn't that important. So I'm stuck in a supermarket line with 6 people. So what? So really what?” But I have to summon in the Zen, ‘cause for Kath it would be, “So you're standing there, amuse yourself.” That's what Kath would do, she's got a great fantasy world in her head and there's always things to rearrange in her pocketbook if we're waiting for a plane that's boarding late. How can you be bored when there's all this stuff to do? So I've gotten – not to make it be like “Oh, she's this perfect person...,” but the Zen of Kathy works so well ‘cause I think, “I don't need to be nuts.” P8

Table 4

Descriptions of Self

	Participants												n =
	1	2	3	4	5	6	7	8	9	10	11	12	
Loyal	-	x	-	x	x	-	-	x	-	-	x	X	6
Caring/Considerate/ Compassionate/Patient	-	-	x	x	x	x	x	x	-	x	x	X	9
Sensitive/Thoughtful/Aware	x	x	-	x	-	x	x	x	x	x	x	X	10
Empathic	-	-	x	-	-	-	x	-	-	-	x	X	4
Helpful	x	-	x	x	x	-	-	-	-	x	-	X	6
Creative	x	-	-	-	-	-	-	x	-	x	x	-	4
Independent	-	x	-	x	-	-	-	x	x	x	x	-	6
Studious/Hardworking	-	x	-	x	-	x	x	-	x	x	-	-	6
Reserved/Introspective/Private	x	x	-	-	x	-	x	-	x	x	x	X	8
Fun/funny	-	-	x	-	x	x	x	-	-	-	-	-	4
Problem-solver	-	x	-	-	-	-	-	-	-	-	x	-	2
Passionate	-	-	-	-	-	-	x	-	x	x	-	-	3

Another sibling shared that she had to accept her brother's disability and, in doing so, in being a witness to her brother's struggles with his disability, it allowed her to keep her own challenges in perspective:

I think Mark helped me to be more sensitive and to...slow down, accept someone else's pace... He'll have these periods of obsession. When I was little it was karaoke, and then he'd move on to a certain band...and he's completely cool with his absorption, so that is kind of neat because when you're absorbed in something there's a real...calmness.... And if I wasn't a part of that, accepting of that, then I might not sort of welcome a similar peace in me when I was with people... so I guess he sort of opened a new rhythm for me. And I guess I see that life isn't – you know, Mark struggles, he struggles with some very basic things, so very early on I accepted that, you know, life isn't just – there's going to be some struggles here and that's part of the ride. You got to deal with it. You got to deal with it and get up in the morning, and go through it, and talk about it, absolutely, but run with it because fighting Williams Syndrome isn't going to help him get through the day. You gotta, you know - I think there's a certain accept it, accept it and yeah, I guess I can throw pillows or a plate if I needed to but, really, at the end of the day, yeah, he's [my] brother. P10

Finally, as one participant shared, her sibling's disability allowed her to make meaning of and more gracefully accept that which was hard in life:

[Something] that I've realized as I've gotten older is that everyone has something in their life like that and it makes me feel more at peace with my brother's disability because it felt stigmatized when I was young, like, "Why do I have this thing?" You know, I deal. Everyone has their thing it's just for me, it has a name, you know? It's autism. And I think one of the difficulties of that is that I can look at a picture and know what some of my challenges are going to be, but everyone's going to have challenges they just can't necessarily predict them, so that's good and bad but that's just the way my life has worked out. P7

Participants' responses not only demonstrate how their relationship with their sibling changed their outlook. A sub-theme throughout is that their DS taught each of them how to be a "better person" – be more sensitive, be more patient, or how to put things in perspective.

View of and Relationships with Others

As some of the participants already shared, the roles they took on in childhood and adolescence not only influenced how they perceive themselves, but also how they interact with or perceive others currently. All participants (n=12) expressed that having a disabled sibling affects how they interact with people – strangers, friends, family members, and significant others - either because they continue to enact roles that they grew up performing, or because their perception of and ways of relating to those around them have been influenced by having a disabled sibling. Stated one participant,

I know that my early role as a helper in the family is something that really informs how I interact with people. I'm an intuitive listener and a natural assistant. I think I'm ... I wouldn't say I'm free of prejudice or anything like that, but I definitely feel that I always try to understand people's human experiences even if I don't agree with them or they don't make sense to me. I understand that there's just sort of a wide range of people out there and they all behave in ways which don't always sort of make sense, but they're all a part of the human condition, so... maybe there's a level of tolerance. P1

Several siblings (n=6) shared the general belief that, inherently, *everyone* has value and that it was important to not only respect that but also acknowledge it.

My heart is more- really open to Mark and to people who are handicapped, and it makes me want to be beside him, [and] let him not know he's alone, that he's seen and recognized and loved for who he is. I guess I would say that that's the most significant [way he's influenced me]; that I want to be a witness to who he is and [to] validate that, that cool person. P10

Ten of twelve participants felt their siblings disability made them more sensitive to other people's needs. For example, one brother shared how the relationship made him more attuned to others: “[I]t's made me a good listener, and sort of aware of other people's internal lives and different ways of expressing themselves” (P1). Another

sibling noted how her sister affected interpersonal dynamics within the family, as well as her (and her family's) outward perspective:

I ... still sort of think that a lot of what happens and a lot of the dynamics that exist are because of Katie, or center around Katie. Even if it's just involving my father and me... [it] always has some sort of thing of, I don't know. I guess she informs a lot of how we make our decisions and a lot of our outlooks. P2

Three siblings shared that having a disabled sibling made them less patient with others, and two shared that their spouses were the most frequent recipients of their impatience. One sister shared that she saw others as more able and, therefore, more advantaged, thus contributing to her impatience:

I expect other people to get it and manage and not need so much assistance.... 'cause people without disability especially, well, mainly, intellectual disability, I really don't have that much patience with [them] because I figure, "You have all these capabilities, you understand different vocabulary... Do I need to tell you three times to do this? Why didn't you get it the first two times?" ...I'm much more impatient with everybody else. P8

For all participants, their ways of interacting with others also extended to how they approached and viewed larger society.

View of the World

For the purposes of this study, "identity" refers to an individual's extrinsic experience of oneself as seen through one's views of the world and of others, and consisting of a person's subjective, anecdotal experience in one's familial and social environment. How one views the world exemplifies the ways in which the individual perceives, understands, and interacts with society; there is an *external* exchange between the individual and larger systems – organizations, groups of people, etc. – that takes place in which the individual enacts pieces of his or her beliefs. When all twelve participants were asked about the way(s) in which this experience affected their view of the world,

they unanimously shared a subjective sense that they were more sensitive or open to, aware or tolerant of others' differences. Some related it directly to moments in which others were cruel to their sibling:

...when kids would ...pick on her more...I think that ...made me a little bit more tolerant and accepting...just having grown up with somebody I found I was always having to stick up for. So I think it has affected my world view in just that I, I don't know, I tend to think I'm more accepting of differences just because of it. Also, not taking things at face value, 'cause I think there were a lot of limitations that people were ready to stick on her. They say "she's not going to be able to do this, she's not going to be able to do that" and so ...I *try* to be conscious of those limitations when I meet or interact with people, I tend – I try not to maybe give them the same limitations that I've seen people give my sister.
P2

One sister, who works with the Department of Mental Retardation, noted other people's tendency to be dismissive of people with disabilities. Implicit in this is her sense that society perceives those with disability as not fully human or, at the very least, incompetent:

I feel like a lot of people don't have [empathy]....They don't see [disability] or they don't want to see it, it seems. They just kind of ignore what's going on....[and] I feel sad for the people that – actually for both people. Some people are ignoring [disabled people] and they don't see how much joy and happiness these people [have] or they don't see them as real people. And I feel really sad for the people with disabilities because [they don't have the opportunity to be independent or] people [don't want] to meet them or get to know them; [people don't] see them as being in the community. We have that problem a lot with my work. P3

She noted a similar tendency for people, even friends, to act blind to all different kinds of disability:

...with some friends, I don't really - I'm friends with them but they don't come over. I don't think they see the world the same way 'cause some of them, even watching shows or going out to the mall noticing people, I notice they don't help someone with the door. That just gets to me. I feel like a lot of people don't have that [same awareness]. They don't see it or they don't want to see it, it seems. They just kind of ignore what's going on. P3

One sister's DS had a difficult time communicating as a result of her disability. Subsequently, she and other family members spent a great deal of time and expended significant effort to understand what she was trying to communicate. As a result, this participant expressed wanting to hear and understand what people had to say: "I want to understand why they're doing what they're doing.... I think it just gives you an awareness and a sensitivity to people in the world, people who have suffered. And why they may be reacting the way they're reacting" (P11). For one participant, the experience not only influenced her perception of the world, but it also informed her religious, political and occupational decisions.

I think for me what's most important to me is that every person has value, and every person has potential, no matter what. And that it's important to remember that with whomever you cross paths with and do whatever you can to help them ... assuming that everyone's worthy of love and giving them that automatically. When you think about, it's a really hard practice because some people you don't automatically appreciate but if you practice trying to appreciate who they are or how someone who loves them might see them, then that is like a whole way of living your life. I think that is how I try and see people and help people... but it really truly significantly impacts everything so I guess how I see the world you know is a good way to sum it up, but I think it's impacted what religion makes sense for me, what political point of view makes sense for me, how I am in relationships, how I've chosen my career. It's just....Yeah, it touches everything.
P7

Developmental Stages and Psychological Tasks of NDC

"I think my attitude about her has definitely changed over time and will probably continue to evolve."

