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It’s Different: Perceptions of Risk and Resilience in Older Siblings of Children with Disabilities

Bradley Hugh Reimers

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UNIVERSITY OF NORTHERN COLORADO

Greeley, Colorado

The Graduate School

IT’S DIFFERENT: PERCEPTIONS OF RISK AND RESILIENCE IN OLDER SIBLINGS OF CHILDREN WITH DISABILITIES

A Dissertation Submitted in Partial Fulfillment Of the Requirements for the Degree of Doctor of Philosophy

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has been approved as meeting the requirement for the Degree of Doctor of Philosophy in the College of Education and Behavioral Sciences in the Department of School Psychology, Program of School Psychology.

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The entry of a child with a disability into the family system can contribute to unique challenges, and potentially, joys for their families. Designed from a psychological resilience framework, this post-intentional phenomenological study specifically focused on the process of adaptation for five older siblings who had a younger sibling with an intellectual disability. To understand their perspectives about what their experiences had entailed, each adolescent participant wrote a daily check-in journal and completed both a photo-elicitation interview and a semi-structured interview.

The results of this study indicated that adolescent older siblings adjusted to having a sibling with a disability by engaging in protective processes at the individual and familial levels. While participants described facing significant sources of stress, they also perceived that they had benefited because of their sibling relationship. While this study detailed how older siblings can adapt to having a sibling with a disability, additional research is needed to further understand the sources of risk and resilience these older siblings can encounter. Findings from this study might be applied by parents, families, and professionals to promote resilience processes for these older siblings.
ACKNOWLEDGEMENTS

I was taught as a child that wherever God led, I would be provided for. In the seasons of my life, I have found this to be true. I have always been surrounded by the right people, found myself in the places that I belonged, and have been supported by a remarkable community of family and friends. I have been blessed.

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CHAPTER I

INTRODUCTION

The beginning of wisdom is to call things by their right names.

--Chinese proverb

Throughout the world, the significance of sibling relationships is universally appreciated. A Vietnamese proverb succinctly states that “brothers and sisters are as close as hands and feet” (Sarkis, 2011, p.1.), exemplifying the connection that siblings can have. Sibling relationships usually last longer than any other affiliation, and unlike most it endures throughout different life contexts (Orsmond & Seltzer, 2007). These unique bonds are thought to contribute beneficially to the overall development of both members of the dyad. The positive role that siblings can have on each other’s social, emotional, cognitive, and behavioral development is well-established. For example, older siblings have been identified as providing nurturance to younger siblings and providing a social model to imitate (Brody, 2004). In such an idealized relationship, where siblings are as metaphorically close as hands and feet, their impact on each other can facilitate beneficial development for both individuals (McAlister & Peterson, 2007).

Based on these parameters, the model sibling relationship in the United States has been described as being “warm, supportive, and free of conflict” (Stoneman, 2005, p. 339). Although this level of intimacy describes some sibling relationships, it may not be representative of the experiences of all siblings. Some children face unique challenges in relating to their sibling in these ideal ways. For siblings of children with a disability, different patterns of supports and challenges may emerge. Although there are distinct
differences between disabilities, as a whole having a sibling with a special need may introduce obstacles to typical sibling interactions. Because of characteristics associated with their disabilities, children may have greater difficulty regulating their emotions and being responsive to the needs of their siblings. Impairments in domains such as communication often make it challenging for siblings to reciprocally interact and form stable bonds (Kaminsky & Dewey, 2001). This impaired communication may contribute to sibling relationships characterized by lower levels of closeness and higher levels of avoidance (Kaminsky & Dewey, 2001; Walton & Ingersoll, 2015).

When compared to typical sibling interactions that are marked by shared interests and high levels of engagement, relationships between siblings with and without disabilities function differently. Anitha, an 8-year-old sibling to a child with an intellectual disability, described the way she takes care of her brother: “When my brother has made a mess, just guess who is asked to clean it up? Right, me! Even when I’m busy or doing my homework” (Moyson & Roeyers, 2012, p. 93). As this quote suggests, siblings of children with disabilities tend to assume more responsibilities than brothers and sisters of typically developing siblings. Instead of simply sharing a bond more akin to a friendship, these siblings also take caregiving roles of “looking out” for their brother or sister. Researchers have consistently identified that these children assume increased responsibilities beyond those typical for their age. They are often required to take on parental identities to assist their parents in meeting the needs of their sibling (Damiani, 1999; McHale & Gamble, 1989). Because of this nontraditional relationship, siblings of children with disabilities face obstacles to typical development that most children do not. Siblings of children with disabilities tend to experience elevated levels of stress when
compared to their peers (Senal & Akkok, 1995), which can in turn create heightened risk for negative outcomes. Siblings experience stress not only individually but also at a familial level as the family unit adapts to having a child with a disability.

**The Impact of Disabilities on Families**

Having a child with a disability impacts the entire family system, yet much of the research in this area has focused on the impact that having a child with a disability has on parents. These findings consistently indicate that these parents report experiencing higher levels of stress than other parents do (Baker, Blacher, Crnic & Edelbrock, 2002; Hassall, Rose, & McDonald, 2005; Smith, Oliver, & Innocenti, 2001). This elevated stress appears to come from a variety of different areas including the level of the child’s needs, and the challenges that parents experience in raising their child because of their disability (Baker et al., 2003). Parents of children with disabilities often have to manage significant behavioral and emotional difficulties, which can become more pronounced throughout childhood (Woodman, 2014). In addition, children with more substantial impairments may have lower levels of adaptive functioning including difficulty communicating, which can exhaust parents (Schieve, Blumberg, Rice, Visser, & Boyle, 2007).

Although the direct effects of disabilities are substantial, they also can impact other areas of family life and contribute to parental stress. Having a child with a disability can lead to significant financial burden for these families because many must pay out of pocket for expensive services (Bouder, Spielman, & Mandell, 2009), and some parents must reduce their hours at work to care for their child (Gould, 2004; Leonard, Brust, & Sapienza, 1992). Collectively, these sources of stress contribute to increased rates of depression for mothers of children with disabilities (Singer, 2006), who typically report


providing the majority of care for children (Olsson & Hwang, 2001). Cumulative stress from parenting a child with a disability also creates risk for other health concerns such as chronic fatigue, which can significantly lower the quality of life for these parents (Miodrag, Burke, Tanner-Smith, & Hodapp, 2015). This extra level of stress can also create significant strain on the functioning of families. Parents of children with a disability have an elevated likelihood to have their marriage end in divorce, possibly because of the large amounts of stress they experience (Hartley et al., 2010).

**The Impact of Disabilities on Siblings**

Although parents of children with disabilities experience high levels of risk, the impact of this stress also extends to other members of the family unit. In fact, children are also impacted by having a sibling with a disability. Researchers have found that there is a strong association between levels of parental stress and sibling functioning. In a study of parents and children who have special needs, Giallo and Gavidia-Payne (2006) found a significant correlation between parental stress and internalizing difficulties for their sibling children. When parental stress was high, these siblings were also perceived by their parents as displaying less positive behaviors (Giallo & Gavidia-Payne, 2006). Similar findings were reported by Quintero and McIntyre (2010), who found that parental depression was associated with behavioral and academic concerns for siblings of children diagnosed with autism spectrum disorder. These findings suggest that sibling development is influenced by the ability of their parents to successfully adapt to the stress of having a child with a disability.

Furthermore, siblings are influenced by their direct interactions with their brothers and sisters regardless of their disability status. When compared to their peers, siblings of
children with disabilities report experiencing elevated levels of stressors (Senal & Akkok, 1995). Much of this stress appears to be attributable to characteristics of their sibling which may disrupt regular family functioning. For siblings of children with high externalizing behaviors, completing everyday tasks can become challenging as family tension increases (Benson & Karlof, 2008). Siblings often must set aside their personal needs to help their family care for the child with a disability. As family stress increases, many siblings also take on additional care giving responsibilities to assist their parents (Damiani, 1999; McHale & Gamble, 1989) which may contribute to feelings of anxiety for siblings who now are overwhelmed by their responsibilities (McHale & Gamble, 1989).

The impact of this stress can impair the relationship shared between the sibling and his or her parents. Research has suggested that differential treatment may be highest in families of children with disabilities (McHale & Pawletko, 1992). Children may perceive the attention directed toward a sibling with a disability as being unfair, and may be confused about why they receive less attention than the other child (Kowal, Krull, & Kramer, 2004). Siblings may also take personal responsibility for challenges faced by their families (Nixon & Cummings, 1999). In a qualitative study by Murphy, Christian, Caplin, and Young (2007), one parent described the weight of responsibility experienced by her child and how it has influenced their relationship. She noted, “I worry about him the most because I don’t know what else he’s feeling that he hasn’t told us about, because he doesn’t want to worry us more” (Murphy et al., p. 182). In another study by Moyson and Roeyers (2012), a sibling to a child with a disability similarly mentioned not wanting to burden his parents:
It’s hard for my parents too to handle my brother, day after day. So, in the evening, when my brother is in bed, they’re just happy that they can sit down and relax. I don’t want to disturb them with my worries or my problems (Moyson & Roeyers, 2012, p. 96).

The influence that these risk factors can have on siblings is substantial. Many studies have demonstrated that siblings of children with disabilities are at greater risk for expressing depressive symptoms (Gold, 1993; Rossiter & Sharpe, 2001; Walton & Ingersoll, 2015). The large amount of stress that they experience may also negatively influence their relationships with peers (Cuzzocrea, Larcan, Costa, & Gazzano, 2014). Although relatively fewer studies have focused on older siblings, it appears that compared to younger siblings of children with disabilities, these siblings are more likely to experience emotional and behavioral difficulties (Macks & Reeve, 2007). For example, male siblings are reported to have especially high levels of externalizing behavior difficulties as they advance through childhood and adolescence (Walton & Ingersoll, 2015). One reason that older siblings may sometimes have greater difficulties is because they are required to adapt to changes that occur once their younger sibling has entered the family. It is thought that older siblings may actively take on new roles and adjust to changes in family functioning so that younger siblings do not have to (Costigan, Floyd, Harter, & McClintock, 1997). In general, it appears that older children have elevated levels of behavioral and emotional concerns as they advance through adolescence. Taken together, research in this area highlights the impact that having a brother or sister with a disability can have on development.
Positive Adaptations to Stress

Many siblings are able to overcome the challenges they face as related to having a sibling with a disability. In the context of adversity these individuals display resilience and are able to positively adapt to these stressors. Although the stressors these siblings face are substantial, many siblings are able to positively adjust to this stress and overcome the challenges they face. Despite the risk these siblings face, some are able to thrive socially, emotionally, and academically. In general, these siblings are persistent in adapting to the challenges and issues that they are faced with (Rivers & Stoneman, 2008; Verte, Roeyers, & Buyusse, 2003). Literature in this area suggests that protective factors at the individual, family, and community levels can help siblings overcome the stressors and risks associated with living with a child with a disability (Rivers & Stoneman, 2008; Verte et al., 2003).

Organizations within the community may also help siblings and their families in adapting to living with a child that has a disability. Programs that provide education about disabilities can help siblings learn to better understand and relate to their brother or sister that has a disability. A study by Lobato and Kao (2002) identified that siblings indicate feeling closer to their siblings after attending support groups that provide this type of information. Similarly, these siblings and families appear to benefit from the use of respite services available in the community. These services provide temporary specialized care for children with disabilities, and allow siblings a chance to have time apart from their brother or sister. When compared to families who do not use such services, families that use such disability-related services indicate feeling more connected to their family and experiencing less overall stress (Chan & Sigafoos, 2001).
Sibling resilience also is fostered by characteristics of the family. Hardy families that are able to recover from disruptions to normal family processes appear to be related to the ability of siblings to positively adjust to challenges that they face (Patterson, 2002; Walsh, 2003). One such family component associated with this adaptation is the presence of regular family routines and rituals (Giallo & Gavidia-Payne, 2006). Although having a child with a disability can result in systemic changes in the family, these routines ground families by providing stability. In addition, they provide chances for family members to emotionally invest in each other and engage in preferred activities (Giallo & Gavidia-Payne, 2006; Spagnola & Fiese, 2007).

Parents are integral to the creation of the overall emotional climate of the family, which dictates how it functions. Similarly, the meaning that families ascribe to having a child with a disability can be powerful. Families that hold a positive worldview and a strong sense of cohesion create a fertile environment for beneficial sibling adjustment (Patterson, 2002; Patterson & Garwick, 1994). Siblings also benefit from sharing an encouraging relationship with their parents (Dyson, 1999; Williams et al., 1999). In these protective relationships, individual growth is emphasized and siblings are encouraged to pursue their unique dreams and interests (Dyson, 1999). By providing nurturance and support, positive parenting can increase a siblings’ self-esteem and belief in their own abilities (Williams et al., 1999).

Certain personal characteristics appear related to helping siblings adjust to having a brother or sister with a disability. High self-concept and persistence have both been implicated as protective processes facilitating positive growth (Rivers & Stoneman, 2008; Verte et al., 2003). These characteristics appear to influence the way that individuals
perceive problems when they arise, and dictate the ways that they respond to stressors. In
turn, these qualities may contribute to higher quality sibling relationships and an overall
willingness to proactively address problems that arise. Siblings with these qualities can
perceive that obstacles are surmountable, and can possess high self-efficacy in their
ability to overcome them (Rivers & Stoneman, 2008; Verte et al., 2003). In the context of
having a sibling with a disability, they are more able to endure the emotional highs and
lows that they experience. The use of coping strategies for these siblings has also been
found to reduce the risk of experiencing anxiety or depression. While younger siblings
reduce these risks by identifying mistakes in their thinking, older siblings appear to
benefit most from utilizing strategies to reduce the anger they feel (Bitsika, Sharpley, &
Mailli, 2015).

Beyond merely adapting to their relationship to a brother or sister with a
disability, some siblings may actually incur individual benefit from their unique
experiences. Because of the responsibilities that these siblings assume, many are reported
by their parents as displaying heightened empathy and maturity for their age (Cuskelly &
Gunn, 2003). For these siblings, this empathy may aid them by providing a heightened
respect for individual differences (Mulroy, Robertson, Aiberti, Leonard, & Bower, 2008).
In a qualitative study of parent perspectives by Resch and colleagues (2010), parents
described the challenges and joys that they have experienced raising a child with a
disability. Although parents noted many difficulties that they have had to overcome,
many also shared positive experiences the positive experiences of their families. One
parent noted that their children had become advocates for their sibling with a disability:

It’s been such an amazing thing to see how [my other] kids defend and stand-up
and try to educate their peers, their friends about him, about the disability and
what he can and can’t do and don’t try to make [him] special, try to make [him] like you and me (Resch, et al., 2010, p.146).

Although research has demonstrated that many siblings of children with disabilities are able to overcome adversity, relatively little has focused exclusively on older siblings of children with disabilities. Although some studies have included older children, most of these have grouped older and younger siblings together. However, it appears that siblings face specific risks as they become older. In a study comparing older siblings to younger siblings, older siblings were found to have elevated difficulties in social and emotional functioning. Related to this, older siblings were also reported to have more pronounced difficulties at school (Macks & Reeve, 2007). More specifically, a study by Walton and Ingersoll (2015) found older male siblings to have significantly higher levels of externalizing behavior concerns when compared to other siblings. Because there appear to be significant challenges that siblings of children with disabilities face as they journey through adolescence, it is important to understand the resilience processes of these older siblings. Research in this area would benefit from not only understanding what protects individuals but also understanding the individual contexts in which resilience can occurs.