Over the course of being interviewed, participants not only spoke about how they first understood their sibling's disability and conceptualized its effect on their family and themselves, they also revealed how this understanding shifted with time. Their sibling's disability, its effect on the family, and the NDCs relationship to their sibling came to

mean different things to them as they progress through different developmental stages and as they reached important benchmarks in their lives. These developmental periods can be categorized into childhood (birth to age 12), adolescence (13-19), and young (20-35), middle (35-50) and late adulthood (50 and older), and were categorized based on participants' descriptions of when events occurred in their development, or when they anticipate encountering specific tasks in the future. Each period has certain characteristics that reflect the participants' understanding of, emotional reactions to, thoughts about, and decisions related to their DS that, in turn, were formative to their experience and the development of their self-concept. Though not all participants had the exact same experience, the timelines in their personal stories share common threads.

Childhood

For all participants, childhood was punctuated with knowing that their sibling was somehow different. With this implicit knowledge, there was a search to know or understand more concretely that which made him/her different. However, children are limited in their ability to fully understand certain concepts or even connect them with their emotions on a cognitive level. As one participant said, when asked how her feelings changed over time,

Hmm...I'm guessing that one way it changed was just having more capacity to understand it or connect that even to some of the feelings I did have. I think part of the difficulty of thinking about elementary school and younger is I didn't, at that age, [have] the same ability to process things... I can theorize what I think was going on but I don't remember actually what it felt like. You know, a lot of the frustrations I felt...at that age I don't know if I even realized what they were connected to and why that was so difficult, but if I look back I was certainly not getting as much attention as my brother and sister a lot of the time and I imagine there was a lot of frustration and anger about that. Let's see... as an adolescent I was much more aware... P12

As stated throughout this chapter, however, children feel and sense when something is off, even if they cannot fully understand it. Despite this, they attempt to resolve hurt, sadness, or discomfort that they experience through their behavior. One participant did so by taking on certain the role of quiet, well-behaved child and his brother's caretaker: "[Around] the age of 6 or 8 it meant that as a family there were certain things that we had to do to take care of him and there were – that meant different roles for me as a brother" (P1). As another participant shared, her sense of wanting to care for her parents came from picking up on their emotional struggles with her brother's disability. In this portion of her story, one also sees how their response to her reaction to them set the stage for a life-long battle with self-doubt:

(P) [In addition to] knowing something was wrong with my brother, [I also knew that] that my parents, underneath their can-do attitude, weren't feeling so good and I think that was something I didn't intellectually know. I had no way of thinking about that until I was an adult. But I look back and I kind of see that and I think that there was such a desire to protect my parents, make everything okay for them.

(I) And why do you think that is?

(P) I think part of it was probably sensing the underlying anxiety and their sadness. And part of it, too, was - it was nonverbal...there were things they said that weren't always so direct but I think some of the way that they would praise me very excessively or tell me how good I was at everything - which I wasn't good at everything, [but] I certainly had the sense that I kind of needed to be that for them. They really wanted to see me as being extra good, to make up somehow. I felt this pressure to...be really good. Both in terms of schoolwork but other pursuits and I think in terms of stuffing down anger, to be a really good girl. P12

In describing herself later on in the interview, this participant stated,

This is so tough. I hate describing myself.... I've had some friends tell me I'm funny or I'm smart....It's not the first way that I always think of myself. And that's one [attribute] I question a lot, too - the whole smart thing, because my parents were so full of praise with that. I'm like, "Am I smart? I'm smart, and I'm not smart." You know, and it's like just back and forth. P12

From her, we understand that the meaning made, behaviors copied, and roles taken on in childhood may continue into adolescence and adulthood for some individuals.

Adolescence

More so than any other phase, participants cited adolescence as particularly difficult while growing up. While participants' cognitive capacity to appreciate the source, nature and manifestations of their sibling's disability had increased at this stage, many struggled to integrate this information into *their* own lives. Eleven of twelve stated that they experienced intense emotions such as embarrassment, anger, jealousy and resentment during adolescence and even into young adulthood. Some of these feelings were attributed to their parents (this was directly correlated to family dynamics around the disabled sibling) and others described it as typical adolescence in which everyone is awkward and embarrassed. One participant captured the particular difficulty of being both embarrassed by and feeling protective of her brother – and the confusion this created for her:

I remember hitting adolescence and middle school and just getting really embarrassed by him, like, “Oh my god, my brother does these things and my friends know about it and they're just really embarrassing!” ... Most of the time [I was] really pissed off and resentful at him, like, “Can you not see why doing these things gets people teasing you and you know, kind of, can't you understand how you're setting yourself up for all this social dynamic to happen?” and not getting that, no, he really didn't. And at the same time, if I ever witnessed any of it, feeling horrible and just wanting to come to his rescue and you know beat everybody up and say, “You can't say that to my brother!” ... [I was] never quite sure what I to make of these two things, like, “I'm so angry and I'm so resentful and I'm pretty mean to him, sometimes but God forbid if anyone else is mean to him, I'm ready to defend him.” P9

Ten of twelve participants shared how, at this particular stage, figuring out *who* to tell, *what* to say, and *when* to share that they had a disabled sibling required serious

consideration and was often accompanied by fear of rejection, concern about bringing friends home, and/or embarrassment about their sibling's behavior or presentation.

I went through a year where I had a hard time with it. I wasn't really embarrassed of her but [I was] having a hard time inviting my friends over and explaining to them about her disability and a lot of people would feel nervous about it.... [It] was maybe two years when it was like that.... It was on the lines of embarrassment but more other people's perspective of it, how they'd react, that would make me nervous. [It was kind] of a mix of both [being worried about how people would react to my sister and to me] 'cause some people – I had one friend who just didn't like the idea of it and refused to come over. We're not friends anymore. P3

Another sister shared how she had to carefully assess *others* to see whether they could handle the information that her sibling was disabled.

Well, I rarely invited people over because it was hard to explain. I just was like, "This is too hard." But, there were times and I had a few friends who, in high school, I became very close to. And I was like, "Ok, I feel like they could handle it." It was weird. I was like, "Ok, can they handle this and deal with it appropriately.... can they deal with meeting her?" And, so I felt like, "Ok. They've become really good friends and I'll invite them over. They can meet Kit and they can hang out. What's their reaction going to be?" P11

Eight of twelve participants expressed that leaving home, either for boarding school or college, was a very important factor in allowing them to develop an identity separate from that of their family, and, especially, as a sibling to a disabled child.

[J]ust growing up has enough of it's own challenges and so when I think we add elements of difference, I think for me I was really ready to go away to boarding school...I was a very independent person. I think it was good for me to develop my own identity separate of my sister. I had never been separate from my sister and I could choose – you know, had I been in a regular public school setting [there were people who] would've absolutely known who my sister was and I think I'd never had the opportunity to develop an identity separate of her, and to choose who knew that information about her. And it's not anything that I ever wanted to repress or that I consciously didn't want to share with people, but on the other hand – you know ... I acknowledge who she is and certainly that aspect of her - but I think I'd never had an ability to share my sister as I saw her, free of somebody else's perception of her, and I think what was great about --- is that I was able to – I guess I had some time for myself, I was able to do a little of the

growing up that I had started but hadn't really...I think I liked having the ability to share or not share that information as I so chose. P2

Another participant shared how individuating from his parents as an adolescent specifically around his brother's disability, allowed him to explore and claim other parts of himself, later, as an adult:

I can say I don't think I would've been able to come out of the closet until I had gone through that part of my teen years where I had to assert my independence and tell my parents I wasn't going to take care of my brother anymore. Because until then there was no room in my internal life to sort out what was happening with my own identity around being gay. P1

Finally, another common theme participants shared that first came up in adolescence and then repeatedly throughout adulthood (and with different feelings attached) was the wish for a "normal sibling." Seven of twelve participants expressed at least once having wished for or having desired another sibling. Some participants specifically wanted an older sibling. Of those who did not speak to this point, one was not asked about it as he was the first interview, and the remaining four had other siblings. The wish for a "normal" sibling reflected sadness and/or a sense of loss, especially because this sibling relationship was experienced as not being reciprocal:

I think the hardest – not the hardest part, but it's been challenging sometimes. I think the sentiment I had recently is the realization that...I was talking with a couple of friends who all had sisters and they were talking about going to visit – one of them was going to visit over spring break or something, and I said... something to the effect of "I wish I had a sister" and I didn't even realize what I was saying and I think because sometimes I don't think of her - I think I see other people and their sibling relationships now as they grow up, and you know they're friends with their siblings or they do social things with their siblings and I sort of forget, I sort of forget that aspect of it. Like she isn't my peer, and I mean, I still have a blast hanging out with her and I think of her as my sister, but it's just, I think sometimes I just forget and I don't think of it in the same way. P2

The wish for another "normal" sibling also expressed a desire for commiseration and validation:

Ohh! Yes! “Why isn’t there somebody here to help me think about this?” Oh, for years I wanted a big brother and all my friends who had big brothers said, “Oh, no you don’t!” And I’m like, “Yes, I do!” So, yeah, especially the idea of one other sibling that’s older than me so I’m not the oldest with my sense of eldest responsibility to, you know, “You need to make sure the family holds it together.” Or just another family member who’d lived it, been in it, knew what it was like, who could say, “Yeah, you know...Didn’t it drive you crazy when such and such used to happen?” And, “Gosh, we’re dealing with it like this now, maybe we should do it differently” or just someone who had lived it with you who you could bounce things off of. P9

Young Adulthood

This process of negotiating defining oneself as an entity separate from one’s family continued for all twelve participants. As one participant, aged 24, shared,

As I started entering college, I was realizing that that experience was so intense that I sometimes completely enmeshed that experience with my identity and so I really wanted to know, like, “What am I beyond that experience?” because there were so many qualities about myself that I attributed to [my brother]: “Because my brother is that way, I’m empathetic” or “because my brother is that way, I want to ...be in the helping profession.” But I wanted to be connected to that apart from just that experience, have other experiences that feed into that so that I was more than a sister of someone with a disability. And I think I also became more aware of what will this mean as we become adults. What’s my role going to be? What if my parents die? Which was always something that kind of freaked me out but when I got older it was like, “Well someday my parents are going to pass away and it’s going to be my brother and I, so what’s that going to look like?” So really processing some of that stuff and, still, processing that stuff. P7

At this age, having left home, is when ten of the participants expressed that, with time and space away from their family, they came to terms with what growing up with a disabled sibling felt like and what it meant to them. Shared one,

Now that it’s not a part of my life, I don’t I don’t have strong feelings about the disability or even particularly about the disability in our family. It’s a part of what has informed my understanding of people and the way they are, and even myself. P1

Eight shared that it was only then that they had greater appreciation for the job their parents did and they had developed an understanding that many had done the best they

could with an immutable situation. It was also during young adulthood that five of seven participants engaged in therapy and, using therapy as a catalyst, uncovered and made sense of much of their growing up and how having a disabled sibling affected them. As an adult, one sibling retrospectively discussed the ways in which she coped, how her ways of coping changed over time. She also explored the different feelings she had at these times:

(P) I'd get upset a lot and cry, and if I said that I didn't like something about her or didn't want her to live there, I was told to go to my room. I spent time in my room, but I [also] spent a lot of time over at friends' houses. [My friend Diane – her family] almost became my second family in that her mom, *her* mom taught me to ride a bike. And I was able to do some trips with them, and it was a place to get away. She was an only child and she had all this cool stuff, so, you know, so it was a great place for me to hang out....But as far as understanding or knowing how to relieve stress, no, I had no idea about that. I think I just stuffed a lot of it inside and I think that if, at that time, if people that asked me or talked to me, I would start crying ...because I had a lot of emotion built up.... [Then] I started writing, journaling in 6th grade. I wrote a story about my sister....And it sounds horrible at the time, but I wrote a story called, "The Monster in My Life." And then I wrote another one in high school about my sister and it was very loving and kind and understanding.

(I) That's a pretty marked change. What happened over the course of those years, do you think?

(P) Well, I think I became older. You know, mature. And seeing this over and over again and understanding and like, "Ok, I get it." To a certain degree. And you know, you deal with it. P11

The process of gaining insight into one's childhood and adolescence was one that many described as emotional and transformative, especially as it helped them make sense of who they were.

All twelve participants expressed an evolving understanding and relationship to their sibling's disability, and the complexities of how it affected them (the NDC) and the family, over time. For the younger participants in the study, early adulthood also marked

a period during which they began to think ahead to the possibility that they might become guardian to their disabled sibling. Of the seven participants aged 21-34, all reported having thought about the future and what will happen to their sibling when their parents die. Five have already begun to make plans or take steps toward arranging guardianship. As one said, “At some point I’m...going to have to figure out where she’s going to be. Right now that’s my mom’s job, but that will be my job soon enough” (P6). This was also the point at which some siblings, particularly those who only had the one other, disabled sibling, wished for another brother or sister with whom they could talk. One participant expressed:

[Sometimes] I think of it as my parents age, that camaraderie, having that someone to make decisions with. I don’t know. There’s sort of - there’s the realization that I don’t have anybody like that to share those experiences with. I think it can be challenging...

For those young adults who have yet to create their own families but for whom this is a consideration, knowing that they will have a sibling to take care of raises many considerations about finding a partner who will know about and be supportive of the disabled sibling, too; being aware of genetics and the possibility of having a disabled child of one’s own; being responsible for one’s sibling and having less time of one’s own.

One participant shared her thoughts on these topics:

I look to the future when I’m a mom and when I’m more of a real adult, rather than the adult I am now, and it’s painful for me to think of being so distracted by my brother that it affects my own kids. When...what was hard for you, [I don’t want to] do that in my own kids’ life, even though I think ultimately of taking the good but removing some of the bad of that experience for my own kids. [Also], in terms of where to live, location-wise, that’s really tricky because I don’t really want to move back to -----.... Also, [being] in romantic relationship it’s been like, “Can this guy handle it?” ... because I’ve always kind of felt like, “No guy’s going to get this and if a guy doesn’t get it, he’s out.’ [Something] else I thought about was about having kids someday and being scared about the

potential of having someone with a disability and if, just, I don't, I'm not thinking about having kids anytime soon but knowing that that will be something to think about.... I don't – there isn't a lot understood about autism. From what I have heard recently, it's not so much of a risk, but it doesn't matter because I'm still sensitive to it, you know I'd still worry about it. If someone told me that there was a high likelihood that I would have a child with a disability, would I still make that choice? And I don't know, I don't know if I could, I don't know if I would want to make that the theme of my life the whole way through, so.... [People] who don't have siblings [with a disability], they don't worry about having kids, they just get pregnant, whereas I think I'll be more aware of "okay, what are the risks, and what could happen?" P7

Middle to Late Adulthood

Of the twelve participants, nine report having plans to take on care of their sibling. Two have older siblings who have already assumed this responsibility, and one participant did not discuss her family's plans. Of the two who are the primary caretakers of their siblings, one takes direct care of her brother (he lives with her and her family) and the other cares for her sister from afar, as the latter is in a group home in the town where her family grew up.

For the sibling whose brother recently moved in with her and her family, she finds herself negotiating similar tasks that she had in high school. Here, she describes the mix of emotions that accompanies supporting him in the transition to her home and community:

I had some hope for him coming to live with us here ...because I thought there are a lot of neighbors around us that he will see frequently...and that will take some of the pressure off of me as being sort of his only social contact . I'm sort of his buffer between him and the world, you know, and I need some relief from that role and that pressure and here he'll have more people to interact with. Yet, at the same time, knowing how he was likely to act and that he would come across with kind of these bizarre mannerisms and awkward, I felt really reluctant to encourage him to get out into the community and do stuff, like, "Oh my god, what are these people going to say? How many of these people really understand Asperger's? How do I explain it, or is it even my role to explain it? Maybe he should just go out there and they take him for who he is, and they take him for whatever he is."

[There was] this bizarre tug of war going on in me between how much do I buffer his introduction to the community and pave the way for him, versus say, “Hey, you’re an adult. Get out there. How people and you interact is totally separate from me. I don’t need to be in the midst of it.” P9

The other participant, in taking on her sister’s care, has taken on several roles: she’s become her sister Kathy’s health proxy and is Kathy’s primary advocate when it comes to ensuring that her sister continues to receive good care. She has had to make arrangements in the event of her own death, identifying other family members who would be willing to take on guardianship. She has been the one to break the news to Kathy that their parents had died. This, she notes, was especially difficult: “I only regretted once or twice that she [had] Down’s, or [I wished] that she was normal, and that was when both my parents died because then there was no one to really take care of me.” They visit regularly, but it has now reached the point where she sees her sister is declining in ability and she has had to begin considering what will happen if her sister begins to develop Alzheimer’s, a common side effect of Down syndrome. Here she highlights some of the questions she faces:

Now that I’m getting older I’m more aware of [death]. The idea – sometimes I can’t think of what’s worse – if I go first, because then in my eyes there won’t be anybody to take care of her, even though obviously she’s taken care of but not the same way – or if she goes and then I’m the one without her. And she’s been such a huge part of my life. P9

For other participants, who have yet to take on this role, the question of what the future holds for them elicited a myriad of thoughts and feelings. The majority of them (n = 9) were concerned with being their sibling’s guardian. Four thought about the possibility that their sibling might die an early death. Three wished to spend a different kind of time with their sibling than the time they spent together growing up. One

considered the role of genetics when thinking about creating her own family in the future. For those who look ahead and anticipate being guardians, this thought is met with some apprehension. One sister said,

“Gosh, what if I can’t do this as well as my parents did? It’s really important to.” And then there’s the piece of just how much time will that take? As much as I really enjoy him, I have a lot going on in my own life and I don’t want to have to give up lots of time, and then the guilt that goes along with that. How am I going to balance that? And what will that be like? And you just don’t know. There’s just no way to know how that’s all going to play out. P12

For one participant, it brought up old feelings about being overwhelmed and absorbed by her brother’s disability:

I’m scared. I don’t really know what it’s going to be like. Again, that struggle that’s always inside of me of wanting to help, help, help but knowing that I also need to set limits and only take on what I can take on. And so I just feel kind of nervous about that, and I think ahead of when my parents aren’t around and I, I don’t know what the sharing is going to be like between me and my sister. I just don’t know – it’s kind of this big unknown. So I’m not really sure. I mean I know my parents don’t expect either me or my sister to have them in our homes. So that’s a relief that we can have some distance. And also keep them in our lives. I don’t know. P5

One participant took a wait-and-see approach:

Right now, I’m happy that I don’t really have to think about the future. I’ve built a nice, a nice supportive life for myself that’s away from my family. By no means have we disowned each other, we still enjoy each other’s company but I’m not responsible for my brother’s future yet, so I know that someday there will come a time when I need to be involved, but right now I’m enjoying the fact that my parents are able-bodied and are taking care of him....Again, my parents have been very good advocates and I think that they are doing a lot to set up good structures for my brother. And I know that I won’t be the only person, the only caregiver or advocate for my brother, but that someday – a long ways from now, hopefully - my parents won’t be around and I’ll be a part of that mix but right now I don’t have to be.... [When I think about that time, I have a wait-and-see kind of feeling, like, I could be worried about it but I don’t really know what’s going to happen and, so, I’m not going to spend a lot of time thinking about it or worrying about it. P1

For many siblings, the passage of time has allowed them to make meaning of this unique relationship, and to understand it in different contexts, using different lenses colored by their own experiences. Therapy, for some, has been another process through which some participants have made sense of this relationship and its impact on their identity.