**Statement of the Problem**

Siblings of children with disabilities face unique challenges when compared to other children. These siblings report experiencing more stress than their peers do (Senal & Akkok, 1995), and are more sensitive to conflicts that arise within the family (Nixon & Cummings, 1999). These siblings often experience difficulties interacting with their brother or sister (Walton & Ingersoll, 2015), and many are required to assume care giving roles atypical for their age (McHale & Gamble, 1989). Siblings of children with
disabilities often feel neglected by their parents because of the disproportionate amount of time they spend meeting the other child’s needs (Cate & Loots, 2000). The added stress experienced by siblings in these areas places them at risk for mental health concerns such as depression (Rossiter & Sharpe, 2001) and peer avoidance (Cuzzocrea et al., 2014). Taken together, these stressors can disrupt normal development for these individuals.

Although all siblings of children with disabilities experience risk, it appears to be most pronounced in older siblings. As these siblings grow older, they are reportedly at greater risk for emotional, social, and academic concerns (Macks & Reeve, 2007). In spite of these significant risks to development, many older siblings are able to positively adapt to having a sibling with a disability. To date, few studies have focused on resilience processes in this group. This study examined the specific perceptions of these siblings and their families in order to better understand how they adapt to having a sibling with a disability.

**Significance of the Study**

This study is significant in three ways. First, it focused on the positive adaptation of siblings of children with disabilities rather than parents. In general, research with this population is relatively new (Hodapp, Glidden, & Kaiser, 2005; Stoneman, 2005). Previous research in this area emphasizes the impact that siblings and sibling relationships have on the overall functioning of the family (Bogels & Brechman-Toussaint, 2006; Kaminsky & Dewey, 2001). Research that has focused on the adaptation of siblings has typically focused on the risks associated with development and has been guided by an overall philosophy that “having a sibling with a disability must be bad for
children” (Stoneman, 2005, p.340). However, some siblings are able to positively adapt and derive positive meaning from their experiences. Exploring the positive adaptation of these individuals appears to be a relatively unexplored area of inquiry that merits further research.

A second contribution of this study is that it focused specifically on resilience in older siblings. As Hodapp, Glidden, and Kaiser (2005) noted, the overwhelming majority of research on siblings of children with disabilities has grouped older and younger siblings together. As older siblings must actively adapt to changes in the family arising from having a sibling with a disability, it posits that their experiences will be unique. Some research has demonstrated that these siblings may be at increased risk as they advance through adolescence (Macks & Reeve, 2007; Walton & Ingersoll, 2015). However, the reasons for why this might be or how individuals can overcome this risk remain unclear and need to be investigated further. By focusing specifically on older siblings, it may be possible to learn more about why these risks are more pronounced for adolescents. This study sought to contribute to the literature focusing on psychological resilience by focusing on the specific processes and context of adaptation for these siblings.

Finally, this study expanded on previous research by focusing on the specific perspectives of these older siblings using a post-intentional phenomenological qualitative methodology. While most studies have focused on parental report of siblings, fewer have actually emphasized the perspective of the older sibling. This study addressed this limitation by relying primarily on interviews with these older siblings. Taken together, the desired outcome of this study is that it will contribute to our understanding of
resilience, risk, and development for older siblings of children with disabilities. This information can provide a richer understanding of the risks that these older siblings face, and the ways that individuals overcome the challenges that they face. By understanding both the risks and the resilience processes for these siblings, this study sought to arrive at a tentative manifestation the phenomenon of being an older sibling to a child with a disability. This added insight can be used not only to spur future research, but also in practice by psychologists who work with these siblings. Understanding the actual perspectives of these siblings may also illuminate factors involved in sibling resilience that have not previously been identified.

**Research Questions**

This study was guided by three primary research questions focused on understanding the specific experiences of older siblings of children with intellectual disabilities. A variety of techniques, such as semi-structured interviews, photo elicitation interviews, and daily check-in journals, were used to understand the unique perspectives of these older siblings. To understand the phenomenon of being an older sibling to a child with a disability, research questions were developed around understanding the unique risks and resilience processes for these individuals.

- Q1 What challenges and risks do older siblings identify in adjusting to living with a sibling with an intellectual disability?
- Q3 How do older siblings perceive their adaptation to having a brother or sister with an intellectual disability?
- Q3 What meaning do older siblings of children with disabilities make of their experiences in this role?
Delimitations

There are a few delimitations that must be considered in regards to this study. It should be noted that although each older sibling was recruited based on pre-established criteria, these participants were purposefully sampled. Related to this, the participants that participated either lived in or near to mid-sized cities. Because of this, it is likely that the experiences that these siblings and families have had would differ in some regards from families who have less access to services and supports. Instead of focusing on one gender, both male and female siblings participated in this study. Although it is assumed that resilience processes are similar for these groups, there could potentially be some differences.

Beyond the transferability of this study, the choice to use a qualitative methodology provides certain strengths and weaknesses. While I sought to understand the phenomenon of being an older sibling to a child with a disability by hearing their unique perspectives, my perspectives may have also influenced the way that I interpreted the data. However, throughout this study I attempted to reduce my own voice by sharing my beliefs and experiences interacting with siblings of children with disabilities before beginning this study. While seeking to minimize these preconceived beliefs, I also acknowledged that I held an intentional relationship with the phenomenon that could not be fully removed (Vagle, 2014). Finally, although multiple techniques were used to ensure the trustworthiness of the data that was obtained, it is possible that participant responses were positively skewed based on their awareness that they were by being studied.
Definition of Terms

*Assets*- In this study assets are used to refer to internal attributes that benefit individuals in completing daily, developmentally-expected tasks.

*Intellectual Disability*- The term intellectual disability is used based on diagnostic criteria established in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5). Intellectual disabilities are characterized by deficits in intellectual and adaptive functioning that lead to difficulties in completing daily tasks (American Psychiatric Association, 2013). For this study, younger siblings with multiple disabilities including an intellectual disability were included.

*Protective Processes*- Protective processes are defined as interactions that reduce the negative outcomes associated with risk and that facilitate resilience (O’Dougherty & Masten, 2005).

*Resilience*- This study utilized the definition of resilience proposed by Luthar and colleagues (2000, p. 543) as “a dynamic process encompassing positive adaptation within the context of significant adversity.” Specific to this study, resilience is described as a pattern of positive adaptation to having a sibling with an intellectual disability. This definition emphasizes resilience as a process rather than a trait and emphasizes the context-specificity of the construct.

*Risk Factor*- Risk factors refer to any characteristic of an individual’s environment that poses a threat to development or might lead to negative outcomes (O’Dougherty & Masten, 2005).

*Vulnerability*- Vulnerability refers to susceptibility to context-specific negative outcomes based on the specific risks encountered (O’Dougherty & Masten, 2005).
CHAPTER II

REVIEW OF LITERATURE

A family is like a forest, when you are outside it is dense, when you are inside you see that each tree has its place.

--African proverb

With 6.4 million school-aged children receiving services for a disability (Kena et al., 2015), there is an abundant amount of research in both education and psychology focusing on issues of difference, intervention, and other topics related to this broad area. For example, there has been much written on not only the nature of disability, but the ways that families adapt to having a child with a disability. Within this body of family-oriented research, there has been limited focus on the specific stressors and protective factors present in the siblings of children with low incidence disabilities, especially those of older siblings who would have experienced a change in their family unit after the birth of their sibling with a significant disability. In order to better understand this phenomenon, in this chapter I presented an overview of resilience, the impact of disability on families, and an exploration of the risk and protective factors experienced by siblings of children with disabilities. A synthesis of this scholarship provided the framework for this study on how older siblings of children with disabilities adapt to stressors in their lives.

An Overview of Resilience

Before reviewing literature on the impact that having a child with a disability has on families it is necessary to provide an overview of resilience, which can be defined as
the positive adaptation of individuals when confronted with adversity (Masten, Cutuli, Herbers, & Reed, 2009). This understanding of resilience can be used to understand the stressors and risks that these families face, with specific emphasis placed on the positive adaptation of older siblings of children with intellectual disabilities.

**Early Studies of Resilience**

Initial inquiry into psychological resilience arose in the 1960s and ‘70s largely in response to the predominant views of psychopathology of that time (Masten, 2001; Mednick & Schulsinger, 1968). Medical models of psychopathology typically emphasized the likelihood of negative outcomes accrued to individuals experiencing high levels of stress, living in adverse environments, or having relatives suffering from mental illness (Garmezy, 1971; Masten & Powell, 2003; Rutter, 1985). These models, although useful for understanding the impact of risk factors, did not account for how some individuals displayed competence in spite of risk (Masten & Powell, 2003). Early studies of psychopathology relying on the medical model were conducted with children from high-risk populations who would be most susceptible to developing mental health concerns (Goldstein & Brooks, 2005).

A foundational study in this area focused on the potential onset of schizophrenic symptoms in the offspring of mothers diagnosed with schizophrenia. Although these children were at high risk for developing schizophrenia themselves, as adults many did not develop this disorder and functioned adaptively in society. Environmental factors such as having a mother institutionalized during childhood appeared to contribute to later onset of schizophrenia in offspring (Mednick & Schulsinger, 1968), but the relationship was not absolute. Although this scholarship demonstrated that individuals were capable
of overcoming adversity, it left many questions unanswered about how this process occurs.

Seminal studies in this area typically sought to distinguish “vulnerable” children from “invulnerable” children and focused primarily on the risk factors contributing to psychopathology (Garmezy, 1971; Masten & Powell, 2003). Building off of this foundation, future studies began to investigate factors implicated in positive adaptation (O’Dougherty & Masten, 2005). As such, emphasis was placed not only on examining what factors might contribute to vulnerability but also what influences might buffer against psychopathology (Garmezy, 1971; Masten & Powell, 2003). This research focused primarily on innate characteristics within children that were thought to protect them from vulnerability to psychopathology (Luthar et al., 2000). These studies tended to focus on individual differences such as temperament and disposition (Rutter, 1985). Early studies on psychological resilience labeled these buffering agents that facilitate positive adaptation in the context of experienced adversity as protective factors (O’Dougherty & Masten, 2005; Rutter, 1985).

Longitudinal studies that follow individual development across time and in different conditions have been influential in changing our understanding of resilience as an internal attribute to a developmental process (Luthar et al., 2000). These studies emphasized that resilience is facilitated not only by static factors but also by protective processes that can be changed (O’Dougherty & Masten, 2005). One determining study in this area, the Kauai Longitudinal Study (Werner, 1993), followed the development of individuals from infancy into their adulthood. Of 698 children born in the year 1955, 201 were determined to be vulnerable to psychopathology because of risk factors including
poverty, having a parent with mental health concerns, and prenatal stress (Werner, 1993). Because these individuals were followed into adulthood, the Kauai study allowed Werner and her colleagues to observe the influence of risk factors and protective processes at different stages of development. Among those children initially determined to be at-risk, the trajectory of development between children varied remarkably. Some children adapted positively throughout their lives despite adverse situations, while close to two-thirds of the vulnerable children displayed additional concerns by age 18. Even for those individuals who had difficulties during their adolescence, many were able to overcome these setbacks and thrive later in adulthood. As an example, the majority of individuals who had committed one legal offense as a juvenile did not have repeat crimes as adults (Werner, 1993). These changes across developmental trajectory exemplify that individuals may display resilience at some points but not at other times (Luthar et al., 2000).

Elements of the Kauai Longitudinal Study underscore common themes prevalent in current resilience research. Modern conceptualizations of resilience as a process emphasize that it is a context-specific process (Anthony, 1987; Goldstein & Brooks, 2005). This context-specificity relates not only to characteristics of the adversity being faced, but also assets of the individual (O’Dougherty & Masten, 2005). Werner (1993) examined adaptation from the specific risk conditions each infant was born to, and observed this development across different points in each individual’s life. In following these children across the lifespan, the Kauai Longitudinal Study also emphasized that protective processes and risk vary based on the development of the child and the type of stressors experienced. For example, having a close relationship with a teacher appeared
protective for grade-school children, but experiencing partner support became more important as individuals entered adulthood (Werner, 1993).

Protective processes also occur in other aspects of an individual’s environment including within the family and the larger social environment (Luthar et al., 2000; O’Dougherty & Masten, 2005). For infant children at risk, Werner (1993) identified parental involvement and infant temperament as factors facilitating normative development. When these infants became adolescents, participation in extracurricular activities appeared to provide a safe environment protecting against risk (Werner, 1993). Because these risk factors and protective processes occur at different contextual levels, ecological models emphasizing the relationship between individuals and their environment are helpful for studying resilience.

**Resilience within an Ecological Perspective**

In their review of literature, Luthar and colleagues (2000) highlighted how protective processes can be found at three levels: individual, familial, and at the community level of the environment. Because of these contextual protective processes, ecological perspectives have been incorporated into resilience models (Luthar et al., 2000; Ungar, Ghazinour, & Richter, 2013; Waller, 2001). Ecological theories of development, which emphasize that development is influenced by different levels of an individual’s environment, are based largely on the influential work of Urie Bronfenbrenner. According to Bronfenbrenner’s (1977, 1979, 1994, 2005) bioecological development theory, individuals interact with their environments in idiosyncratic ways. To describe the organization of an individual’s environment, Bronfenbrenner (1977, 1979, 1994) postulated that there are five different levels of the environment with which
an individual either directly or indirectly interacts. These systems or levels included the microsystem, mesosystem, exosystem, macrosystem, and chronosystem, which were conceptually organized as a series of concentric circles (Bronfenbrenner, 1979, 1994).

A central tenet of ecological theories of development is that levels of the environment interact with each other and subsequently influence human development. Not only are individuals influenced by their environments, but characteristics of each individual influence each level of the environment that they interact with. Closest to the individual, the term microsystem is used to refer to contexts within the environment in which individuals experience daily, direct contact such as family and schools (Bronfenbrenner, 1977). To explain the way that multiple microsystems interact with each other, Bronfenbrenner (1977) used the term mesosystems. Exosystems, such as neighborhoods and community resources, both directly and indirectly influence the individual and the microsystems that they belong to. Shaping each of these levels of the environment is the macrosystem, which encompasses the predominant customs and patterns that a culture endorses (Bronfenbrenner, 1977). Finally, the chronosystem is used to refer to changes in culture and history across bounded time (Bronfenbrenner, 1994).

As a specific type of microsystem, the family unit has received considerable attention in ecological theory. From this perspective individual development is directly shaped in many regards by family characteristics, which are subsequently affected by agencies outside of the family (Bronfenbrenner, 1979). Understanding the relationship that the family shares with other levels of the environment can be helpful to understanding the development of a child. Not only is the development of the child influenced by the family, but the child also influences the functioning of the family.
When a family shares positive relationships with other institutions in the environment, such as schools or health agencies, collaborative relationships may form that can serve as protective factors for the child. In contrast familial stress can arise when these relationships are disrupted or nonexistent, which may contribute to stress and place a child at risk (Bronfenbrenner, 1979).

In addition to the influence of different levels of the environment, the bioecological model of human development also emphasizes the importance of internal characteristics. Central to this interaction shared between internal characteristics and the individual’s environment is how each reciprocally determine each other. These interactions differ based on each individual’s developmental level and the larger chronosystem, which can subsequently influence the formation of personal disposition and behavioral and cognitive repertoires. These influence the ability of individuals to successfully complete developmental tasks, which alters the way that individuals will interact with their environments in the future (Bronfenbrenner & Morris, 2006).

Beyond focusing on interactions shared by individuals with their environments, Unger’s work on resilience (2008b) also focused on how individuals are able to navigate their ecological environments and negotiate for the resources they need. From this perspective, resilience must specifically account for the resources available in an individual’s environment. Demographic characteristics of the individual, such as socioeconomic status or place of residency, may influence the ability of individuals to access these resources (Unger, 2008b). From this perspective, individuals differentially interact with their environments to gain resources that promote resilience. Stated more succinctly, “an individual is resilient only to the extent he finds among his family and
community the resources he needs to develop the internal strengths that are associated with experiences of resilience” (Ungar, 2008a, p.4).