The Role of Therapy

“Wow, the world has completely changed because I don’t ever remember – I never spoke to a professional about my role in the family around him.”

The sibling who provided this quotation entered therapy as an adult and found it enormously useful. Above, he ruefully remarked about how much things had changed since he was a child, not only because services were not offered to NDC, but over thirty years ago NDC were not identified as a population possibly needing additional support. Not everyone who has a disabled sibling feels the need for or wants therapy, but the majority of participants in this study (n=10) found or believed therapy was or could have been useful. Only seven participants actually entered into therapy and dealt with issues pertaining to their DS. Of the five who did not engage in therapy, three stated they wished they had done so at an earlier point in their lives; one stated that he would have preferred something less formal than therapy, but did say that he would have appreciated support from others who had had similar experiences as him. Only one participant expressed that she felt no need to attend therapy related to her disabled sibling.

Of the seven participants who did participate in therapy, six found individual therapy useful. Four of participants took advantage of one-on-one therapy as adults whereas three of these engaged in it and found it useful as adolescents. Two participants

shared how individual therapy, in particular, helped them makes sense of their experience growing up. One brother shared how therapy helped him grow those parts of himself that had, essentially, been retarded as a result of putting his parents and his brother ahead of himself:

When I went to college I sought therapy. And I would say a good portion of the time that was spent in therapy then was around my feelings about my own identity and the things that happened in my family and was sort of the things I felt were sort of lacking in terms of my own care and attention. [Obtaining therapy], I think, it was an important part of my growing up. I was probably twenty at the time and a lot of my own sort of problems around self-care and I don't remember, just coping with my own emotional life it helped to revisit the family dynamics and kind of recognize the, um, the things – the ways in which I was sort of caring, hurt or confusion or other things..... talking about those things in therapy helped to I guess concretize some and understand some of my difficulties around taking care of my own feelings and making time to recognize what's going on in my own internal life instead of always others instead of me. And it also helped me to I think I said I was angry without even knowing it, and it was really in that period of time that I got to sort of (unwrap) my anger and live with it and not be angry anymore. P1

Another shared how individual therapy provided her with mirroring that she had not had as a child, and it helped her make sense of the non-verbal messages she received when she was younger:

It was great to have someone who really was listening to what was going on for me because my parents never did that for me. I don't think they could, I think it was too threatening for them. And that was another thing that my therapist sort of helped me make sense of, is stuff that was so non-verbal, like thinking back to all the time where I don't have concrete memories of what was happening [but] imagining how there must have been so much anxiety for my parents. I mean, this was new to them, they didn't really know what to do, what was happening. You know, not all their friends could support them. There were people who just sort of disappeared from their life when I was four, so it helped me get a sense of how much I was probably picking up on just the feeling in the home environment, which is something that I don't think, at that age, I could've understood on my own. The therapist really helped me to get a sense that kids absorb that and just sort of take it on, and I was like, "Oh, that explains a lot." P12

This same sibling also noted that therapy helped her recognize the feelings that she had internalized, and allowed her to transmute them into something more positive:

It really helped provide a context for a lot of feelings that - I didn't know where they were coming from, so I just assigned them to myself, like it's just something inherently bad in me. So that's a really bad feeling! Therapy helped me realize that depression is a state that you're in and underneath that is a lot of anger. And these are all things you can feel, and it's not who you are. And that was such an awakening, I was like, "Oh, wow, so there's hope!" It gave me a lot more - over time - compassion for myself and for my family. [I was able to see] more realistically what we'd all gone through together, and the good and the bad of that. It was so validating and helpful for someone to see what that was for me and help me make sense of that. It felt a lot less crazy and sort of normalized a lot of the feelings that I had that I felt bad about. P12

Three participants stated that they wished their family had engaged in therapy together, when the participants were children, with one saying that she would have also found it useful as an adolescent. One described how, when she suggested to her mother that the family go to therapy together, her mother laughed and then became angry. This same participant eventually attended group therapy as an adult. It was an important experience for her in seeing the more subtle ways in which she'd been affected by the experience – including her overwhelming tendency to push her feelings aside, which led to self-doubt and difficulty expressing herself:

When I was growing up I was covering up a lot of that stuff without realizing it and I didn't really have the ability to express it and I think I kind of silenced myself a lot.... [These coping mechanisms], they have their strengths and their limitations. When a situation arises, I'll kind of barrel through and I'll be the one who kind of leads other people and then it'll, sometimes it'll hit me afterwards or later, after I'm fully into something to realize, "Oh, wait a second..." So I feel like I sort of have this delayed response to things, which I think has gotten better, but it takes me a long time to process to really connect with my emotions because I was so cut off from them for so long. I've gotten a lot better but you know a lot of times I won't realize that I'm upset about something until afterwards or when I realize that I'm upset about something, it's hard for me to put a voice to it. And so, that has – that drive in me to be so strong has, you know, been helpful or has held me back, depending on the situation.... [When I started therapy] I didn't

even really know how to talk about myself. I mean I got into the group and I immediately went into that quiet mode...I had no idea what to say... [D]uring the week events would happen and I would question, “Should I bring this up in group? Should I not?” then I’d go and then I would feel like it was too small to even talk about. So it was so helpful to be in the group because the group was really focused on being authentic and calling people on stuff and helping. The group really helped me look at that and why. We found a way to get me to practice talking. It was like this huge process just to get me to talk, which I felt so silly about but at the same time, I don’t know what I would’ve done without that experience because it was so helpful. Just to learn those basic skills of being able to do that and having all these people witness it was so powerful... P5

Three participants had participated in group therapy, two of these as adults and one as a child. The participant who attended it as a child did not find it to be useful, whereas those who attended as adults found it to be a supportive environment in which they experienced commonality with other group members. Six participants said they wished they had engaged in some kind of group therapy, three as children, two as adolescents and one as an adult. Two participants noted how therapy would have been particularly helpful in managing difficult feelings and transitions into different roles. One shared how the nature of group therapy, in particular, would have helped during two major developmental stages:

It especially would’ve been helpful to talk to other people who had disabled siblings... High school would’ve been a good place to start, but [therapy] would’ve served different purposes at different times. Like in high school getting over the embarrassment and learning to value it, and then as more of a young adult there’s learning what your new role is, learning how to process it, learning how your behavior is related to that experience. How that can be good or can be bad, and learning how to move past it or integrate it; make it an asset. P7

For some, the timing of therapy and the therapeutic modality – individual, group, or family, was critical. One participant participated in three groups as a child later in elementary and into middle school. However, she did not choose to be in these groups, noting that, retrospectively, they felt “campy” or “hokey.” She talked later about her

belief that family therapy would have been preferable but shared how determining *when* that would have most useful was not as straightforward:

[Here's] where I think the tricky part would come, talking about the [when to start therapy]. I talked about being skeptical in elementary school. If I thought I was skeptical and sort of wary then, I can't imagine what a family therapy session would've been like in high school. So I think, ideally, it would've been something that started [in my] pre-middle school, pre-adolescent [years, and that] worked to create the foundation... [Because] when somebody's younger, they might be a little more receptive than adolescence where shit's already hitting the fan, you know? P2

The majority of participants in this study -- regardless of whether they participated in therapy or not - overwhelmingly supported therapy as a needed and important intervention that helped them make meaning of their experience, especially insofar as this process helped them better understand their own feelings, behaviors, and relational patterns in having grown up with a disabled sibling.

The next chapter of this study will discuss the relevance of the themes in the eight major categories to the literature previously reviewed and it will discuss the ways in which this data can inform a social work practice

CHAPTER V

DISCUSSION

This study sought to answer the question: What is the long-term impact on the identity formation of adults who grew up with a disabled sibling? This chapter will discuss in greater depth the findings from this study. It will also contextualize them relative to the prior studies and theoretical frameworks presented in the literature review. Toward the end of this chapter, the strengths and limitations of this study, future areas of research, and implications for practice will be further discussed.

The bulk of the literature examining people who have disabled siblings is primarily quantitative in nature and, thus, takes place over a short period of time, capturing its participants in a single snapshot – a moment in what will be a lifetime of making meaning of this particular relationship. The drawback to such studies, particularly the ones that look primarily at children and adolescents, is that they present their data as empirical information that is representative of the participants' pasts and of their futures. This study found that understanding what it means to be brother or sister to a disabled sibling is, in fact, an *ongoing process* through which the non-disabled sibling takes in and makes sense his or her sibling's disability, and the nature of this process is important.

The Importance and Impact of Knowing

“Why does my brother/sister act, look, sound ‘different’? How did it happen? Will it happen to me? Why does s/he do that?” These questions highlight the curiosity of

and observations made by children that characterize early childhood. They underscore the uncanny knack that children have of knowing when “this thing is not like the other.” These questions are also tasks particular to this stage of life. “Why?” is a normal and expected question by children between the ages of 2 and 8 years of age. It lends structure and meaning to the child’s internal and external world by explaining how and why the world (and people) works as it does; this is bedrock knowledge to which the child refers back in times of uncertainty.

Whether or not NDC are told by their parents about their sibling’s disability, they know, implicitly, that something is going on, and from this instinctual place they begin to respond to their sibling’s needs, to their parents’ feelings about the disability, and to others’ reactions to the disability. This initial response begins to inform *who* they are. All twelve participants in this study knew that their sibling was disabled before anyone ever told them, and before they were able to put a name to their sibling’s difference. For seven of these participants, explicit information - the name, etiology and/or how the disability affected their sibling - helped them place it in a context that then informed how they related to their sibling, to the disability, and how they understood it within their family. As one participant in this study stated,

[O]ne of the early things was [that understanding the autism] provided a language around his behaviors and his temper tantrums, which were pretty explosive even prior to that period of time but you know, it was the autism that made the temper tantrums happen and then maybe later... I understood that he had to be schooled separately and then sometime around the age of 6 and 8 - it meant you know, that as a family there were certain things that we had to do to take care of him and that meant different roles for me as a brother. P1

Not only did knowledge help him contextualize his brother's difficult-to-understand behaviors, it helped him understand family dynamics, and, for better or for worse, it helped him identify where and how he fit into his family.

The literature spends little time on the NDC's *in vivo* experience of learning about his or her sibling's disability, but it does discuss the importance of open communication between family members and dissemination of information about the disability by parents to their NDC, citing these as a protective factors for NDC while growing up (Giallo & Gavidia-Payne, 2006; Levy-Wasser & Katz, 2004; Opperman & Alant, 2003). For children, knowledge provides understanding and can temper negative feelings and responses. For one participant it helped her to externalize the negative feelings and reactions she had to her brother's disability. "My knowledge... helps me to not take him personally or get frustrated if I know that he's not his behavior" (P10).

The importance of information is most noticeable for the participants who did *not* have information. They had difficulty identifying which behaviors resulted from the disability, and which reflected their brother's or sister's personality. Not knowing also contributed to a sense of isolation, an experience common among NDC (Dew et al., 2008; Lobato et al., 2005; Rossiter & Sharpe, 2001; Sharpe & Rossiter, 2002). In the case of one participant whose brother was diagnosed with Asperger's late in life, having this knowledge finally provided her access to a community of people who knew about the disease, could help her understand it, and could provide her with information about resources available to support her *and* him. In her late forties, it did not quite erase her experience of her brother's social awkwardness and intemperate outbursts and their impact on her; as she stated, "there's too much baggage." However, she noted that had

she known earlier, it might have helped her make sense of behavior that, otherwise, simply seemed inappropriate and embarrassing to her.

As with most things, however, obtaining this knowledge comes in stages and is a more fluid process than is generally assumed. For example, nine siblings, regardless of whether they received information about their sibling's disability as a child, continued to independently seek out facts about their sibling's disability throughout adolescence and adulthood. Not only was that information important for their own understanding, that participants sought it out at different stages of life underscores how one's perception, as it relates to age and one's growing ability to make sense of complex issues, changes with time. This supports the idea that identity is not formed and then fixed during the early stages of one's life but is an ever-evolving process that is informed by experiences and important relationships the individual has over the course of one's lifetime (Seligman & Shanok, 1995). Nowhere in the literature is the ongoing nature of this process measured, noted, or remarked upon and, yet, studies suggest that having a DS puts one at higher risk for depression and anxiety (Giallo & Gavidia-Payne, 2006; Naylor & Prescott, 2004; Rossiter & Sharpe, 2001; Sharpe & Rossiter, 2002). The findings of this study support the importance of considering the longer-term effects of this relationship upon the individual, as well as the significance of how the individual understands his or her sibling and makes meaning of the disability over the course of his or her life.

Parents' Handling of the Disability

There is no one uniform way in which families and parents handle the news that their child is disabled. While the literature indicates that NDC are at lesser risk for developing symptoms of depression and anxiety in families who communicate regularly

and openly about the disability, it also reflects that the parents of a disabled child experience a higher degree of stress than average, and this can lead to marital problems and significant strain on each parent (Giallo & Gavidia-Payne, 2003; Fisman et al., 2000). In this study, the stress of having a disabled child and the division between parents over how to manage this contributed to the breakup of two marriages, as reported by two participants. While the other ten participants' families remained intact, participants observed that the disability resulted in the significant bifurcation of parental roles, usually between that of caretaker and financial provider. In these roles, participants noted that parents had significantly different attitudes about and approaches to the disability. These informed how participants coped with their sibling's disability, with several participants sharing that they tended to take on the attitude or approach of one parent more so than the other.

Just as the presence of disability alters the family landscape and parents' roles, so does it frequently result in increased time and energy for the disabled child. In this study, this dynamic consistently resulted in the NDC receiving not only a different amount, but a different kind of time and attention from their parents. All twelve participants expressed that they received less time and/or attention from at least one parent, an experience regularly reported by NDC at all ages in the literature (Davis & Salkin, 2005; Dodd, 2004; Lobato et al., 2005; Richmond et al., 2005; Safer, 2002; Strohm, 2007). The most explicit way in which NDC reacted to this disparate attention was by way of feelings: they felt neglected, angry, frustrated, and jealous toward their parents and/or their disabled sibling. The findings of this study indicate that lack of time and attention given to the NDC resulted in NDC experiencing different kinds of expectations, though

these may be expressed explicitly by parents or felt implicitly by NDC. Reactions to or coping mechanisms developed to deal with these pressures are more subtle and can manifest in ambivalence, as Opperman and Alant (2003) noted. For example, in one way or another all participants appeared to take their parents diverted attention in stride, noting that the latter “did the best they could” under arguably difficult circumstances. Others expressed ambivalent feelings that sometimes appear in a participant’s tendency to contradict him/herself. For example, one participant stated several times throughout her interview that her parents had equally high expectations for both her and her sibling. She stated that her own sense of having to achieve “above and beyond” was something *she* had taken on, and she said very clearly that it was never something they had expressed to or asked of her. It was only toward the very end of her interview that she finally said,

They have a set of expectations for both of us, but they expect me to achieve. I think my father wants me to achieve for the both of us what she can’t. I think for him it isn’t good enough just to have someone who’s mediocre; it’s got to be someone who really excels ‘cause then you’ve got this one child to be like...you know? P2

Regardless of whether her parents expressed this sentiment out loud, this participant had a very clear idea what they – her father, in particular - expected of her and how she could and should live up to that. The theme of implicit versus explicit once again becomes clear: what is felt, observed, or experienced on an emotional or intuitive level contributes just as significantly to one’s experience as does that which is expressed explicitly. The majority of participants did not report that their parents voiced explicit expectations of or for them, and yet they still experienced *feeling* as if they had to take on certain roles, perform better, help out at home, or they thought it would be best to put aside their own

feelings. Certainly the literature reflects the ways in which NDC react to differential treatment, e.g. by acting out or withdrawing (Davis & Salkin, 2005, Richmond et al., 2005), or take on these expectations, but the literature does not delve into how these expectations are communicated.

Advocating for one's disabled child was also a common role taken on by parents and observed by participants. Seven participants noted that their parents were staunch advocates for their disabled child, working hard to afford the latter services and support in the form of education, therapy, and social activities. While there is no link between the degree of parents' advocacy and the NDC's feelings around having unequal or qualitatively similar time and attention, what implicit message is sent when a parent's time and energy is focused on helping one child succeed? Is the assumption that the other requires less by virtue of his or her own ability? Do these dynamics contribute to NDC learning at an earlier age how to care for themselves, be more independent, or differently identify what it means to ask for help (for, what does help "look" like when one's sibling requires help for even basic tasks)?

The data from this study suggests that participants viewed their parents' advocacy as admirable in the sense that it was and is an action that society perceives to be positive. However, for the NDC, it also meant that one's parent was unavailable. As one participant shared,

My dad was there – he seemed there for Kit but he wasn't there for us, or at least for me. I didn't feel like he was there for my brother, Kevin. When I was in high school, he was getting his master's in business and then, so he was not around a lot and I was like, "Dad, God... Kevin really needs you. He needs you to like hang out with him." ... So, yeah, I really had to grieve that. That my dad wasn't there. It was hard. P11

That other participants related their parents' unavailability with learning to be independent, suggests that the time consumed by a parent's advocacy could well have a similar impact. What the literature does reflect, is that differential treatment, as defined as different time for or expectations of one child versus another, by parents is linked to more negative external behaviors and depression in children (Brody, Stoneman, & McCoy, 1992; Richmond, Stocker, & Rienks, 2005).