The Psychological Resilience Framework

Resilience has been defined in the psychological literature as “a dynamic process encompassing positive adaptation within the context of significant adversity” (Luthar et al., 2000, p. 543). Although this is a generally accepted definition, research in resilience has been challenged by the use of varying definitions and measurement techniques by a number of researchers (Luthar et al., 2000). The concept of what constitutes resilience has changed with early references to resilience as a static trait within the individual (Garmezy, 1971) to more recent conceptualizations as “good outcomes in spite of serious threats” (Masten, 2001, p. 228). There is general agreement that an appraisal of resilience requires two stipulations to be met (Luthar et al., 2000; Masten, 2001; Masten & Powell, 2003; O’Dougherty & Masten, 2005). The first involves an appraisal that the individual has experienced or is currently experiencing adversity (Luthar et al., 2000) that might conceivably challenge normal development (Masten, 2001). Secondly, an appraisal of resilience requires that the individual is positively developing or adjusting satisfactorily despite these challenges (Luthar et al., 2000; Masten, 2001; Masten & Powell, 2003; O’Dougherty & Masten, 2005).

Beyond these two criteria, researchers have disagreed about how to determine whether or not this positive adaptation has occurred. Some researchers have used vague criteria to judge this adaptation such as that the individual is “doing okay” (Masten & Powell, 2003, p. 4) or that overall adjustment is satisfactory (O’Dougherty & Masten, 2005). In her comprehensive review, Luthar (1993) noted that most studies had relied on
measures of social outcomes to determine whether beneficial adjustment had occurred. Although there is still no consensus in this area, researchers commonly measure resilience by examining the developmental tasks associated with the individual’s age (Masten et al., 2009). These age specific tasks are based largely on societal expectations and norms, and may differ by culture (Havighurst, 1980; Masten et al., 2009). Research in resilience has typically focused on both internal and external tasks such as academic achievement, mental health, and personal conduct as parameters for measuring resilience (Masten et al., 2009). For example, Werner (1993) used academic records, teacher reports, and delinquency reports as indicators of resilience in her longitudinal study.

Current frameworks of resilience focus on the interplay between protective processes, assets, and risk factors across developmental pathways (Masten et al., 2009; O’Dougherty & Masten, 2005). Pathway models portray development as occurring across the lifespan, with protective processes and risk exerting differential influence throughout time (Masten et al., 2009). From this perspective, resilience is an unstable process that individuals may exhibit at some times but not at others (O’Dougherty & Masten, 2005). It is aided by protective processes which buffer against negative outcomes and occur at individual, familial, and community levels (Masten et al., 2009). As a subset of these, assets refer to individual characteristics, such as cognitive abilities, that can help individuals positively adapt to the risks they face (O’Dougherty & Masten, 2005).

Generally speaking, risk factors are believed to increase vulnerability to negative outcomes. Although many resilience studies have been framed from the specific type of non-normative stressor experienced, normative stressors (e.g., puberty, transitioning schools) also contribute to an individual’s overall vulnerability (Masten, 2001). Research
suggests that major life events have a negative precipitous effect that increases the frequency of normative stressors, and that both can collectively contribute to psychological concerns (Kanner, Coyne, Schaefer, & Lazarus, 1981; Patterson, 2002). Cumulative stress, which can be measured across gradients, occurs as stress accumulates throughout time from different risk factors (Masten, 2001; Masten et al., 2009). There is also increasing emphasis in the literature not only on the nature of stress but the ways that it is individually appraised. Perceptions of stress, and personal beliefs about whether it can be overcome, may contribute to the differential effects that stress can have (Fletcher & Sarkar, 2013; Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986).

Regardless of the risk experienced, the ability of individuals to demonstrate resilience is influenced by their ability to manage normative and non-normative stressors (Patterson, 2002).

It appears that risk factors and stressors experienced in childhood might contribute to both short and long term negative outcomes for individuals. An important series of studies known as the “Adverse Childhood Experiences Studies” have focused on the longitudinal impact that risk factors experienced in early childhood can subsequently have on adult development (Felitti et al., 1998). In an initial study of over 13,000 participants, individuals completed a questionnaire detailing any adverse experiences they had experienced as children. These adverse experiences were categorized into risk categories such as physical, emotional and sexual abuse, family mental health concerns, and exposure to household dysfunction. In addition to indicating what risks they had experienced as children, participants in this study also were asked to report their current health and the habits that they engage in. Through regression, Felitti and colleagues
(1998) found a significant relationship between exposure to adversities in childhood and health difficulties in adulthood. The likelihood that an individual experienced health risks in adulthood, such as depression or substance abuse, increased substantially if individuals had been exposed to four or more of the identified risk factors as children (Felitti et al., 1998). Related studies with large amounts of participants, such as by Edwards, Holden, Felitti, and Anda (2003), have similarly demonstrated the negative impact that risk factors experienced in childhood can have throughout the lifespan. Taken together, studies in this area emphasize the longitudinal impact that risk experienced in childhood can have.

There is growing concern that risk and resilience have been studied primarily from a western orientation of what positive development should entail (Arrington & Wilson, 2000; Ungar & Liebenberg, 2011). In reviewing public policies in the United States, Karen Seccombe (2002) argued that oppressive economic policies may bias our understanding of resilience processes in marginalized groups. Central to her argument is the unequal distribution of financial resources in American society. Access to financial resources is often needed to access helpful services such as professional counseling, childcare, or disability-related services. Because financial resources are often requisite for accessing these services, Seccombe (2002) argues that resilience processes in oppressed groups are often overlooked (Seccombe, 2002). Related to this, the developmental tasks frequently used to measure resilience need to be understood from a multicultural, systemic process. Individuals from a minority background often exist in environments that are discriminatory and oppressive, which places unique challenges on their ability to complete developmental tasks (Arrington & Wilson, 2000). As such, studies of resilience
must also examine pre-existing societal power structures and the way that resources are distributed in society (Ungar, 2010). For this reason, Arrington and Wilson (2000) argue that resilience studies must place emphasis on understanding the unique environment each individual comes from. Understanding both the environments and social class of an individual are necessary towards understanding how they positively adapt to the risk that they face (Arrington & Wilson, 2000; Seccombe, 2002).

Although the majority of research has utilized a quantitative design, an emphasis has been placed on studying resilience from a qualitative approach. Because resilience is a context-specific process, it appears naturally suited for qualitative inquiry (Ungar, 2003). Instead of reducing resilience to a list of protective processes and risks, Ungar (2003) noted that narrative approaches allow for a rich exploration of resilience processes for specific types of risks. Qualitative research also focuses on the perspectives and meanings of the individuals studied (Creswell, 2013), and can be used to understand resilience processes across different cultures and in minority populations (Ungar, 2003, 2008b). As personal meaning appears to be an important predictor of how effectively individuals and families will cope with stress (Patterson, 2002; Tugade & Fredrickson, 2004), the qualitative emphasis on meaning-making may further an understanding of resilience (Creswell, 2013).

With a framework of resilience established, it is now possible to examine the impact of having a family member with a disability. As siblings of children with disabilities experience higher levels of stress than siblings typically do (Senel & Akkok, 1995), they can be classified as an at-risk population. Therefore, it is important to
understand the risks they experience and the ways that they positively adapt to stress in their lives. An overview of family stress related to disabilities is reviewed next.

**Family Stress Related to Disabilities**

The ability of individuals to positively adapt, or be resilient, in the face of adversity is dependent on the difficulties experienced as well as their response to these events. These hardships and stressors are not only handled individually but may also be experienced collectively by families. Within a family, each individual’s response to stress is influenced by the structure and characteristics of the family. Because families are conceptualized as an interactive system, one family member’s reactions to the stressor influences the ways in which the entire family operates as a system (Walsh, 2003). An understanding of individual resilience relies on understanding characteristics of both the individual and his or her family unit.

**Models of Family Stress**

Family systems theory posits that tension is experienced by all members of a family, and that the emotional unit of the family largely dictates individual responses to stress. It emphasizes that stress is experienced at all levels of the family and influences the ability of families to function (Bowen, 1976). Determining whether a family and individual are resilient is based in part on how they appraise their current, specific stressors. In general, high levels of stress are assumed to interfere with typical functioning and may contribute towards the onset of aversive health concerns (Ingram & Price, 2010).

Families with a child who has a disability appear to experience unique stressors (Hastings, 2002; Stoneman, 2005). Disabilities can take many forms and can be
diagnosed differently by various agencies. From birth to age 3, families are able to access services that are available to them in their community. From the age of 3 and up, children can receive services through public schools if they meet the eligibility requirements for any of the 13 disabilities found in Part B of the Individuals with Disabilities Education Improvement Act (United States Department of Education, 2004). In 2013, 6.4 million children received services under IDEIA Part B, with the majority receiving services for specific learning disability or a speech and language impairment (Kena et al., 2015).

Under IDEIA Part B, students can receive services if they are determined to have an intellectual disability. A determination of an intellectual disability is based on three primary criteria being met. In order to meet the criteria for an intellectual disability, a student must first display significantly impaired cognitive functioning (American Psychiatric Association, 2013; United States Department of Education, 2004). In addition to this, intellectual disabilities also involve an impairment in adaptive skills that limits their ability to receive instruction in the general classroom. Taken together, these cognitive and adaptive deficits lead to significant impairment in academic functioning (Colorado Department of Education, 2013; United States Department of Education, 2004). Although intellectual disabilities encompass a variety of specific disabilities, such as autism and Down syndrome, all share common deficits in cognitive and adaptive functioning that lead to academic difficulties.

Different models have been proposed to describe the ways that families handle adversities. One seminal model, the Double ABCX Model of Family Adjustment and Adaptation (McCubbin & Patterson, 1983), posits that families function differently before, during, and after a stressor is encountered. Central to this model is the
idiosyncratic interplay between stressors (labeled \(aA\) in this model), the skills of the family to handle stress (labeled \(bB\)), and the ability of the family to ascribe meaning to the stressor (labeled \(cC\)). Each of these ultimately influence the ability of the family to adapt (McCubbin & Patterson, 1983). The Double ABCX Model of Family Adjustment and Adaption has been used to conceptualize the stress experienced by families who have children with disabilities. In a study of fathers and mothers from Finland parenting a child with a disability, Saloviita, Itallinna, and Leinonen (2003) used the Double ABCX model to examine the types of stressors these parents faced and the ways they addressed them. After a general measure of parenting stress was given, the authors measured family demands (\(aA\)) based on the age, disability, adaptive skills, and identified problematic behaviors of the child. The family’s adaptive resources (\(bB\)) were measured based on a variety of factors including the intimacy of the shared relationship between partners, feelings of spousal support, and perceptions of control over life events. Finally, levels of family definition and meaning (\(cC\)) were assessed by using measures of meaning to stressful events. Through multiple regression analysis, the authors determined that the family demands (\(aA\)) related to parenting the child contributed minimally to experienced stress. For both mothers and fathers, variables related to the family resources (\(bB\)) and family definitions of the situation (\(cC\)) were much more related to lower levels of stress (Saloviita et al., 2003).

Related to the Double ABCX Model, Patterson (2002) posited that family units can display resilience when they successfully navigate stress. From this perspective, family adaptation relies on families using their capabilities to meet the demands that stressors present. Capabilities include personal resources, coping behaviors of the family,
and services available in the community. When the stressors are non-normative and substantive, families must use these capabilities liberally to functioning adequately. If these resources become depleted or if demands cannot be met, crisis may occur which creates changes to the family and requires family members to take on new roles and responsibilities. Crises are resolved when families can successfully balance these demands with new capabilities and find meaning in the challenges that they face (Patterson, 2002).

The nature of stressors experienced by families who have a child with a disability differentially influences their ability to adapt. The family unit may experience stress from either isolated events or from the accumulative strain of multiple stressors experienced across time (McCubbin & Patterson, 1983; Patterson, 2002). Stress also arises as the structure of families and role of each member changes, which creates ambiguity within the family system (McCubin & Patterson, 1983). Because of these stressors, families of children with disabilities report having lower overall functioning and adaptability (Rao & Beidel, 2009).

**Parental Stress**

Much of the literature has focused on the stress experienced by adults parenting a child with a disability (Baker et al., 2002; Hassall et al., 2005; Smith et al., 2001). Parents of children with disabilities typically experience more stress than other parents do (Baker et al., 2002; Baker-Erickzn, Brookman-Frazee, & Stahmer, 2005; Peer & Hillman, 2014). The added stress that these parents face is related to many different factors. Parental stress often arises from conditions specific to their children (Baker et al., 2003; Hastings, 2002; Mash & Johnston, 1990), such as behavior concerns (Baker et al., 2003),
difficulties in communication, and low self-care and poor physical health (Schieve et al., 2007). These areas, and challenges associated with each, may contribute differently to parental stress throughout the development of the child (Ellingson, Baker, Blacher, & Crnic, 2014; Woodman, Mawdsley, & Hauser-Cram, 2015). Stress for many of these parents peaks during middle childhood, when behavioral and emotional difficulties often become more pronounced (Woodman, 2014).

Parents of a child with a disability often incur substantial financial burden related to meeting the needs of their child. Economic models have suggested that the direct and indirect costs of parenting a child with a disability average close to $30,000 a year (Stabile & Allin, 2012). Although schools are required to provide free services under IDEIA Part B (United States Department of Education, 2004), children with disabilities typically need additional services beyond those available in schools (Sharpe & Baker, 2007). These services are typically expensive and may not be fully covered by insurance (Bouder, et al., 2009). In addition, parents of children with disabilities typically have lower financial resources to draw from and may have lower income (Neely-Barnes & Graff, 2011; Worcester, Nesman, Mendez, & Keller, 2008). In many instances, the substantial amount of time that these parents report allotting to meet the needs of their child limits their availability for work (Gould, 2004; Leonard et al., 1992).

The stress that arises from parenting a child with a disability may also contribute to later physical and psychological concerns. Parents of children with disabilities indicate having more health concerns and report using health services more frequently than other parents (Gallagher & Whiteley, 2013). A meta-analysis of studies examining the health of parents who have a child with a disability suggests they are at elevated risk for multiple
health concerns, such as insomnia and chronic fatigue (Miodrag et al., 2015). As parents of individuals with disabilities often care for their offspring well into their adulthood, these problems may proliferate as parents age (Cuskelly, 2006). These parents also are at an elevated risk for mental health concerns. A meta-analysis exploring depressive symptoms between mothers of children either with a disability or without indicated that mothers of children with a disability were more likely to suffer from depressive symptoms (Singer, 2006). Mental health concerns may be more prevalent in mothers than fathers because they typically provide much of the care to children with disabilities and may experience associated stresses more directly (Olsson & Hwang, 2001).

Qualitative studies have explored how parents handle the challenges that are associated with parenting a child with a disability (Resch et al., 2010; Worcester et al., 2008). For example, Resch et al. (2010) found that difficulty accessing services for children was a substantial contributor to parent stress. Parents in this study indicated frustration in obtaining information about resources available to them, as well as difficulty navigating services once they were located. Related to these services, parents also expressed feeling financial stress for the services provided for their child and noted the high cost of many programs prohibited parents from being able to utilize them (Resch et al., 2010). In their study, one mother described how financial issues limited families’ ability to access needed services:

A lot of time people that are having financial hardships kind of shut down and really don’t want to get involved in the programs, because first fear of the cost and then fear of they’re going to look down on us because they are financially hard (Resch et al., 2010, p.143).