So what does differential treatment, and the subsequent feelings and reactions by NDC, look like in adulthood and how does it inform identity development? All participants spoke about differential treatment as a phenomenon that existed in the past. In fact, a common experience of participants upon reaching adulthood was greater empathy for their parents and the acknowledgement that the circumstances were difficult for the entire family. In this, as in other parts of this study, it is difficult to compare and contrast the experience of adults with literature that focuses mainly on children, although it does highlight the need for further studies that interview an older population and look for pertinent parallels between them and the existing literature base.

Identity Formation: The Creation of the Emotional and Psychic Self

Dueling Emotions

Participants in the study expressed a wide range of emotions and shared a diversity of experiences when asked about what it was like to grow up with a disabled sibling: there was both anger and resentment, as well as pride and a unique sense of personal self-confidence. Some participants did not feel safe in their homes growing up as a result of their sibling's tendency to act out or be aggressive, whereas others describe a disabled sibling who was more docile, loving, and (seemingly) easygoing and happy.

This reflects more recent literature that having a disabled sibling offers a range of experiences that cannot be simply categorized and then generalized (Caro & Derevensky, 1997; Davis & Salkin, 2005; Dew et al., 2008; Grissom & Borkowski, 2002).

So what of the supposition by some that having a disabled sibling places a child at risk, more so than the average person, for anxiety and depression (Giallo & Gavidia-Payne, 2006; Lobato et al., 1987; Naylor & Prescott, 2004; Opperman & Alant, 2003; Rossiter & Sharpe, 2001; Sharpe & Rossiter, 2002)? This study suggests that growing up with a disabled sibling is likely to pose challenges for parents and children that are not commonplace and are more difficult to cope with. However, to solely attribute anxiety and depression to the disability without recognizing the myriad of other factors that also contribute to the NDC's experience – including the type and degree of disability, family dynamics, individual resiliency factors, socioeconomic status and the availability of familial and communal resources – equates these negative feelings and experiences with the disability, and with the disabled person. Reviews of the literature, more so than studies themselves, note the number of variables that can affect a family and the non-disabled child, and generally call for further research of these variables to further explicate these (Dew et al., 2008).

As it pertains to this study and relative to the literature that predicts negative development of pathology in NDC, it is notable that only two participants in this study expressed feeling depressed while growing up and none of the participants described feeling anxious during their childhood. While this does not mean that participants did not report feeling this way then or now, it is possible that feelings of anxiety have been sublimated and present in different ways, i.e. as seen in NDC taking care of others or by

expressing the sentiment that parents “did the best they could.” It might also suggest that, as adults looking back on this experience retrospectively, this may not their predominant memory nor is it reflective of their current experience.

In this study, the majority of participants expressed both positive and negative feelings, but shared that they experienced the latter more while growing up. Their current experience, and how they have made meaning of it, was much more positive; they described feeling more open and aware, tolerant, and independent as a result of having a disabled sibling, a finding supported by Dew et al. (2008), Burton & Parks (1994), and Marks et al. (2005). While their childhood emotional experience corresponds with the literature, their adult experience stands in stark contrast to it and, again, emphasizes why more studies on adults are necessary to understand how this relationship affects non-disabled siblings over the span of their lifetime, and in different ways at different times.

It is also possible that there appears to be less congruence between the child and adult experience of having a disabled sibling because so much of the literature on children is quantitative. Also, in many instances, results were obtained using parents (mostly mothers) and/or teachers as opposed to the NDC themselves. This suggests that directly interviewing children and adolescents, as well as adults, about their experiences could yield responses that more accurately reflect a range of feelings and experiences about what is clearly a complicated relationship.

View of Oneself, Others, and the World

This study highlights the degree to which this relationship is formative to the non-disabled adult’s identity, as defined by how one sees the world, others, and oneself.

Adult quantitative studies enumerate particular ways in which the NDC experience has

impacted them and the findings of these studies closely match those found in here. For example, Grossman (1972) noted that non-disabled siblings expressed more tolerance of difference and felt as if they had greater sensitivity to and compassion for others, an experience echoed by all twelve participants in this study. Burton and Parks (1994) found the non-disabled adults with a disabled sibling had a higher locus of control* than siblings who did not have a disabled brother or sister. While that particular quality was not measured in this study, participants did describe seeing themselves as independent and resourceful. Begun (1989) studied the NDC-DS relationship and found that NDC saw the relationship as positive but not intimate and not competitive. Similarly, the majority of participants in this study felt the relationship was a good one and that they loved their DS, but that the nature of the relationship was different in that it was not reciprocal. In discussing how it was different and what this translated to over time is where the value of a different type of study – qualitative versus quantitative – is useful.

Qualitative studies are better able to exemplify in greater depth the inextricably formative nature of this relationship in the identity formation of NDC (Davis & Salkin, 2005; Flaton, 2006; Safer, 2002; Strohm, 2007). In these studies, as in this study, non-disabled adults share the unique factors particular to their family and their environment that then contribute to their experience. In so doing, each individual was able to relate how s/he was impacted. This was most often seen in the roles that participants took on (caretaker, nurturer, high achiever, helper, advocate) and how they described themselves (sensitive, aware, responsible, caring, patient, introspective, loyal).

* Locus of control is defined as the “realization that one has control over personal decision making and can exert significant influence on life events. How an individual perceives the viability of his or her personal control is greatly influenced by how he or she values himself or herself.” (Burton & Parks, 1994, p. 181).

The literature on adults confirms these experiences of the non-disabled adult's self-concept (Davis & Salkin, (2005); Flaton, 2006; Marks et al., 2005). It is most noticeable how these attributes and roles play out when looking at what professions NDC choose. While a quantitative study would note and speculate on the correlation between the how frequently NDC go into "helping" professions and growing up with a disabled sibling (Burton & Parks, 1994), this study and that by Marks et al. (2005) directly pinpoint why NDC go into helping professions in higher numbers, relative to their peers who do not have disabled siblings. For the majority of participants in this study, their experience of their sibling provided them with certain skills and beliefs that led them to feel most comfortable and efficacious in a helping profession. Some also entered into these fields because they wanted to advocate for others who were disabled or because they wanted to improve others' lives. Marks et al. (2005) discovered that, similarly, non-disabled siblings most frequently went into Special Education because they wanted to make positive change, and they attributed this to having grown up with a DS noting that, had their sibling not been disabled, they likely would not have entered the field.

This echoed another sentiment by participants: the sense that who they were was inextricably related to the fact that their sibling was disabled. Not only did this alter some participants' career paths, but it changed how they related to others. For example, some participants spoke about having to consider and choose friends and partners who can "handle" their sibling's disability, an experience discussed by Flaton (2007) and Safer (2002). Although more difficult to articulate, it also affected how they saw the world. Many participants simply stated that they could not imagine their lives or what

they would think if their sibling had not been disabled, suggesting that this relationship and the role of disability have made an indelible mark upon them.

Gender

Most studies accounted for here speculate about birth order and gender as potentially influencing factors, although there is no consensus as to what does or does not make a difference (Marks et al., 2005). Insofar as this study is concerned gender made a reported difference to only two participants, who felt that, as women, they were more likely to have been socialized into caretaking roles. Other participants were unable to speculate as to how any difference in their own or their sibling's gender would have made a significant difference in the sibling relationship. Three participants did share their experience of feeling as if their gender made a difference to their parent. One participant, who was the youngest of four boys, talked about he feels that his mother was looking for an ally with whom she could commiserate. Another participant shared how larger family dynamics contributed to her sense that her father wished for an able-bodied son, and how she strove to meet that need:

I feel like I was really raised androgynously, and fell into that so much because the other brothers... weren't showing up as the son that [my father] wanted. One was absent, the other one had a mental breakdown and was always mentally a little weaker than my father wanted him to be and emotionally more female, and then Mark, and for whatever reason I do think that I knew that. I do think that my father was longing for more of a son, not that he wasn't *delighted* for me to be born. He was and we have an amazing relationship but I think I put on myself a kind of "be-both son and daughter to them, trouble free and take care of everything; don't- don't- don't be a problem, don't be a kid." P10

What this data does highlight is the grief and loss experienced by parents when they discover a child is disabled (Boushey, 2002), and how NDC sense and interpret this information.

Birth Order

Similarly, birth order amongst siblings has generated a significant amount of attention but mixed reviews as to its import. Grossman (1972) and Seligman et al. (2007) found that older siblings are better adjusted, and Breslau's (1981) findings suggest that younger siblings encounter significant problems in adjusting to surpassing their older disabled sibling's cognitive abilities. But what happens when even younger siblings feel as if they *are* the older sibling? In her study, Begun (1989) cites the "role confusion" model first identified and articulated by Farber (1959), which describes how

the developmentally disabled individual progressively functions as "youngest" in the sibling subsystem as non-disabled children achieve normal developmental milestones and this individual lags behind. [In this scenario], despite true birth order, the sibling role structure must be modified when a chronologically younger sibling eventually functions as the "older" sibling of a disabled person (p.567).

This model – or the notion that younger NDC feel as if they are the older sibling in the relationship, and their ensuing confusion - is referenced in passing in the literature, usually when discussing adolescent NDC (Grissom & Borkowski, 2002; Stoneman & Brody, 1993). In this study, however, seven of the participants in this study were younger siblings and all of them reported feeling as if they were the older or oldest sibling in the relationship by virtue of the increased responsibility, protectiveness, and/or caretaking they took on – qualities they attributed to being an older sibling. Begun (1989) did theorize that this "role confusion" might contribute to feelings of increased anxiety, frustration, and conflict. Participants in this study more readily expressed that it felt ironic that they were younger, suggesting that there was incongruity between their own experience and other's expectations around what it means to be the older or younger sibling in the relationship.

Developmental Stages and Characteristics

The adult studies cited in this literature review provide a more balanced perspective of what it means to be brother or sister to a disabled sibling (Begun, 1989; Burton & Parks, 1994; Davis & Salkin, 2005; Dew et al., 2008; Orsmond & Seltzer, 2007). The majority of these are still quantitative in nature, however, and do not capture a unique finding of this study. With the luxury of time afforded through qualitative interviews, participants were able to reflect on emotions felt and experiences had that were particular to a given stage of life. Childhood tended to be characterized by confusion about the disability, feelings of jealousy or unfairness about different time and attention, and sadness. These feelings are most accurately reflected in the qualitative literature (Davis & Salkin, 2005; Safer, 2002; Strohm, 2005) and are referred to more frequently in the quantitative literature as internalized or externalized negative feelings and behaviors (Dodd, 2004; Naylor and Prescott, 2004; Rossiter & Sharpe, 2001; Sharpe & Rossiter, 2002).

Adolescence was another particular period during which participants re-evaluated or made “new” sense of their sibling’s disability. Begun (1989) noted that “adolescent subjects reported more conflict in relationships with their disabled siblings than did either adult group” (p. 569). Opperman and Alant (2003) specified that the “impact of having a disabled sibling may exacerbate the challenges in the psychological adjustment of adolescents, as they appear to be prone to experiences of shame, guilt, stigma and extra caregiving responsibilities” (p.442). Eleven of the twelve participants in this study verified these theories and expressed having an intensification of feelings toward or about their DS; many experienced embarrassment about their sibling’s disability, especially in

how it appeared to others, and how they (the NDC) might be perceived as a result. Many participants also shared that they had trouble knowing when and how to tell friends about their DS, and that they felt particularly sensitive to how their peers would react to the information. Worry about this interaction contributed to anxiety and embarrassment, but then also triggered feelings of guilt. It was at this time that many participants also took on the unique role of babysitting their disabled (sometimes older) sibling – a phenomenon particular to the NDC-DS relationship, and one that elicited a negative response in some participants.

Few studies examine the continuation of this process into adulthood, although those that do generally reflect this transition and they are qualitative in nature (Davis & Salkin, 2005; Safer, 2002). As adults, a period during which eleven of the participants had time away from home and away from their sibling, all participants participated in a more introspective assessment focusing particularly on how their sibling and his/her disability affected them emotionally and psychically. Participants expressed having less negative emotions (e.g. resentment, jealousy) toward their sibling and expressed having greater acceptance of its role in their life. Many noted retrospectively the difficulties inherent in the relationship and in how the disability affected family dynamics, but also emphasized that they had learned something important from the experience. As Dew et al. (2008) stated, “It is possible that young adults have had time to work through any negative feelings they may have toward their sibling with ... disability as children and to develop a more positive view of their early experiences” (p. 497).

Therapy

Seven of twelve participants in this study participated in therapy and found it useful. Of the five who did not have therapy, three wished they had and one more stated that some form of communal support would have been helpful while growing up. While there were varied reports on what modality would have been useful and when, the majority of participants wanted or needed an external reference point with whom they could share this experience, process it, and make meaning of it.

Jeanne Safer (2002) and Kate Strohm (2005) discuss, anecdotally, the benefits of having sought out therapy as adults but do not study it as a phenomenon. Currently, there is no literature that addresses specific ways in which therapy can be useful to this adult population. However, this study highlights that, for adults, understanding how this relationship and, in particular, how the disability has affected them in the past and continues to affect them in their current lives is useful for integrating past and present experiences of oneself. While not all participants agreed that therapy would have been useful at different points growing up, ten of the participants did express a need or desire for it at younger ages. The participants' desire for therapy supports the literature which suggests that early intervention for NDC and therapeutic interventions promote positive adjustment and alleviate some of the stressors that accompany being a sibling to a disabled child (Dodd, 2004; Giallo & Gavidia-Payne, 2008; Naylor & Prescott, 2004).

Strengths and Limitations

The idea for this study came out of research indicating there were long-term negative effects of growing up with a disabled sibling. Not only were some of the findings in the literature incongruent with the researcher's experience but, when

searching for adult studies that could speak to whether or not that hypothesis was, in fact, empirically true or not, few were found and a gap in the literature was discovered. This study was an attempt to further explore and give voice to the longer-term experience and identity development of adults who have grown up with a disabled sibling, thus deepening the understanding of this issue and permitting a more balanced perspective of this population's experience.

In interviewing adults, a range of experience was uncovered. Due to the limited time afforded by the structure and duration of the study for plumbing the depths of information provided by participants, the findings here represent only a portion of participant's experiences. In addition, this study was limited in size as well as gender and racial diversity. However, in the process of conducting it, several areas for further study were illuminated.

Future Areas of Research

Despite concerted efforts to attract families of color and ethnic diversity through a local outreach agency that works specifically with this population and by advertising online, this study, like those represented in the literature, obtained the testimonies of predominantly White, European-American, middle-class participants. It is possible that the use of the internet, though it was intended to widen the scope of the sample, also requires a certain level of privilege in being able to afford and/or access a computer. It is also possible that families of color are significantly more difficult to recruit due to having familial and communal structures that promote looking internally for resources and support as opposed to externally where they encounter higher degrees of racism (Bank and Kahn, 2007). One cannot ignore, however, the links that exist between racism, class,

and disability (Seligman & Darling, 2007). If the field is to reflect on and accurately assess the ways in which NDC are affected by their DS, there must be a representative sample from which to draw conclusions. This is a portion of the population whose stories, to date, have not yet been represented.

A broader topic that also requires further exploration is that of the sibling relationship itself. An interesting result of this particular study was the revelation that siblings – particularly brothers and sisters who are one of two children - in addition to their parents, experience grief and loss upon learning and understanding that their sibling is disabled. Several participants spoke about wishing for or fantasizing about having a “normal” brother or sister with whom they could talk about the intimate details of their lives, commiserate about intra-familial experiences, or share the major life cycle events affecting their family (e.g. the aging and death of their parents). This speaks to a singular, special bond that exists between siblings, the nature of which suggests a deeper connection that parallels the relationship that exists between parents and their children. It is the nature and quality of this bond that deserves greater exploration, as does the possibility that it has a theoretical foundation in contemporary relational and, possibly, psychoanalytic theory.

Within the NDC-DS relationship itself, greater understanding of the emotional and psychological stages NDC go through while growing up, and the developmental tasks which accompany them and are particular to the NDC-DS relationship must be explored further. While some of these tasks have been put forth as a finding in this study, they require a more in-depth look to suss out the particulars of each given stage. Next, future studies should take into account the process through which NDC conceptualize

their sibling's disability and make meaning of it, relative to their own identity. Though this was within the scope of this study, the amount of time allotted to explore this question was limited. Based on this study, additional qualitative studies that involve multiple interviews are likely to yield more in-depth answers that also pay attention to a number of influencing variables, as opposed to quantitative studies that capture data but not, necessarily, depth of experience, a detail also noted by Dew et al (2008). Finally, the degree to which the type, nature, and severity of the disability affect the NDC-DS must be examined further. Though participants could only speak to their own experiences (and could not compare their experience to that of other NDC whose siblings were affected in other ways by their disabilities), participants in this study whose siblings were physically aggressive or socially limited had a particularly difficult time relating to their sibling. They spoke about the difficulties in growing up in a home where they felt their safety was in danger, their own movements constricted, or where verbal interaction with their DS was limited or nonexistent. Focus groups further examining this topic may be able to shed light on how type and/or degree of disability are an influential factor in the NDCs experience and, subsequently, his/her self-concept. Marks et al. (2005) note the potential for type and degree of disability to impact NDC and literature reviews by Dew et al. (2008) as well as Rossiter and Sharpe (2001) call for further research on this facet of the NDC-DS relationship.

Finally, in the course of reviewing literature for this study, parents' advocacy roles were not a theme discussed. Yet, in this study many participants described how their parents took on this role and some correlated it with their parent being unavailable to them. While there was insufficient data to make a clear correlation between parents'

advocacy roles and disparate time and attention for their NDC, that seven of the twelve noted that this activity was a significant part of where one or both parents devoted their time, suggests that the relationship between the two be studied further.

Attending to “Invisible” Children: the Clinical Relevance of Working with NDC

Social workers, marriage and family therapists, and psychologists all take into account the formative experiences of a client’s life. The presence of a disabled child in a family is life-changing; as one participant said, “it touches everything.” As such, questions about and forays into this experience and its attendant memories, meanings and influences should be a regular consideration when working with clients who have grown up with a disabled sibling. Failure to take into account this relationship and the role of disability neglects what participants of this study, and those of previous studies, describe as a unique and unambiguously seminal experience in the creation of oneself.