These findings were similar to earlier work by Worcester et al. (2008) who found that parental stress was related to issues of financing and locating services for their child.
Parents in this study also indicated difficulty in acquiring accurate and relevant information about their child’s disability. Many parents also experienced social isolation from their community because of the challenging behaviors that their child exhibited (Worcester et al., 2008).

**Sibling Stress and Vulnerability**

Siblings of children with disabilities have been referred to as “invisible children” both because they are sometimes overshadowed within the family (Naylor & Prescott, 2004), but also because there has been limited research as related to their needs and strengths. Although recent literature in this area has made these children more visible, much of their experience remains unexplored. Furthermore, when they are included in research, siblings have been grouped together regardless of age which may mask different experiences between siblings based on developmental level. Older siblings conceivably experience different forms of stress than younger siblings do because they were part of the family before a sibling with a disability entered the unit. As such, they must adapt to changes in the family structure brought about not only by the addition of a new sibling, but one who also may require more care and parental attention than with a typically developing child. Because of their age, they may also be tasked with caretaking responsibilities more so than younger siblings (Stoneman, Brody, Davis, & Crapps, 1989).

Although my focus was to more fully understand the experiences of these older siblings, it is also recognized that there are similarities in the risks that all siblings of children with disabilities face. Furthermore, because existing research has tended to group siblings together regardless of age, it is only possible to review these studies with
an understanding that the findings are not specific to adolescent siblings of children with disabilities. However, the types and sources of stress and the influence of parental stress in families with children with disabilities are likely to be somewhat common across siblings regardless of age.

**Relationship Between Parental and Sibling Stress**

As models of family stress posit, stress is experienced at all levels of the family and is experienced both individually and collectively (Patterson, 2002). The ability of parents to effectively navigate stress can have a significant impact on other members of the family, including siblings of children with disabilities. Research in family stress emphasizes the reciprocal interaction that parental stress shares with children stress. The stress that parents experience mediates the overall family environment, which then has indirect and direct effects on the stress that each child experiences. Conversely, behaviors and stress that children experience can influence the family environment and the stress that parents feel (Hastings, 2002; Mash & Johnston, 1990). As such, parents experiencing high levels of stress may be less effective and patient in handling their child’s problem behaviors, which might subsequently increase the instances in which the child acts out.

The influence that parental stress can have on other family members is exemplified in research on siblings of children with disabilities. Siblings are members of the family unit who appear to be uniquely affected by the experience of being related to and living with an individual with a disability (Stoneman, 2005). Their development, and the ways that they personally handle stress, are related to the perceived amount of stress reported by their parents (Giallo & Gavidia-Payne, 2006). Possibly because parents of children with disabilities typically have more stress than other parents, siblings of
children with disabilities appear to have a heightened sensitivity to family conflict and stressors that occur. Siblings of children with disabilities are more likely than siblings of typically-developing children to perceive everyday stressors as threatening. In addition, they are more likely to take personal responsibility when conflict does arise (Nixon & Cummings, 1999).

A study by Cuzzocrea and colleagues (2014) further examined the relationship between family factors on sibling adjustment in families with and without children with disabilities. Parents completed multiple measures including levels of overall stress and assessments of family functioning. To examine the development of children, siblings and their teachers completed measures of interpersonal relationships and emotional functioning. Teachers rated students who were siblings of children with disabilities as having greater difficulty engaging with peers and displaying more depressive symptoms than students raised in families without a sibling with a disability. With the siblings of children with disabilities, difficult relationships with parents appeared to influence problems at school. Significant relationships were determined to exist between siblings’ depressive symptoms at school and difficulties relating to their mothers, while having trouble relating to fathers was significantly associated with peer avoidance behaviors (Cuzzocrea et al., 2014). These school-based difficulties build on earlier findings from Hannah and Midlarsky (1999) that siblings of children with disabilities may have lower academic achievement than their peers and that teachers have lower expectations for these siblings as students (Richey & Ysseldyke, 1983).

The stress that parents of children with disabilities experience may strain their relationship with their typically developing children. Parents experiencing high levels of
stress are more likely to appraise their child without a disability as being more challenging and displaying more pronounced difficulties (Dyson, 2003). The way that parents treat each child may also vary because of the pronounced needs of the child with a disability. Levels of differential treatment appear to be higher in families with a child who has a disability than in other families (McHale & Pawletko, 1992), and siblings may feel neglected by the unequal amount of parental attention given to the child with a disability (Cate & Loots, 2000). The sibling’s perception of parenting also appears to be an important predictor of the quality of the parent and child relationship. For example, differential parenting is associated with negative parent and child interactions only if it is viewed by the child as being unfair (Kowal et al., 2004). Specifically for siblings of children with disabilities, differential parenting that is equated with favoritism towards the other child is correlated with elevated behavioral and emotional concerns in the sibling (Wolf, Fisman, Ellison, & Freeman, 1998).

**Stress from the Sibling Relationship**

The relationship shared between siblings with their brother or sister who has a disability is often challenging and may contribute to stress. Although these siblings appear to spend comparable amounts of time with each other as other siblings do (Knott, Lewis, & Williams, 1995), their interactions appear unique in many ways. The quality of sibling relationships is often decreased by challenges specific to a child’s disability and can vary between disability categories. For example, Kaminsky and Dewey (2001) found that siblings of children with Down syndrome report having higher quality sibling relationships than siblings related to a child diagnosed with autism. Differences in these relationships were noted in specific areas such as pro-social interactions and
communication, which appear related to feelings of closeness and reciprocity in sibling relationships (Kaminsky & Dewey, 2001). Sibling relationships when one child has a disability are typically more avoidant, with less contact and reciprocal play than other sibling relationships (Walton & Ingersoll, 2015).

One factor influencing the nature of the relationship between siblings is the role assumed by the child without a disability. Siblings often take on added family responsibilities and duties to help their family function. These roles may include caring for their sibling with substantial needs or assuming other responsibilities at home that parents typically have handled (Damiani, 1999). Siblings of children with disabilities report taking on additional household chores that their parents do not have the time for, and consequently may experience anxiety about these new responsibilities (McHale & Gamble, 1989). Older siblings appear to take on unique roles when relating to their sibling with a disability. Rather than playing with them or joining in cooperative activities, older siblings often taken on supervisory or guardian roles (Stoneman et al., 1989). As parents age and are less able to care for their child with a disability, siblings may face increased responsibility towards meeting the needs of this individual (Saxena, 2015).

**Emotional Functioning of Siblings**

Siblings of children with disabilities may experience impaired emotional functioning because of their level of stress. For example, in a study of depression in siblings of children with and without disabilities, siblings of children with autism were more likely to report feeling depressed (Gold, 1993). More recently, Walton and Ingersoll (2015) reported that siblings of children diagnosed with autism did not have significantly
different levels of behavioral difficulties, although in this case, developmental level was considered. Older male siblings of children diagnosed with autism were found to have higher rates of behavioral difficulties (Walton & Ingersoll, 2015). A meta-analysis of 25 studies in this area conducted by Rossiter and Sharpe (2001) found a slight negative effect for depressive symptoms among siblings of children with a disability. One consistent contributing factor to sibling adjustment identified within the literature is the severity of symptoms and behaviors in the child with a disability (Benson & Karlof, 2008; Mohammadi & Zarafshan, 2014). That is, children with more substantial behavioral concerns are more likely to negatively influence sibling adjustment, possibly because they demand more family resources and contribute to higher levels of stress (Benson & Karlof, 2008; Mohammadi & Zarafshan, 2014).

A Cascade of Risk

There is some evidence to suggest that siblings face risk not only from having a sibling with a disability, but from concurrent risk factors associated with disability. A propensity analysis by Neely-Barnes and Graff (2011) explored other factors associated with having a child with a disability that contribute to sibling stress. When examining sibling groups of children with and without disabilities, the researchers found many noticeable differences between these two types of families. Siblings of children with disabilities were more likely to live in low socioeconomic households with only one parent. In addition, families raising a child with a disability were also more likely to have another family member with a disability (Neely-Barnes & Graff, 2011). In addition to these risks, parents of children with a disability have a significantly higher divorce rate for parents of children with autism when compared to other parents (Hartley et al., 2010).
Beyond focusing on having a sibling with a disability, these findings highlight the need for researchers to focus on additional characteristics of these families. The presence or absence of these concurrent risks may explain the inconsistent findings related to sibling outcomes.

In fact, family socioeconomic status appears to be an important factor as related to sibling resilience. Macks and Reeve (2007) studied 51 families who had a child diagnosed with autism. Both older and younger siblings completed a measure of depression and a scale of self-concept. Parents also rated these children and provided information about their household income. Families of children without disabilities completed these same measures and served as a comparison group. In general, siblings of children diagnosed with autism reported higher self-concepts than siblings in the other group. However, there were significant differences between these groups when risk factors such as socioeconomic status were controlled. When comparing younger siblings to older siblings, older siblings were found to be more at risk for a variety of negative social and emotional outcomes. Of note, older siblings of children with autism living in low-SES households displayed more adjustment problems than similar siblings living in higher income households. These findings suggest that having a sibling with a disability may actually lead to positive outcomes, but that other family characteristics such as SES may contribute to challenges in development (Macks & Reeve, 2007). As 28 percent of siblings of children with disabilities live in families experiencing poverty (Park, Turnbull, & Turnbull, 2002), it is important for researchers to consider the negative impact of limited resources on family functioning.
Protective Processes and Assets Promoting Sibling Resilience

Despite the challenges associated with having a sibling with a disability, many children show great adaptation to this heightened risk. From an ecological perspective, resilience processes that these individuals engage are influenced by each level of their environment that they are in. Each of these contributes to the overall positive development of siblings adjusting to having a brother or sister with an intellectual disability.

Community-Level Protective Factors

At a community level, agencies and programs available in the community can serve as protective factors for siblings of children with disabilities. Programs that provide information can be beneficial to siblings by providing them with education about disabilities. In their study with 54 siblings of children with disabilities and their parents, Lobato and Kao (2002) investigated the efficacy of a parent and child education group. Participants attended six group sessions together that provided information about disabilities and their associated characteristics. These groups allowed parents and children to interact with other families and discuss their specific experiences. Measures were given to each sibling to assess their overall adjustment, their knowledge of the disability, and their feelings of connectedness to their brother or sister. When ratings were compared before and after participation in the group, siblings reported increased awareness of the impact of disability, feeling closer to their sibling, and reported less adjustment difficulties (Lobato & Kao, 2002). This study suggests that siblings of
children with disabilities may benefit from gaining information about their sibling’s disabilities.

Specific agencies within the community can also aid older siblings in positively adjusting to living with a sibling with special needs. Respite facilities that provide specialized care can assist families in providing for the unique needs of their child. Utilizing these services provides alone time for siblings and parents to spend quality time together engaging in activities that they choose. Families of children with disabilities who utilize these services report having higher family cohesion and reduced stress than similar families who do not access these (Chan & Sigafoos, 2001).

**Family-Level Protective Factors**

Families appear to be particularly important in facilitating the positive adjustment of siblings of children with disabilities. Families who can effectively handle stressors engage in protective processes that promote resilience in individual family members (Patterson, 2002). As models of family adjustment suggest, family meaning is an important predictor of how a family will face challenges (McCubbin & Patterson, 1983; Patterson, 2002). Family meaning comes from three separate sources: (a) family appraisal of the stressors and family resources; (b) concepts of family identity and cohesiveness; and (c) the worldview of the family and their ability to make connections to other systems within their environment. (Patterson, 2002; Patterson & Garwick, 1994). Positive worldviews, such as those shaped by belief in a higher power, may be a source of hope for these families that allows them and siblings to optimistically frame the challenges they face (Poston & Turnbull, 2004).
Bayat (2007) examined personal meaning in parents having a child with a disability. When asked about positive changes that had occurred since having a child with autism, many parents indicated that their overall perspective of life had changed. Although initially feeling sadness and uncertainty when hearing that their child had a disability, over time most parents had adjusted and ascribed positive meaning to their circumstances. Many parents indicated that they had developed a more positive worldview and derived significant purpose from parenting their child with a disability. Some parents reported gaining meaning from their spiritual beliefs and from a sense that they were called to parent their child with a disability. Interestingly, many parents’ worldviews had expanded to embrace challenges as an opportunity to strengthen family ties. As one mother noted, “Through working together, we all learned how to help my son together. In some sense this also makes our family closer, because an individual cannot handle the toughness alone” (Bayat, 2007, p. 709).

The types and quality of the relationships within the family context are critical influences on the development of siblings. Positive relationships shared between siblings of children with a disability and parents has been consistently identified in the literature as a protective process promoting positive adaptation (Ellingsen et al., 2014; Giallo & Gavidia-Payne, 2006; Williams et al., 1999). Parents with positive moods appear to beneficially influence siblings of children with disabilities by making them feel supported, increasing their self-esteem, and contributing to their own positive disposition (Williams et al., 1999).

Not only are emotional dispositions important, but also structural components. For examples, family engagement in regular routines is associated with greater sibling
adjustment because it provides siblings with support and stability (Giallo & Gavidia-Payne, 2006). Family routines provide structure while also allowing family members to emotionally invest in each other (Spagnola & Fiese, 2007). Families who seek to solve problems rather than just mediate problem behaviors also promote family and sibling resilience (Costigan et al., 1997). Overall, these components contribute to family satisfaction which has been demonstrated to be positively correlated with high-quality relationships within the family (Bellin & Rice, 2009).

Although time together and family engagement are important to sibling development, there is also a need to recognize siblings as individuals apart from the family. Moyson and Roeyers (2012) examined sibling perceptions of their quality of life as related to an individual with a disability. Siblings emphasized that characteristics of their family were important in helping them adjust to having a sibling with a disability. Although these siblings reported enjoying spending time with their sibling, they also reported benefiting from being allowed to spend time alone. Many siblings also appreciated when their parents arranged time to interact with them one-on-one and engaged in activities that they preferred (Moyson & Roeyers, 2012). Richard, an 8-year-old brother to a child with a disability, described a ritual that he enjoys sharing with his parents: “Sometimes, at night-time, we go to bed and when my brother is sleeping, I may go downstairs and then my mum and I play a game or watch television together. My brother doesn’t know this!” (Moyson & Roeyers, 2012, p.94). These structured activities appeared to contribute to feelings of inclusion and provided respite for both the parent and the sibling.
**Individual Assets**

In addition to the protective processes of families, individual characteristics of siblings of children with disabilities also play an important role in contributing to resilience processes. One personal quality, self-concept, appears to influence the ways that siblings perceive stressors. A positive self-concept is correlated with social competence and appears to help siblings of children with disabilities positively adapt (Verte et al., 2003). Furthermore, siblings of children with disabilities who indicated greater levels of persistence reported having higher quality relationships with their sibling and appeared to be less influenced by differential parenting. Siblings indicating high levels of persistence appear more willing to work through problems and not be overcome by adversity (Rivers & Stoneman, 2008).

Siblings who utilize cognitive coping strategies such as changing negative thoughts through reframing and reflection are also more able to successfully handle the stresses that come with living with an individual with a disability (Bitsika et al., 2015). In a study of both older and younger siblings, the relationship between coping skills and mental health was explored. While both older and younger siblings used coping strategies, it appeared that the effectiveness of each strategy varied between these groups. Younger siblings benefited most by using a strategy of identifying mistakes in their thinking; older siblings who utilized strategies to reduce their anger displayed less anxiety and depressive symptoms (Bitsika et al., 2015).

**Thriving Despite Risk**

The ability of individuals to positively adapt may not only reduce risk but lead to unique positive benefits relative to their circumstances. A study of siblings of children
with either Rett or Down syndrome asked parents to describe the advantages and disadvantages that their children have faced. Although parents noted that their children had experienced many unique challenges and stressors, many believed it had contributed positively to their overall development. Parents indicated that their children had learned patience, were willing to assist their parents when they needed help, and were caring and compassionate individuals. Overall, parents in this study perceived the challenges that their children had faced as character-building (Mulroy et al., 2008). As one parent stated, “Their acceptance of people for who they are extends beyond the front door” (Mulroy et al., p.224). Although parents of children with disabilities often perceive that their typically developing child is struggling (Dyson, 2003), this quote illustrates that they may also view their children as resilient.

Although siblings of children with disabilities may take on greater responsibilities (McHale & Gamble, 1989), there may be positive benefit associated with completing these tasks. A study by Cuskelley and Gunn (2003) examined the types of responsibilities that siblings of children with Down syndrome assume with their sibling. Siblings were asked to complete inventories of the types and quality of interactions that they shared with their sibling with a disability. To supplement these, parents and siblings of the child were also interviewed to provide more contextual understanding. As a comparison group, siblings of children without a disability completed similar measures about their relationship with their brothers or sisters. When compared to their peers, sibling interactions when one child had Down syndrome were characterized by higher levels of care-related behaviors than typical sibling relationships. Although these added responsibilities could be stressful, siblings of children with Down syndrome who
provided more care were perceived by themselves and their parents as being more involved in the family and having a more empathetic sibling relationship (Cuskelly & Gunn, 2003). This finding was consistent with work by Taunt and Hastings (2002) who found that siblings of children with disabilities often showed heightened levels of responsibility and maturity when compared to their peers.

**Summary**

Having a child with an intellectual disability can have a substantial impact on the entire family. Most research has focused on the stress that parents experience related to meeting the needs of their child. However, the stress experienced by parents has direct and indirect effects on other members of the family including siblings. There has been a proliferation of recent research focusing on the risk that these siblings experience. Siblings may experience risk as the structures of their families change to meet the needs of the child with a disability (Patterson, 2002). This restructuring can create strain between the relationship shared by siblings and their parents and with their brother or sister with a disability, contributing to increased behavioral and emotional concerns for these siblings (Rossiter & Sharpe, 2001).

Although these siblings are at risk for negative outcomes such as depression, some are able to positively adapt and find meaning in the specific challenges they face. This line of research is relatively new and it appears that factors at the individual, family, and societal level contribute to this beneficial adaptation. Research in this area has typically focused on parental report and often has not differentiated between younger and older siblings. As such, the specific resilience processes of older siblings have rarely been addressed in the literature. Older siblings of children with disabilities may face particular
challenges and adjust differently as they are asked to take on new roles and responsibilities. This study sought to address this gap in the literature by qualitatively studying the specific context and process of adaptation of these older siblings.
CHAPTER III

METHODS

Tell me, I’ll forget; Show me, I may remember; but involve me, and I’ll understand.

--Chinese proverb

There are a variety of hallmarks that differentiate qualitative research designs from other types of research. Understanding these provides a justification for the use of a qualitative approach, and the potential contributions to the literature. A qualitative design is advantageous to use when the researcher wants to understand how individuals construct meaning from their experiences. By gathering information from a wide variety of sources (Creswell, 2013), each can collectively provide substantial detail about both the subject and the individual context. This detail can then be applied to create an overall understanding of the perspectives and experiences of these individuals (Creswell, 2013; Merriam & Tisdell, 2016).

The application of qualitative designs to the construct of resilience can address some limitations in previous resilience studies. One preeminent scholar of resilience, Michael Ungar (2003), argued that using a qualitative design allows a focus on the actual perspectives of specific individuals at-risk rather than researchers arbitrarily focusing on the risk and protective factors included in their studies. Instead, in qualitative studies, participants can describe the resiliency factors that are most salient and impactful to them. The qualitative perspective can also be useful in providing a rich exploration of different environmental contexts. Ungar (2003) argued that understanding these
environmental contexts is integral to describing how positive adaptation occurs. From a social justice perspective, the actual voices and perspectives of marginalized and underrepresented populations can be brought forth through qualitative research. This aspect is especially important for siblings of children with disabilities, who have been described in previous research as “invisible children” (Naylor & Prescott, 2004).

Because I considered the voices of each older sibling to be the best indicator of his or her unique experiences, a qualitative research design was used in this study. The focus of this study was to examine the process of adaptation for older siblings of children with disabilities with a focus on resilience processes. To understand how this process occurred for each participant, a variety of data sources were utilized. First, in-depth interviews were conducted with these older siblings that focused on their perspectives related to how they had adjusted, the challenges and joys they had experienced, and the meaning that they had created about having a younger sibling with a disability. This interview was supplemented with the use of photo elicitation interviews, which allowed older siblings to visually describe their experiences and relationship with each of their siblings. Each participant also wrote daily journal entries, in which they provided information about the ways that they had related to and interacted with their siblings throughout the day. Finally, I also collected artifacts and documents, field notes, and written journals throughout the entirety of the data collection process. Taken together, this variety of data sources provides a rich contextual understanding of how participants perceived their adaptation to having a younger sibling with a disability.
Theoretical Framework

Qualitative research is guided by the philosophical assumptions of the researcher (Creswell, 2013; Merriam & Tisdell, 2016). These assumptions not only inform the interests of the researcher, but also dictate how the process of research occurs (Creswell, 2013). A researcher’s overall philosophy is determined by interconnected characteristics: ontology, epistemology, and axiology. The first, ontology, refers to the researcher’s perspective about what reality entails and whether it can be subjectively derived (Creswell, 2013; Merriam & Tisdell, 2016). As Creswell (2013) noted, qualitative research operates from a stance that each individual has a unique perspective on reality. As such, the aim of qualitative research is to capture the specific view of reality held by an individual or group of individuals (Creswell, 2013). Related to this concept, epistemology describes the nature of knowledge and ways in which it is derived (Creswell, 2013; Merriam & Tisdell, 2016). The axiology, or values, that the researcher brings into the research process influences the ways in which findings are interpreted. Collectively, each of these aspects informs the methodology chosen by the researcher.

I chose to frame this study from a social constructivist perspective of knowledge which supports the idea that participants gained knowledge and derived meaning from their unique environments. Older siblings learned from their experiences and relationships throughout their childhoods, with each of these contributing to the idiosyncratic construction of beliefs and worldviews (Creswell, 2013). This understanding of knowledge as occurring at an individual level is associated with a phenomenological research design, which I also utilized in this study to understand the unique phenomenon of being an older sibling of a child with a disability.
On a broad level, this study was guided by a psychological resilience framework. Researchers of resilience seek to understand the process of positive adaptation for individuals encountering specific risks. This can be examined through the interplay between risk, vulnerability, and protective processes (Masten, 2001). For each older sibling, I sought to understand their individual adaptation process by understanding how they viewed the overall functioning of their families. From a family resilience perspective, each family member adapts to stress both personally as well as collectively as a family unit. As such, the ability of each family to adjust to stress influenced how effective each older sibling was in personally handling stress (Patterson, 2002). To conceptualize this process, I designed my research materials to incorporate elements of Double ABCX Model of Adjustment and Adaptation developed by McCubbin and Patterson (1983). Using this model, I sought to understand how older siblings viewed how they had adapted to challenges associated with having a younger sibling with a disability. Through their stories, I hoped to understand how families engaged in new patterns of behaviors, accessed resources, and created meaning in order to proactively address the stressors that they faced (McCubbin & Patterson, 1983).

**Methodology**

Phenomenological studies focus on understanding the experiences that individuals have in relation to a specific event, or phenomenon (Creswell, 2013). Central to phenomenological studies is awareness, which differentially dictates what individuals attend to and the meaning they attribute to it (Giorgi, 1997). Phenomenological studies focus on understanding the experiences that numerous individuals have had with a certain phenomenon, and arriving at a common meaning for all members of this group (Creswell,
Researchers who use this methodology seek to describe the experiences their participants have had and how they interpreted their unique experiences (Merriam & Tisdell, 2016).

There are four primary assumptions inherent within phenomenological research (Creswell, 2013). First, the phenomenological approach is rooted in a traditional approach that seeks to understand the elemental essence of truth, meaning, and experience through systematic exploration. As a researcher, this required me to acknowledge my preconceived notions and withhold judgment until the phenomenon had been investigated in detail. Once it had been studied, truth emerged from the perspectives and experiences that individuals shared with me related to their unique experiences and contexts (Creswell, 2013).

Phenomenology is also framed from a belief in the intentionality of consciousness. This belief places consciousness at the forefront of all human experience, so that individual reality is dictated by how individuals consciously perceive themselves and the environments they are in. Finally, the phenomenological emphasis on consciousness makes it impossible to dichotomize objects from experience. Consciousness drives what objects an individual perceives, and reality is shaped by how individuals consciously interpret their environments and interact with the objects they have perceived (Creswell, 2013).

Within the broad field of phenomenology, there are differing perspectives about the nature of meaning and how it can be systematically uncovered (Creswell, 2013; Vagle, 2014). In this study, I examined resilience processes through a post-intentional phenomenological perspective. Of central important in post-intentional phenomenology
is intentionality, which refers to the ways that individuals form connections with their environments. Vagle (2009, p.589) described intentionality as the “in-between spaces between subjects and the world and that which connects us.” To discover the phenomenon in question, I sought to understand the intentional relationships each participant shared with their siblings, families, and their environments. In post-intentional phenomenology, these meaningful intentions are viewed as constantly changing and ephemeral. That is, the ways that participants connected to their environments were not absolute; these intentional relationships constantly changed as participants experienced the world in new ways (Vagle, 2009, 2014). The goal of post-intentional phenomenology is to capture “tentative manifestations” that explain the phenomenon as it is experienced by specific individuals at particular times (Vagle, 2014). In this study, I sought to capture a snapshot representing how each older sibling had adapted to the experience of having a younger sibling with a disability.

In contrast to other branches of phenomenology, the post-intentional approach also sees the researcher as inevitably having an intentional relationship with the phenomenon (Vagle, 2009, 2014). As such, in this study I detailed not only how participants related to the phenomenon, but also how I personally did. While in other branches of phenomenology the researcher is asked to put his previous beliefs aside, from a post-intentional perspective I sought to be constantly reflexive of my own beliefs throughout the study. Additionally, I challenged myself to remain open to changing these beliefs as I gained new insight (Vagle, 2014). As a whole, the post-intentional approach is summarized by phenomenologist researcher Mark Vagle (2014) as “seeing knowledge as partial, situated, endlessly deferred, and circulating through relations” (p.111-112). My
personal beliefs were challenged, changed, and clarified as my awareness of the phenomenon expanded.

This study utilized a post-intentional phenomenological approach by seeking to describe the specific phenomenon of being an older sibling to a child with an intellectual disability. Five older siblings were interviewed about their experiences, and perspectives related to having a sibling with a disability. Specific to this, the present study focused on the challenges these siblings had encountered and the ways in which they had positively adapted to these. By interviewing multiple older siblings, common themes emerged between narratives that explained the meaning and reality that these siblings had constructed from their experiences. Taken collectively, their stories described the overall essence of what this experience had been like for each older sibling, explaining both the “how” and “what” of what their journey alongside their sibling had entailed (Creswell, 2013; Merriam & Tisdell, 2016).

**The Researcher and Initial Reflexivity Statement**

A central tenet of the phenomenological approach is that the researcher is an instrument that influences the nature of the study (Merriam & Tisdell, 2016). As with any research instrument, it is important for consumers of research to examine my pertinent qualities as a researcher. Reflexivity is commonly used in qualitative research to describe the researcher’s stance to the subject being investigated (Creswell, 2013). From a traditional phenomenological perspective, the researcher is required to acknowledge any presuppositions they hold about the phenomenon as it is investigated (Creswell, 2013).

However, in post-intentional phenomenology, the researcher is also tasked with “bridling” their previous beliefs. Bridling is a process of gradually loosening
preconceived beliefs and ideas, and holding an open posture towards acquiring new insights and a greater understanding. Although the conscious experiences of the individuals experiencing the phenomenon were the primary unit of study, bridling required me as a researcher to also be aware of my own responses and reactions to the phenomenon (Vagle, 2014). Although it was impossible for me to completely remove myself from this study, first acknowledging my previous beliefs and experiences was necessary to moving beyond these. As Vagle (2014) noted, “We bridle understanding so that we do not understand too quickly or carelessly or that we do not attempt to make definite what is indefinite” (p.67). In order to separate my voice from those of my participants, I have detailed the beliefs and assumptions held prior to beginning my interviews.

One of the reasons I became interested in this topic was through my personal experiences with siblings of children with disabilities. Although this provided me with certain insights into this area, I was aware that these experiences might impact my perspectives within the context of this study. My initial knowledge of the impact of disabilities largely stemmed from my vocational experiences. After my undergraduate studies, I accepted a position working with school-aged children with developmental disabilities. I found this work to be both challenging and immensely rewarding. Throughout the duration of this job I also became acquainted with many parents and siblings of the children with disabilities that I had worked alongside. In meeting these families and having conversations with them, I observed that their lives had been uniquely impacted by parenting or being a sibling to a child with a disability. Many had
reported to me not only the challenges they had faced, but also the joy that this life experience had brought them.

My decision to pursue a doctoral degree in school psychology stemmed largely from a desire to work professionally with this population of students in academic settings. School psychology as a field appealed to me because of the opportunity to work with students who have disabilities and their families. Early into my training, I identified families of children with disabilities as a personal research interest. Reviewing literature in this area, it became immediately clear that the majority of research in this area had focused primarily on the experiences of parents and the child with a disability. Of the limited research focused on siblings, most of it seemed to operate from the perspective that having a sibling with a disability is generally a negative experience that leads to adverse outcomes. In my conversations with siblings of children with disabilities, I had heard their frustrations. Often they described the unique challenges they had encountered and the difficulties they had experienced learning to relate to their sibling. Many siblings had taken on extra family duties, sometimes making personal sacrifices to help their families function.

However, I had also observed that many of these siblings were thriving. I had noticed that many appeared to have derived positive meaning from their experiences and seemed to have had adapted well to having a sibling with a disability. Some had mentioned that they felt fortunate to be the sibling to an individual with a disability, and had learned much from the process. These observations and personal accounts inspired my interest in resilience processes in older siblings of children with intellectual
disabilities, and in learning more about the meaning these siblings derived from this relationship.

While it appeared that many of the children and youth I had met had positively adapted to having a younger sibling with a disability, my own perspective may have influenced this appraisal. By nature I tend to look for the positive in others, and enjoy learning how others overcome the challenges that they face. I have always found myself drawn to stories of perseverance and resilience, and am inspired by those who are able to rise above the difficulties that they face. Although I was certainly interested in learning more about resilience processes in these older siblings, I also understood that some children have had significant difficulty adapting to having a sibling with a disability. The research that I had reviewed not only highlighted the ability for some siblings to display resilience, but also the considerable challenges that many siblings faced. In seeking to understand the particular experiences of the older siblings that I interviewed, I hoped to capture the essence of what it had meant for them to be the older sibling to a child with a disability. This not only involved exploring the ways in which they had positively adapted, but also understanding the challenges they had experienced.

Research Methods

Institutional Review Board Approval

Upon successfully passing my proposal and gaining clearance from my dissertation committee, an Institutional Review Board (IRB) application was submitted to the University of Northern Colorado using the IRBNet portal. As the research did not involve manipulation and posed minimal threat to participants, the study was granted an
exempt review (see Appendix A). Once approval had been granted by both my dissertation committee and the IRB board, I began actively recruiting participants.