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Appendix A

Demographic Survey

1. What is your age? _____
2. What is your gender? _____
3. How do you identify racially? _____
4. How do you identify ethnically? _____
5. How many siblings do you have? _____
6. Where do you fall in the birth order? (1st, 2nd, etc.) _____
7. How many of your siblings are disabled? _____
8. Is your disabled sibling older or younger? _____
9. What is the age difference between you and your disabled sibling?

10. What is the gender of your disabled sibling? _____
11. What is the name of your sibling's disability? _____
12. To what degree was your sibling disabled? (Fill in below.)

1	2	3	4	5
Mildly – s/he could do most things on his/her own and only required my or others' assistance as needed		Moderately – s/he required some assistance with day-to-day living activities but s/he was able to accomplish some things on his/her own		Severely – s/he was entirely dependent on me and/or other family members for basic needs (eating, dressing, hygiene)

13. Did the degree of disability change over time? _____ If so, please note the change in degree with an **X**.
14. Growing up, how would you define your family's socioeconomic status?
 - ___ Poor
 - ___ Working Poor
 - ___ Lower Middle Class
 - ___ Middle Class
 - ___ Upper Middle Class
 - ___ Wealthy
15. What is your current relationship status? Single ___ Married/Partnered ___ In a Relationship ___

Appendix B

Interview Guide

1. (First inquiring about the nature of the disability:) What does _____ look like/how does that manifest?
2. When did you first understand that your sibling was disabled?
3. How did you come to know that your sibling was disabled?
4. What effect did this knowledge or understanding have on you at that point in time?
5. How did you handle that then?
6. How has your understanding of your sibling's disability changed over time (through childhood/adolescence/adulthood)? In what ways?
7. How do you think your feelings about your sibling's disability have changed over time?
8. Have those feelings influenced the way you've thought about yourself? How?
9. How have these feelings affected your view of the world?
10. How did your family deal with your sibling's disability?
11. Specifically, how did your parents deal it? Your other siblings?
12. How did birth order or gender affect how family members responded to or were organized around your sibling's disability?
13. Did you have a particular role in your family? In what ways has this played out in other aspects of your life?
14. Have you received any support – therapeutic or otherwise - around having a disabled sibling? What was effective? What was not? If none, would you consider it? What would be appealing or helpful to you?
15. What is your occupation?
16. What was your motivation for going into that field?
17. How would a close friend describe you?
18. How would you describe yourself?
19. How would you characterize your role when in a relationship? (helper, leader/director, etc.)
20. What do you feel are the most important or significant ways in which you've been influenced by having a sibling with a disability?
21. When you think about you and your sibling in the future, what comes to mind?
22. Is there anything else you feel I should know, or anything else you would like to share about this topic?

Appendix C

Online Recruitment Letter

Dear Participant,

I am looking to interview adults who have grown up with a disabled sibling, in order to explore the ways in which this relationship has affected their identity. Participant criteria are as follows:

- 1) They must be within 10 years of age to their disabled sibling.
- 2) They must have lived at home with their disabled sibling for 10 or more years.
- 3) They must be full, biological siblings (not step- or half- siblings).
- 4) They must be adults (18 years or older) and, ideally, they have lived outside of the family home for 5 or more years (this is not a hard and fast criteria, and I am able to make exceptions to this rule).
- 5) Their sibling must meet the following definition of “disabled”:
A “disadvantage for a given individual...resulting from an impairment or disability, that limits or prevents the fulfillment of a role that is normal, depending on age, sex, social and cultural factors. It is both severe and chronic in nature, and
 - (A) *Is attributable to a mental or physical impairment or combination of mental and physical impairments;*
 - (B) *Is manifested before the individual attains age 22;*
 - (C) *Is likely to continue indefinitely;*
 - (D) *Results in substantial functional limitations in three or more of the following areas of major life activity –*
 - (i) *Self-care;*
 - (ii) *Receptive and expressive language;*
 - (iii) *Learning;*
 - (iv) *Mobility;*
 - (v) *Self-direction;*
 - (vi) *Capacity for independent living; and*
 - (vii) *Economic self-sufficiency; and*
 - (E) *Reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, supports, or other assistance that is of lifelong or extended duration and is individually planned and coordinated, except that such term, when applied to infants and young children means individuals from birth to age 5, inclusive, who have substantial developmental delay or specific congenital or acquired conditions with a high probability of resulting in developmental disabilities if services are not provided.”*

My research to date has shown that children are most often interviewed about their experience of having a disabled sibling. Interviewing adults would balance out the current literature by providing important and unique insight into the sibling

relationship, and disability's impact on it and the non-disabled child over the course of time.

If you or anyone you know is curious to learn more or is interested in participating in this study, please contact me at the following email address and phone number:

C: (415)694-3023
srigney@smith.edu

Thank you in advance for your help and support!

Best,

Sarah

Appendix D

Agency Flier

Did you grow up with a Disabled Sibling?

I am conducting a Masters-level study examining the long-term impact of this relationship on adults who have grown up with a physically and/or cognitively disabled sibling. I am seeking adults between the ages of 23-65, who are within 10 years of age to their disabled sibling, and who grew up with this sibling over the course of 10+ years.

To inquire further or participate, please

contact:

Sarah Rigney, 413.545.1493

Or

srigney@uhs.umass.edu

Appendix E

HSR Approval Letter

January 15, 2009

Sarah Rigney

Dear Sarah,

Your amended materials have been reviewed and all is now in order. We are glad to give final approval to your study.

Please note the following requirements:

Consent Forms: All subjects should be given a copy of the consent form.

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

In addition, these requirements may also be applicable:

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

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

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

Good luck with your very interesting project.

Sincerely,

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

CC: Dana Schneider, Research Advisor

Appendix F

HSR Approval Letter for Amendments

February 26, 2009

Sarah Rigney

Dear Sarah,

Thanks for keeping us up to date. Your suggestions for amendments make a lot of sense and will expand your pool of possible recruits. They are approved. I hope you get more interested participants.

Sincerely,

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

CC: Dana Schneider, Research Advisor

Appendix G

Informed Consent Form

March 13, 2009

Dear Participant,

My name is Sarah Rigney and I am currently in the process of obtaining a Masters in Social Work from Smith College. Thank you for your interest in my study and for taking the time to participate in it. I am conducting a study exploring the relationship between emotional experiences, psychological and behavioral adjustments/coping mechanisms developed in response to having a disabled sibling, how these change or stay the same over time, and how one's identity is subsequently shaped by growing up with a disabled sibling. This is an area that has been understudied and is under-represented in the mental health field. The data from this study will be used for a Masters in Social Work thesis, presentations and publication.

You are being asked to participate in this study, as you have experienced what it is like to grow up with a sibling with a disability. In order to be eligible you must be between the ages of 18-65, with a biological sibling who has a disability, with whom they spent 10 or more years growing up. Participants must be within ten years of age to their disabled sibling, and have, ideally, lived outside the family home for five years. The ability to be conversant in English (the language in which the interview is being conducted) is a criterion of participation.

The interview will take between 1-1 ½ hours and will be audio taped. The interviewer will also be taking notes on non-verbal communication, i.e. body language and facial expressions. All identifying information provided in the interview will be kept confidential.

There may be low risks experienced by participating in this study. For example, you may experience distress when reflecting upon a particular experience with or memories of your sibling. You may be uncomfortable expressing thoughts or feelings about your sibling. Participants will be provided with a list of local, community mental health referrals when they give their Informed Consent.

The benefits of your participation are that you may gain new insight into your relationship with your sibling and its impact on you and your family of origin, and/or current relationships. The information gained from this interview will help me, mental health clinicians, and other researchers work more effectively with individuals, families, schools and community organizations that interact regularly with disabled individuals and their friends and family.

This interview will be entirely confidential and all identifying information will be seen only by me, the interviewer. I will transcribe and analyze all data. My research advisor will also have access to transcribed data but not to identifying information. Confidentiality will be protected by presenting the data in the aggregate, summaries, or presented through vignettes for use in professional publications or presentations, without reference to identifying information or characteristics. Finally, all data, audiotapes, notes and consent forms will be kept securely for a period of three years by me in my office, as stipulated by federal guidelines after which time they can be destroyed or continue to be maintained securely.

Your participation in this study is voluntary. You will not receive compensation for your participation in this study. You may withdraw before the study begins. You may stop your participation in the interview at any point. You may also withdraw from the study any time prior to April 1, 2009. Should you choose to withdraw, all materials from your participation will be destroyed. There is no penalty for withdrawal from the study. Should you choose to withdraw, or if you have any additional questions or concerns about the study, please contact me by phone or email using the contact information listed below. You may also contact the Chair of the Smith College School for Social Work Human Subjects Review Committee at: (413) 585-7974. A copy of this consent letter will be provided to you, along with a list of community resources.

Thank you for your time and willingness to participate in this study.

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

Signature of Participant _____ Date: _____

Signature of Researcher _____ Date: _____

Researcher's contact information:

Att: Sarah Rigney
University Health Center, Hills North
University of Massachusetts-Amherst
Amherst, MA 01003-4310
srigney@uhs.umass.edu
413.545.1493