Participants

**Sampling methods and recruitment.** To gain a rich understanding of the phenomenon, older siblings of a child with a disability were the primary focus of this study. To recruit these older siblings, I utilized a criterion sampling method. In this type of sampling method, each participant was required to meet pre-established criteria to be included in the study (Creswell, 2013). Recruitment began by contacting individuals and families from organizations in the northern Rocky Mountain area that provided services to individuals with disabilities. To provide consistency and to inform participants about the nature of the study, a recruitment letter was provided to each family or professional who might know of a family that was qualified to participate (see Appendix B). This letter provided a brief overview of the study and my contact information. Through this, five families were identified who met the requirements to participate.

The five participants and their families who participated in this study met pre-established criteria set by the researcher and his dissertation committee. First, each participant was the older sibling to a child with an intellectual disability. Legal definitions of what constituted an intellectual disability were taken from Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (American Psychiatric Association, 2013). Individual disorders such as Autism Spectrum Disorder and Down syndrome were included as long there were deficits in cognitive and adaptive functioning.

In order to understand how resilience changes over time, siblings in middle and high school were selected as they had the experience of being in their family both before
and after the birth of the sibling with the disability. I posited that these individuals would be able to describe their experiences but not be so far removed from their experiences that they had forgotten aspects of their adaptation process. With this established, at the point of interviews one participant was 13 years-old, three were 14 years-old, and one was 17 years-old. Both female and male older siblings were invited to participate in this study, with four of the eventual participants identifying as female and one participant identifying as a male. Four participants were in high school, while one participant attended a middle school. As another requirement, each older sibling still needed to reside with their families. Each participant was deemed by their parents to be typically functioning, and no participants received services themselves through an Individualized Education Plan (IEP).

In determining the number of participants needed for this study, pre-established criteria for qualitative research was used. For phenomenological qualitative research, Dukes (1984) recommended using a sample size of between three and ten individuals. Because this range is broad, it was narrowed to include between five and ten participants. However, in qualitative research theme saturation is the ultimate parameter used to determine the number of participants needed. According to Morse (2000), saturation refers to achieving a significant amount of quality data that matches the breadth of the research questions. More specifically for phenomenological research, saturation is reached when the essence of the phenomenon can be explained in detail (Merriam & Tisdell, 2016). In this study, it was determined that saturation had been reached when common themes were noted between participants that encapsulated their experiences as a whole. In this study, the first five families that were contacted by the researcher agreed to
participate in this study and thus constituted the entire sampling pool. After collecting and transcribing data from the fifth participant, it was determined that saturation had been reached based on the rich data collected across participants. A table describing each participant and their younger sibling can be found at the end of this chapter.

Data Collection

To provide a rich contextual understanding of the phenomenon being studied, I collected data from a variety of different sources (Creswell, 2013). These sources included semi-structured interviews, daily check-in journals, photo-elicitation interviews, field notes, and my own personal reflexivity journal. Between each older sibling, the use of multiple data sources provided a large swath of data to be analyzed and interpreted. In total, 273 minutes of interviews were conducted, 25 photos were shared during the photo-elicitation interviews, and collectively 143 pages of data were analyzed. Each of these contributed uniquely to understanding the experiences each participant shared being the older sibling to a child with a disability.

Initial meeting. After identifying prospective participants through the recruitment process, I initially held collective meetings with each older sibling and a guardian. To help participants feel at ease, this first meeting took place at a place and time of their choosing. During this initial meeting I introduced myself, provided a general overview of the study, and detailed what would be required of each participant and answered any questions. As part of this first meeting, I explained to each participant confidentiality and its limits, that participation in this study was completely voluntary, and that participation could be discontinued at any point. After explaining these rights to each participant and their guardian, each older sibling completed an assent form acknowledging his or her
desire to participate in the study. Because of their age, participants completed a child assent form (see Appendix C). As each participant was a minor, their parents also completed an adult consent form (see Appendix D). After signing these consent forms, I provided each family with copies for future reference. Upon being signed, these consent forms were stored for confidentiality in a secure location at the University Northern Colorado.

**Demographics questionnaire.** During this initial meeting, I also provided each parent with a demographic questionnaire to complete (see Appendix E). By completing this form, parents provided information about their family such as their annual income, educational attainment, marital status, and about other members of their family. Related to this study, parents also provided information about their child’s diagnosis and the types of disability-related services their family utilized. Alongside the information gathered from each interview, I used this information to understand more about the environment of each family.

**Daily check-in journals.** After completing these consent forms and the demographic questionnaire, I scheduled a future date to interview each older sibling. Between this first meeting and the next scheduled meeting, each older sibling completed a daily check-in journal for a week (see Appendix F). After consulting with an expert in qualitative methodology, it was determined that a week’s worth of entries would provide sufficient insight into the daily life of each sibling (M. Lahman, personal communication, April 11, 2016). By asking each participant to complete daily entries for a week, I sought to gain insight into the day-to-day experiences of each older sibling and their interactions
with their younger siblings. To guide participants, I read the following directions verbatim to each older sibling:

I want to learn more about what it is like to be an older sibling to a child with a disability. For the next week, I would like for you to complete a daily check-in journal describing your interactions with your younger brother or sister that day. You can use these daily journal entries to describe your feelings about that day, what you did with your sibling that day, or to share your perspective about what it is like to be the older sibling to a child with a disability. Although I have provided you a paper journal that you can write in, each daily check-in can take whatever form you would like. For example, you might choose to record a voice memo for one entry, write a digital note for another, or create a video message. If you would like, you do not need to use the paper journal I have provided you with. Should you choose to record any of your entries digitally, I have provided a flash drive that you can save these with. Please complete one entry each day for a week and bring these to our next meeting. Thanks!

After providing these instructions to each older sibling, I asked them if they had any questions and provided them with them a physical copy of the daily check-in journal (containing a written version of the instructions) as well as a flash drive that they could save their entries to. Although participants were given autonomy to choose what format to complete these entries in, all five participants chose to complete these daily check-in journals by writing their entries.

**Request for images for the photo-elicitation interview.** Finally, during the initial meeting, I asked participants to bring five photos for the next meeting that they believed described what it was like to be the older sibling to a child with a disability. To guide this process, I read the following directions verbatim:

To learn more about your experiences being the older sibling to a child with a disability, I would also like for you to bring in five photos describing your relationship with your sibling. These photos can take a variety of different forms. You might personally choose to take new photos, or you can use pre-existing photographs that you or somebody else have already taken. You may also choose to find images not personally related to you or your sibling but that you think describes your relationship. You can bring in physical copies of these photos, or use the flash drive I have provided you with to bring in digital versions. Please
bring these five photos to our next meeting, where you will have an opportunity to share these with me. Thank you!

After reading these instructions to each older sibling, I answered any questions they had and provided clarification. I also provided them with a physical copy of these instructions to keep (see Appendix G).

**Second meeting.** After this first meeting, I met again with each participant to collect their daily check-in entries, discuss the photos that they had selected, and to interview them about their experiences being an older sibling to a child with a disability. Although I allowed families to choose where to meet, each elected to complete these interviews in their homes. During this second meeting, each participant provided me with their daily check-in journals and completed a short photo-elicitation interview and a semi-structured interview. Siblings were given the option to complete these interviews alone or with their parents in the room; both Carrie and Paige elected to have their mothers also present for the interview. Each interview was digitally recorded, encrypted, and saved to password-protected flash drive. In order to protect the confidentiality of participants and their families, each participant chose a pseudonym for themselves, their younger sibling, and their parents. Once each interview had been transferred from the recording device to the flash drive, the recording device was scrubbed.

**Photo-elicitation interviews.** In qualitative research, photo-elicitation interviews can provide a novel way to gain information that may not be elicited through a traditional interview (Vagle, 2014). They can be empowering for children and adolescent participants because they are responsible for selecting the images that they share, and choosing what to share about each of these selected images (Epstein, Stevens, McKeever, & Baruchel, 2006). Although there are few studies in the disability literature that have
used this approach, a study of siblings of children with trisomy 21 demonstrated the effectiveness of this technique to better understand the experiences of these siblings (Rampton et al., 2007).

Because photo elicitation interviews are less formal than typical interviews, they are often used in research to help participants ease into more structured interviews (Epstein et al., 2006). In this study, I conducted a brief photo-elicitation interview with each participant before transitioning into the semi-structured interview. During this interview, I gave participants the following directions:

If you remember from the last time that we met, I asked you to bring in five photos that describe your relationship with your brother or sister with a disability. Now I’d like for you to share these photos with me, one at a time. You can show them to me in any order that you’d like. We’ll discuss each photo as you show them to me. Now please show me the first photo.

After providing these directions, participants shared each of the photos that they had selected. These interviews, which followed a semi-structured format, lasted 12 minutes on average between the five participants. The questions that were used to guide the photo-elicitation interview are provided in Appendix G. During the interview, I also took brief notes about the general theme and content of each photograph shown.

Semi-structured interviews. Phenomenological research focuses on the specific perspectives of individuals in relation to a particular subject. It does this primarily through the use of interviews, which permit for the actual voice of each individual to be heard (Creswell, 2013). These interviews allowed me to better understand the perspectives of participants throughout their childhood. By focusing on these perspectives, qualitative interviews ultimately provided insight into the meaning each participant attributed to their circumstances (Merriam & Tisdell, 2016).
Semi-structured interviews were conducted in person between myself and each of the five older siblings. Each interview followed a semi-structured format, which allowed me to ask follow-up questions based on the response of participants. These semi-structured interviews lasted an average of 41 minutes. By choosing this format, I gained added flexibility to focus on specific areas that I wanted to learn more about or needed clarification on (Creswell, 2013; Merriam & Tisdell, 2016). Following criteria established by Merriam and Tisdell (2016), questions in these interviews were formulated to better understand the experiences, feelings, values, and opinions of each older sibling. Questions were developed from a psychological resilience framework with the help of an expert in qualitative research. Themes elicited by these questions were related to the process of learning about the disability, the nature of the sibling relationship, changes and adjustments made within the family system, perceptions and meaning, and potential benefits each participant had accrued.

More specifically, I formulated these questions using McCubbin and Paterson’s Double ABCX Model of Family Adjustment and Adaptation (1983), which emphasized that families function differently before and after a disruption in normal family practices occurs. As such questions focused not only on how siblings described presently functioning, but also about how they adapted and changed in light of their new family circumstances after the birth of their younger sibling. I found that this format was conducive for allowing participants to note changes in their life and how they had adapted to them. I also formulated my interview questions from an ecological perspective (Bronfenbrenner, 1977, 1979, 1994, 2006). Questions asked to siblings focused on how
different levels of the environment, such as their family and resources within the community, may have contributed to how they adapted to the stressors encountered.

The semi-structured interview protocol that was used during these interviews can be found in Appendix H. At the beginning of each interview, I gave the following directions:

Now I am going to ask you more specific questions about what it is like to be the sibling to a child with a disability. In this interview I will refer to this individual either as your sibling or by their specific name. Please let me know if you need me to repeat any questions, or if anything seems unclear. Are you ready to begin? Alright, then let’s begin!

After each semi-structured interview was completed, I answered questions and gave each participant a $25 Amazon.com gift card for their participation. Participants and their families were encouraged to contact me if they had any follow up questions or wanted to clarify anything from their interviews.

*Field notes.* Throughout each meeting and interview, I collected and compiled field notes. Field notes are written descriptions of the physical environments, people, and events that make up the “field” being studied (Creswell, 2003). Field notes were collected throughout each interview and these notes focused not only on what I had observed, but also detailed my own perceptions and reactions. Because this study incorporated a post-intentional phenomenological methodology, it was also necessary for me to be aware of my perception of the phenomenon being studied. Throughout the study I also wrote about my own experiences in relation to the phenomenon. This helped foster awareness of my own biases, and allowed me to continually bridle these assumptions throughout the study and more accurately present the voices of the older siblings I interviewed.
Data Analysis

Upon collecting each daily check-in journal and completing each interview, data were recorded and organized into meaningful patterns. Information from the demographic questionnaire was used to provide a rich contextual understanding of each older sibling and their family system. From a post-intentional perspective, the goal of this data analysis was to arrive at tentative manifestations of the phenomenon for these older siblings. Although it was impossible to fully reduce this phenomenon, I sought to understand how it manifested in the “multiple, partial and varied contexts” of these older siblings (Vagle, 2014, p.136). The first step in arriving at these tentative manifestations involved transcribing this information into written documents, which I personally completed. From this point, data were analyzed in a systematic pattern based on recommendations by Creswell (2013) and Vagle (2014) for post-intentional phenomenological research.

As is frequently used in phenomenological studies, I utilized a whole-part-whole approach to data analysis (Vagle, 2014). To achieve this, all transcripts and other data sources were first read as a whole multiple times to gain a general understanding of the main themes that had arisen. After this has been achieved, lines of each transcript were read for more specific meaning (Creswell, 2013; Merriam & Tisdell, 2016; Vagle, 2014). This process involved a far more specific analysis of each line, and looking for similar statements between interviews that appeared to capture the phenomenon of being an older sibling to a child with a disability. Each of these lines was extracted from the transcription and examined in a process called horizontalization in which each statement was initially given equal significance and weight (Creswell, 2013).
Once all the meaningful statements had been extracted through horizontalization, I grouped statements that shared common threads together into more parsimonious “meaning units.” These meaning units were distinct from each other, non-repetitive, and were collectively used to arrive at tentative manifestations describing the phenomenon of what it had been like to be the older sibling to a child with a disability (Creswell, 2013; Vagle, 2014). I then compared these distinct units again to the whole body of transcribed interviews to ensure they were representative of all of the data I had collected (Vagle, 2014). Because this phenomenological study included data from sources beyond the interview, I also analyzed these other data sources when creating each meaning unit. When comparing data from multiple sources, I identified instances where these converged into similar statements or meaning units. To distinguish how these tentative manifestations differed between contexts, I also noted areas where the perspectives of participants differed or diverged from each other (Vagle, 2014). As part of the process of data analysis I also conducted negative case analyses, which brought to the forefront statements or themes that appeared disconfirming to other data analyzed (Creswell, 2013).

After these significant statements had been consolidated into a more manageable number of meaning units, I began to write about the experiences of the older siblings. I first wrote a textural description of the interviews, which described “what” each participant had experienced being an older sibling to a child with a disability. Related to this, I also wrote about “how” the phenomenon occurred for these older siblings by adding structural descriptions to the writing. In order to capture these tentative
manifestations, the use of both structural and textural descriptions provided a rich overview of the multiple contexts of these older siblings (Creswell, 2013; Vagle, 2014).

In order to ensure that their voice was accurately represented in my writing, I reflexively wrote about my own changing perceptions of the phenomenon throughout the entire process of data analysis. Through this introspective writing, I sought to continually loosen my previous beliefs and incorporate the new insights I had gained throughout the study (Vagle, 2014). As recommended by Vagle (2014), I also wrote about moments that I connected with what was said and moments where I found myself surprised. This allowed me to better understand the ways that I intentionally related to the phenomenon being studied, and ultimately helped me minimize my own voice.

After transcribing each interview, I also performed member checks with each older sibling. Based on an email that had been provided to me in the demographics questionnaire, I emailed each older sibling and their family a transcript of their interview. After consulting with a professor in qualitative research, it was determined that it would be appropriate to use my University of Northern Colorado student email address to send these emails (M. Lahman, personal communication, April 11, 2016). Although families did not have to respond back once these transcripts were sent, soliciting their feedback sought to ensure that I had accurately captured their voice (Creswell, 2013). Pseudonyms were used within the email to protect the confidentiality of each participant and their families. At the duration of the study, I deleted these emails from my inbox. Only one participating family (Paige’s) replied to this email, clarifying one response from the semi-structured interview.
Trustworthiness

In qualitative research, the overall trustworthiness of a study is dictated by four related concepts: credibility, transferability, dependability, and confirmability. Credibility refers to the internal validity of the study, or that the phenomenon being studied has been accurately captured (Shenton, 2004). In an attempt to accurately arrive at tentative manifestations of what it had been like for each older sibling to have a family member with a disability, a variety of measures were taken. Triangulation, or the use of multiple data sources, was used to provide corroborative evidence of the phenomenon being studied (Creswell, 2013; Shenton, 2004). Through data analysis, I also conducted negative case analyses, which required me to mention information that was disconfirming to the meaning units I had found (Creswell, 2013). I also sought to increase the credibility of this study by clarifying my own personal stance at the onset, and later in Chapter V. Throughout the process of research, I continued to write reflexively about my own changing intentional relationship to the phenomenon (Vagle, 2014). The use of member checks, in which participants reviewed transcripts to determine their accuracy, was also offered to increase the credibility of this study.

Transferability refers to whether the findings of a study can be transferred to other, similar situations. From a post-intentional phenomenological perspective, this was difficult to achieve because manifestations of this phenomenon were viewed as tentative and changing. Importantly, these tentative manifestations were based on the varied contexts of each participant (Vagle, 2014). To allow the reader to understand the context of this study, I attempted to provide a rich description of each individual’s context and
environment by describing the similarities between each sibling’s context, and also the ways in which they differed, a process supported by Vagle (2014).

Related to this, dependability refers to the reliability of a study. Because manifestations of the phenomenon are tentative and transient, it is not possible to replicate a post-intentional phenomenology study and arrive at precisely the same findings. However, the methods and techniques used by the researcher should be clear and replicable. In order to accomplish this, I have provided information about the design I used, the protocols that were used during interviews, and detailed how data were systematically analyzed. Taken together with specific information about each participant, I sought to provide readers with a rich contextual understanding of how each manifestation of the phenomenon was arrived at (Creswell, 2013; Shenton, 2004).

Finally, confirmability refers to the objectiveness of the researcher. From a post-intentional perspective, it was not possible for me as the researcher to completely remove my own presumptions. I shared an intentional relationship with the phenomenon before data collection, which also influenced the ways that I analyzed these data (Vagle, 2014). However, in this chapter I have tried to minimize the influence of my own voice by detailing my background and my previous experiences interacting with siblings of children with disabilities. Throughout the duration of data collection and analysis, I also continued to write reflexively and bridle my beliefs (Vagle, 2014). The use of professional review from my dissertation committee also increased the trustworthiness of this study. My dissertation committee provided me with useful feedback and an outside perspective, which potentially reduced any bias that I might have inadvertently brought into my interpretation of the data (Shenton, 2004).
Summary

This post-intentional phenomenological study focused on the phenomenon of being an older sibling to a child with an intellectual disability. As part of this study, I interviewed five older siblings to understand how they perceived their own adaptation to having a younger sibling with a disability. In addition to these interviews, each older sibling completed a daily check-in journal describing their interactions and relationship with their sibling. Photo-elicitation interviews and field notes were also utilized to more richly understand the phenomenon. Participants were recruited from organizations that provided services to children with disabilities. Data were analyzed using a whole-parts-whole approach, with analysis focusing on arriving at a tentative manifestation of what it was like for participants to be the older sibling to a child with a disability. A variety of different measures were used to increase the trustworthiness of this study.
### Table 1

**General Information about Participants and their Younger Siblings**

<table>
<thead>
<tr>
<th>Participant’s Name (Pseudonym)</th>
<th>Participant’s Age</th>
<th>Younger Sibling’s Name (Pseudonym)</th>
<th>Younger Sibling’s Age</th>
<th>Disability (or Disabilities) of Younger Sibling</th>
<th>Marital Status of Parents</th>
<th>Other Siblings</th>
<th>Length of Interviews (combined)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rachel</td>
<td>13</td>
<td>Madeline</td>
<td>7</td>
<td>18p-, hypotonia</td>
<td>Separated</td>
<td>1</td>
<td>39 minutes</td>
</tr>
<tr>
<td>Edward</td>
<td>17</td>
<td>Tim</td>
<td>14</td>
<td>Autism spectrum disorder</td>
<td>Married</td>
<td>7</td>
<td>53 minutes</td>
</tr>
<tr>
<td>Paige</td>
<td>14</td>
<td>Ray</td>
<td>11</td>
<td>Down syndrome, autism spectrum disorder</td>
<td>Married</td>
<td>0</td>
<td>46 minutes</td>
</tr>
<tr>
<td>Phoebe</td>
<td>14</td>
<td>Ruby</td>
<td>13</td>
<td>Down syndrome</td>
<td>Separated</td>
<td>0</td>
<td>45 minutes</td>
</tr>
<tr>
<td>Carrie</td>
<td>14</td>
<td>Luke</td>
<td>11</td>
<td>Intractable Epilepsy, developmental delays, hyptonia</td>
<td>Separated</td>
<td>0</td>
<td>87 minutes</td>
</tr>
</tbody>
</table>
CHAPTER IV

RESULTS

The bamboo that bends is stronger than the oak that resists.

--Japanese proverb

Constructed from a post-intentional phenomenological perspective, in this chapter I focused on detailing the experiential journey each participant had being the older sibling to a child with a disability. These experiences provided a snapshot of the different environments each sibling and their family resided in and the unique circumstances each sibling had within their specific family environments. As participants each came from different families and had siblings with significantly different needs, the experiences of each participant in some ways varied considerably from one another.

By exploring each individual sibling’s experiences in significant detail, attention in this chapter is focused on identifying the unique aspects of their stories and the idiosyncratic ways that they adapted to having a sibling with a disability. These summaries allow for an exploration of the resilience processes of each sibling based on the particular stressors and risks encountered, the resources available in their family mesosystem, and the protective processes each sibling and their family engaged in. These individual accounts were used to arrive at the “tentative manifestations” (Vagle, 2014) of what it was like for these participants to be the older sibling to a child with a disability.
Rachel

I just thought that the big part, one of the biggest parts of our relationship is that we make each other laugh, or she makes me laugh a lot.

--Rachel

It was an uncharacteristically warm day for the time of year when I first met with Rachel and her family to discuss my study. As I exited my vehicle and stepped between the puddles that had formed on the concrete from the rapidly melting snow, I noticed my heart racing and my breathing deepen as I thought about the upcoming meeting. I stopped, took a deep breath, and remembered the enthusiasm that Rachel’s family had shown for my study when I first told them about my interest in researching older siblings of children with disabilities. I had worked with Rachel’s mother for a couple of years at a non-profit agency, and had gotten to know Rachel in passing during that time.

As I walked through the establishment’s front doors, I also couldn’t help but smile thinking about where we had chosen to meet. I had never thought that a fast food chain was a place where business got done, and could never possibly have imagined that this is where I would meet to explain my study to an inquiring family. Yet for some reason that I could not quite place my finger on, it felt right to be meeting Rachel and her family here on this radiantly sunny Saturday. Rachel’s mother asked if we could meet here because her youngest daughter, Madeline, was always insisting to come here to play in the play place. Madeline apparently had a particular affinity for the giant slide that snakes through the cavernous indoor atrium that is attached to the restaurant. Not only did meeting here give me a chance to explain my study, but it also afforded Madeline an opportunity to reacquaint herself with her beloved slide.
I noticed Rachel and her family sitting at a table by the play area and was greeted by the familiar and gentle smile of Rachel’s mother. Rachel, her two younger sisters, Sally and Madeline, and her mother had all made the trip out to the establishment this day. Seeing them again, I was struck by the appearance of Rachel’s family. While Rachel, her mother, and Sally all had brown hair and tan complexions, Madeline was distinguished by her blonde curls and fairer complexion. Walking in and seeing their friendly faces, I noticed the slight nervousness I had experienced in the parking lot melt away like the snow outside.

Sitting down and explaining my study to Rachel and her mother, I was impressed by the maturity and poise that Rachel carried as a 13 year-old. She appeared engaged when I was speaking, crossing her arms across the table and nodding her head. I had the impression that she was attentively listening to me. After I had finished my introduction to the study, I was surprised by the thoughtfulness of Rachel’s questions for me. She was interested in what I would do with the information I got from our interview, and about what the dissertation process entailed. In expressing her desire to participate in my study, Rachel seemed genuinely excited about the chance to share her experiences and perspectives with others. My impression of her maturity was only heightened when I offered to bring beverages for our sit-down interview that we would later have at her house. While I had assumed that she might request a juice or soda, Rachel stated that she would enjoy a decaf café Americano to drink while we talked. With her order placed, we agreed to meet again after the winter break.

We met again in January at her mother’s residence across town. Rachel lived there with her two younger sisters while also spending time at her father’s residence. It
was evident that she and her mother had prepared for the interview when I arrived. They had already set out the daily check-in journal, selected five photos, and set up a space for us to meet in the ornately decorated dining room. Throughout the interview Rachel was enthusiastic when discussing her relationship with her youngest sister Madeline, who was seven years-old at the time. She often used the words “fun” or “funny” to describe her interactions with Madeline. Relative to her age, I was again impressed by the depth and quality of the responses she gave to my questions throughout our interview.

Although I had already known Madeline, I learned a lot more about her specific needs through my interviews with Rachel and the demographics questionnaire completed by her mother. Madeline has a diagnosis of 18p deletion syndrome (18p-), which had impacted her in a variety of ways. It had contributed to difficulties such as childhood apraxia of speech, sensory processing difficulties, and decreased cognitive abilities. In addition to these, Madeline’s mother expressed concerns with Madeline’s executive functioning abilities as well as her difficulty regulating her emotions when she was frustrated. During our interview, Rachel also shared that her sister has hypotonia and described the ways that this affected her. Rachel explained that because of the deletion of this specific chromosome in Madeline, her sister had low muscle tone and struggled with activities requiring sustained muscle use. She often fatigued earlier than her sisters, and could become exhausted on the day following rigorous activities. Deletion of the 18p chromosome also explained the stark difference in appearance between Madeline and the rest of her family.

When Madeline was born, her family was not initially aware of any of these difficulties. Rachel described that as a newborn, Madeline acted similarly to how her
younger sister Sally had when she was an infant. Although there were no concerns at first, Rachel identified later knowing that “stuff was different” with Madeline. She attributes this insight to already having a younger sister in Sally, and being able to compare the developmental trajectories of Sally towards those of Madeline. While Rachel and Sally had started speaking early, her family became concerned when they noticed that Madeline was not even babbling. Although Madeline was eventually able to murmur the word “mamma,” she did not graduate to using other words. This was difficult for Rachel, who was confused and wished that her sister would start talking like Sally had. While she had been able to communicate with Sally some when she was younger, Rachel described having greater difficulty relating to Madeline because of the challenges inherent in communicating with her. Although still young, Rachel remembered worrying about what the future might look like for her youngest sister.

Because of these delays in language development, Rachel’s family decided to submit to testing which revealed the deletion of the 18p chromosome in Madeline. Rachel described that this was “kind of like a surprise” for her family to learn. As they learned more about the symptoms typically associated with 18p deletion syndrome, Rachel’s family found some solace in learning that Madeline could have been more heavily impacted by this genetic deletion. Nevertheless, Rachel described having early, specific fears about what might happen to Madeline as she grew older. She remembered fearing that her sister would have substantial difficulties learning and speaking, and worried that Madeline “was never going to be able to do the same things we could.” When dealing with these initial fears, Rachel described that it was helpful talking to her family. Her mother explained that things with Madeline might change again as she got older, such as
her physical appearance or her behavior. Although Rachel’s parents could answer some of her early questions, they were still becoming educated on the matter themselves. Her family took a wait-and-see approach with Madeline, sometimes only being able to answer Rachel’s questions by saying “we don’t really know right now.”

With this added knowledge about Madeline’s needs, Rachel’s family was proactive in seeking services to assist Madeline. Each week, Madeline received services from a speech, physical, and occupational therapists. In addition, her family took advantage of free music therapy sessions that were provided by a local university. With the aid of these services and as Madeline continued to develop, Rachel noticed improvement in Madeline’s functioning and found it easier to communicate with her. Although Rachel noted differences between her relationships with Sally and Madeline, Rachel added that she had “always just been the older sister” to both. Related to being the older sister, Rachel noted that she acted as a protector of Madeline. During the photo elicitation portion of our interview, Rachel shared a photo of her hugging Madeline. In this photograph Madeline was smiling straight into the camera as Rachel held her and looked into the distance. She explained that the photograph symbolized the protective nature of her relationship to Madeline, and how she wanted to protect her from being hurt by others. She noted that especially when she first found out about Madeline’s disability, she worried that others would have difficulty seeing beyond her disability and that she would have trouble making friends.

One of the primary roles Rachel described assuming as the older sister was to help care for Madeline. Rachel described that although her mother or father sometimes asked her to help Madeline, she also independently sought various other types of opportunities
to help. The ways she described helping Madeline varied. During our photo elicitation interview, Rachel shared two pictures that symbolized the nurturing aspect of her relationship to Madeline. In the first, Rachel was putting a sock on Madeline’s foot. Rachel explained that she often helped Madeline put on her clothes and get ready for the day. When sharing this photo, Rachel noted that she found this particular routine of putting on socks to be representative of the ways she had helped her younger sister. Rachel shared that Madeline is extremely particular about the ways that her socks are put on, insisting that the seams be on her toes. Although Rachel described her belief that her sister should be able to put her socks on independently, she expressed that she generally enjoyed helping her sister get ready in the mornings.

Another responsibility that Rachel described taking on was helping Madeline learn things and complete assignments from school. Her other selected photograph showed Rachel and Madeline working on homework together. She noted that sometimes helping Madeline with her homework could be frustrating. Rachel explained that at times, “I don’t understand how she doesn’t know, like, when she’s doing 20 plus 20 or something or she’s doing, like, just simple math problems. Like, I’ve gone through so many of that [sic] already that that’s kind of hard.” Rachel explained that by helping Madeline, she had been able to give her parents and sister a break. As her mother was enrolled in a graduate program and worked as a graduate research assistant, Rachel’s mother often had work to complete outside of her parental responsibilities. To give her mother time to get things done, Rachel would sometimes take Madeline to places like the park. Additionally, if her mother needed time alone with Sally, Rachel would supervise Madeline or take her somewhere else.
As her parents had separated, Rachel described helping bridge the differences between her mother’s and father’s households. Rachel shared that Madeline was “super, super close” to her mother and “always wants be around my mom.” At times, the transition between households could be difficult for Madeline, who understandably shared a different relationship with her mother and father. While Rachel explained that Madeline enjoyed being with both her mother and her father, sometimes her father “doesn’t understand why she can’t do the simple things.” She described that there had been situations at her father’s house when Madeline had difficulty doing something or had felt upset that led to frustration for the entire family. During these times, when her mother was not present, Rachel would talk to Madeline and help her to calm down.

Although Rachel focused on the protective and assistive roles that she had assumed with Madeline, there was also a playful nature to their relationship that was evident throughout our interview. There was a sense of affection present when Rachel shared a photograph of her and Madeline playing with a doll, and another of Madeline watching videos on a tablet while Rachel sat next to her laughing. Rachel described that they enjoyed playing together, even if the things that Madeline preferred to do were often developmentally different than what Rachel typically enjoys. Rachel explained that her sister had the ability to make situations fun by saying something silly or through the spontaneous videos that she recorded on her tablet. Laughing and humor, Rachel explained to me, were a central dynamic of their relationship when they played together.

Rachel also noted that Madeline’s physical needs could make it difficult for them to engage in some of Rachel’s preferred activities together. Because of Madeline’s low muscle tone, Rachel noted that it could be challenging for her younger sister to do things
like go hiking or skiing with their family. Because Rachel had been unable to do some of the things that she would like with her sister, she confided that it was challenging relating to some of Madeline’s interests.

Rachel acknowledged that there are times when it had been difficult to be the older sister to Madeline. On many mornings, Rachel noted waking up to the sound of Madeline “freaking out” because she was having difficulty turning the television on. Rachel admitted that she had sometimes been frustrated when Madeline became upset over seemingly small things. When Madeline became upset, Rachel acknowledged that she and her family “all just kind of want to go on with our day.” When Madeline felt anxious, tired, or when unexpected changes occurred to her schedule, she often had difficulty regulating her emotions. Reflecting this, Rachel wrote in her daily check-in journal about the day after she and her family had stayed out late in Denver after seeing a show. The next day, Madeline was very tired and began to “throw a tantrum” when her family went grocery shopping.

Although Rachel indicated that she typically liked to help Madeline, she could also find it frustrating when Madeline was unable to do some tasks independently. The added responsibility of helping Madeline could also disrupt the plans that Rachel and her family had made for the day. In her daily check-in journal, Rachel described a challenging incident that occurred when she was asked to help Madeline:

My mom asked me to help get my little sisters ready for the day, and they needed to be completely ready so we were on time for Kassidy’s (friends) birthday party. I needed to get ready too, so I helped Madeline find her clothes. Later on after I was ready, Madeline was still having trouble getting completely ready. Our mom came home and Madeline was not ready to go. I had to stay home with Madeline and we both got very frustrated. I felt like Madeline should have been able to get ready herself, and I felt bad that I didn’t spend enough time helping her. Madeline was mad because she had wanted to go with my mom. After a small
fight we made up, and watched TV together. We got along pretty well the rest of the day.

Since Madeline was born, Rachel’s family was required to change and adapt as a family unit to meet her needs. Rachel acknowledged that “sometimes Madeline makes it a little bit harder, but we’ve kind of just learned to go with it.” Rachel identified several factors that had helped her positively adapt to the challenges that she had faced having a younger sister with a disability. Conversations with her parents helped her understand Madeline better and taught her ways to better relate to her. Rachel recalled that her parents helped her understand Madeline’s condition and the types of symptoms she might experience as she gets older. By providing information about Madeline and her needs, Rachel also explained that her parents had helped her learn how to interact and play with Madeline. Her parents had also provided support and comfort when needed, encouraging Rachel when times with Madeline were especially difficult.

Rachel conveyed that since Madeline was born, her family has had to work together, making sacrifices for each other when necessary. To emphasize this point, Rachel shared an anecdote about a recent vacation that she took with her father and sisters to the Atlantis resort. In order for everyone to have an opportunity to experience the rides they wanted, Rachel and her family took turns waiting with Madeline in the children’s pool while the rest of the family went on a ride. Rachel recalled feeling “a little bit frustrated” when it was her turn to wait behind with Madeline. However, everyone took a turn with this responsibility and her sister Sally stayed behind with Madeline so that Rachel could go on a ride of her choice with her father. These sacrifices, while difficult to make, appear to have benefited Rachel and Sally by allowing each of them to continue normal routines with her parents. Rachel also commented that her family had
helped her adjust to having a sibling with a disability by providing her with time to be alone and time to engage in her preferred activities. As Rachel described it, her family had “learned to fit her needs and all of our needs too.”

Despite the challenges that Rachel and her family sometimes faced because of Madeline’s needs, during our interview Rachel relayed many positive experiences she had experienced being Madeline’s older sister. Many of these positive experiences appeared directly related to Madeline’s exuberant personality and the close relationship that Rachel shared with her. Throughout our interview Rachel shared the joy that Madeline had brought to her family, and how Madeline often entertained her family with the random and humorous stories that she often told. Rachel also noted that while she had taught Madeline many things, Madeline had also taught her about contentment and the nature of happiness. As a whole, Rachel noted that her family had derived meaning from providing for Madeline and her needs. As Rachel described it, “we know that it’s going to be a lot harder sometimes but we, since we’re used to it, it’s not that bad. But we know that when she has her hard days we’re there to help her.”

Rachel also described ways in which she had personally grown because of being the older sister to a child with a disability. Because of her circumstances, Rachel relayed to me that she felt like she had a greater understanding not only of her sister’s disability but also about disabilities in general. She shared that her experiences being the older sister to Madeline had taught her not to judge others with disabilities and to look beyond the impact of disabilities and to find the commonalities in all people. Because of her relationship with Madeline, Rachel also noted feeling more comfortable relating to others that have disabilities. Additionally, Rachel expressed that she had found it easier to relate
to other students at her school with disabilities. Rachel explained to me how the depth of her experiences with Madeline had guided her interactions with other children with disabilities:

It makes me, like I said before, it makes me realize and be careful, like, when I’m around other kids with disabilities. Because a lot of kids in my school will just go straight away and, like, judge them, but I have learned and now I know how to just treat them the same as everyone else. Because I know with Madeline, that I don’t think she likes being treated differently than anyone.

To summarize her experiences being the older sibling to a child with a disability, Rachel stated “it’s a little bit different.” Despite the ways that her family had changed because of Madeline’s needs, Rachel shared that it is something that she had gotten used to over time. For all the challenges her family had faced and for every sacrifice that they had made, Rachel was resolute in stating her admiration of Madeline and the ways she had grown by being her older sister. As Rachel stated, being the older sibling to a child with a disability is “something that might be a little bit harder sometimes but it’s also really good too.”

Edward

It’s like, it’s him and it’s kind of unique to him…I’ve never seen anyone make that kind of smile.

--Edward

Edward carried himself with a patient, contemplative presence that was evident from early on in our time together. Walking into their household to meet, I began to introduce myself to Edward and his mother. Being the oldest participant that I would interview at 17 years-old, I was struck not only by how friendly Edward was but also how much taller he was then me. As we exchanged pleasantries, we were interrupted by an unexpected visitor: his brother Tim. Tim had run into the dining room where we were
having our conversation, carrying a book in his hand and clearly upset by something. The book in his hand, “P.B. Bear’s Christmas,” appeared to have weathered quite a few Christmases. Judging by its broken and distressed cover, it appeared that this may not have been the first time that the “P.B. Bear’s Christmas” book needed repair. Running his hand through his sandy blonde hair, Edward smiled at Tim and said that he would help fix the cover when he was done meeting with me. Later in our second meeting, another moment occurred that demonstrated Edward’s patience. As Edward was showing me photographs that represented his relationship with Tim, our interview was put on a temporary hold when we heard Tim yelling from the living room. Edward turned to look over his shoulder, and after locating Tim asked, “You okay, mister?” These unplanned interactions between Edward and his younger brother symbolized the “well-knit” and caring relationship that Edward currently described sharing with Tim.

Edward and Tim lived with their father and mother in what struck me as a palatial house. Although the house was not crowded when I met with Edward, this had not always been the case. In fact, Edward and Tim have eight other siblings who had left home after high school, with the oldest being 36 and Tim being the youngest at 14 years-old. During our interview, Edward shared a photo of his siblings together at a wedding. It was remarkable to see all the siblings together, impeccably dressed in suits and dresses, arranged in line from youngest to oldest. Sharing the photo with me, Edward explained how the wide range of ages had influenced the relationship each sibling had with Tim. While mentioning that all his siblings were close to Tim, Edward also believed that he and his other similarly-aged siblings shared a unique relationship with Tim. Edward noted that some of his older siblings had gone off to college or moved when Tim was
very young, but that he had lived with Tim for most of his life and had more time to interact with him.

Edward remembered being very young when his family first became concerned with Tim’s development. At this early age Edward noted that, “…I wasn’t really coherent, I wasn’t tuned in because I was so young.” Because of this, the knowledge that his brother has Autism Spectrum Disorder (ASD) was something that he always “just grew up with … so it was normal.” In her responses to the demographics questionnaire, Edward’s mother helped provide more context to Tim’s early life. When Tim was around the age of two, his mother described that her youngest son was “very verbal.” Much of Tim’s early verbalization came in the form of singing, especially singing along to the 30 to 40 nursery rhymes that he could identify. However, around his third birthday Tim began to change and “disconnect” from others. Although he had been highly responsive to music in the past, Tim began to become irritable when others would sing to him. Tim’s vocalizations during this time became less frequent, and within six months he no longer communicated at all. As he was about to turn three, Tim was diagnosed with ASD.

Even though Edward was young, he stated that these early years were especially challenging for his family as they learned more about ASD and its associated symptoms. When they first found out about Tim’s disorder, “It was just something brand new and unknown. And I think that weighed down on my parents and some of my older siblings.” Although Edward recalled that it was tough for his family to learn about Tim’s disability, he mentioned that his family quickly took proactive steps to meet Tim’s unique needs. His family did extensive research on ASD, even travelling to Boston to receive autism-specific support and training. Edward remembered viewing videos about ASD with his
family and being struck by what he described as the “crazy things” that he saw people
doing in the video.

Based on the information his family gathered about autism, his family decided to
implement drastic changes in their household to try and support Tim’s special needs.
Edward recalled that at their previous residence, his parents remodeled one of the
bedrooms to include a playroom. This hybrid bedroom and playroom became Tim’s own
space, and his parents would frequently invite family and friends over to socialize and
interact with Tim in the playroom. His mother described these interactions with family
and friends as lasting between 8 to 12 hours a day. Edward believed that providing Tim
with a playroom and giving him large amounts of social interaction in that space had
been instrumental to Tim’s development.

During our interview, Edward noted that his relationship with Tim had changed
dramatically as both he and Tim had grown older. Describing their early relationship,
Edward remembered that they had difficulty interacting with each other. He shared with
me painful instances in which Tim would put his chin into his back and apply pressure.
Recalling their early relationship Edward stated, “I feel like we were enemies.” However,
he believed that as they matured they eventually moved to more of a “neutral stance.”
One event that appeared to have contributed to their improved relationship took place
when his family moved to a new state. Upon moving, his family enrolled both Edward
and Tim in a program aimed at strengthening reflexes and motor abilities. As part of this
program, Edward would work on activities and exercises with Tim at home. Edward
shared that these communal activities, and the chance to be a partner with Tim in his
development, were helpful in bolstering their relationship.
Edward described that their relationship had since evolved into a “master/apprentice” relationship with each other. He noted that Tim is “kind of learning the ways of the world. And, like, I am still too, but I’m kind of teaching him, kind of guiding him through. Kind of like a mentor.” Part of helping guide his brother through adolescence was to initiate opportunities or “create things” for the two of them to do together. Symbolizing this creating role that Edward has assumed, during the photo-elicitation interview he shared a photograph of he and Tim posing together that he recalled planning in advance. Edward viewed himself as instrumental in initiating and maintaining conversations with Tim, who primarily communicated by scripted lines that he had heard from movies. Edward explained that he would often start a conversation with Tim by using a quote himself, which could then be steered into a meaningful conversation. This type of complex conversation relied not only on Edward being able to retrieve a quote to fit into the conversation, but also necessitated understanding the embedded meaning in the quotes that Tim chooses. Edward noted that Tim will “add meaning” to quotes and use them to express himself. Luckily for Tim, Edward shared that his family had always had a propensity to quote. Edward noted that if his family did not have the natural ability to quote, he did not think Tim “really would have a way of communicating with that.”

Beyond mentoring, Edward also shared that he helped care for his younger brother. He described preparing snacks for his brother when he was hungry, especially their shared favorite peanut butter sandwiches. Edward also noted helping his brother with toileting, something that Edward admittedly did not particularly relish. Although part of Edward’s mentoring role involved caring for Tim, there was also an explorative,
playful component to their relationship. In his daily check-in journal, Edward shared a variety of activities that he and Tim had done together during the week, including listening to music and dancing, playing the “microphone game,” and jumping on the trampoline. Beyond viewing himself as a mentor to his younger brother, Edward noted that he and Tim were, “best friends now, too.” Many of the photos Edward shared with me took place during events, such as at one of Tim’s birthday party and another at one of his choir concerts. In one of these photos, Tim had an exaggerated, gregarious smile. Edward shared that there are moments when Tim will deeply connect with something and start skipping in happiness. It represents the unique spirit and vibrant happiness that Edward noted he enjoyed about his brother when they do things together.

Even as best friends, Edward faced significant challenges in relating to his younger brother. While Edward had learned to find activities that he and Tim could enjoy together, there were still certain activities, like playing board games, that Edward noted they could not do together. Edward has sometimes had to defer his own preferences for those of his younger brother and had been unable to do the types of activities that he would like when Tim is nearby. As an example, Edward mentioned to me the frustration he experienced when attempting to play the piano at home. When Edward attempted to practice a song that Tim was not fond of, his brother became upset and “very forcedly” told Edward to stop playing that song. There were also challenging moments when Edward tried to play games alongside his brother. When they tried to play videogames, Tim was often adamant that the game must be played in a particular way and could upset if Edward made a mistake in the game. This had led to Edward sometimes being kicked off of video games by Tim, who typically insisted on playing games his way. Because of
this Edward and Tim, “never ever get any video game time together anymore. It’s, it’s very, very, very hard to do.”

According to Edward, another challenging part of their relationship stemmed from Tim’s tendency to strongly react to the emotions of others. According to Edward, Tim “feels emotions very, very strongly. So, like, I can’t get emotional, especially around him. Because if I get angry, or if I start crying, or if I do anything like that, he will, he will start attacking me. He will start hurting me, you know?” Edward also mentioned how Tim’s need for predictability and routines could sometimes lead to unforeseen difficulties. When seemingly small problems occurred, such as a movie skipping, Tim would yell and plug his ears until the problem was solved. These outbursts could often lead to disruptions in family plans. Sometimes, these types of challenges could be very frustrating for Edward. Small issues could become magnified by Tim’s sensitivity to Edward and his expressions of frustration. Edward shared that it was difficult to display frustration around Tim, because when he did Tim became physically aggressive towards him. Edward detailed to me the difficulty he often experienced handling conflicts with his brother:

I kind of, like, almost stamp off and angrily mutter to myself. And you know the worst part is he picks up that emotion and gets angry himself. And so it’s definitely something I need to work on. But yeah. Like now, I kind of like, you know whenever we have an issue, I kind of just, I’m sad we can’t have this happen because there’s an issue. I kind of take that out in anger.

Although there had been difficult times with Edward that were stressful, Edward noted some factors that had helped him and his family adapt to these challenges. Edward had found strength in his family, and noted that he had benefited from having other siblings. Edward recalled that his family had adapted to meeting Tim’s needs both
collectively and individually. Having older siblings, Edward noted that they benefited him by providing an “example” to him for how to interact and play alongside Tim. Edward also shared that the support of friends and other family members had been crucial. Growing up, Edward watched friends of his brothers and sisters come to his house and forge close relationships with Tim. To him, the experience of getting to know Tim was a “really nice treat” that Edward desired for his friends to have. As Edward noted, it’s “something really exciting that you love and you want to share with the world.”

Edward also identified faith as an important anchor for his family. This faith that Edward and his family shared had influenced the way they viewed having a family member with a disability. Based on this foundation, Edward found spiritual purpose in having a younger sibling with a disability. He shared that not only did he believe his family had been called serve Tim, but also that Tim was brought to help his family.

Throughout our interview, it was also apparent that Edward derived hope from his spiritual beliefs. This hope extended not only to navigating present situations, but also towards a future where Edward believed he would be able “to talk to him and like see his personality to the fullest.” For Edward, his faith gave his relationship with Tim added meaning.

Edward noted ways in which his younger brother had benefited the entire family. While sharing the significant challenges that his family had sometimes faced in meeting Tim’s needs, Edward ultimately believed that his family had been brought closer together because of Tim. Edward shared that this was particularly true for the youngest siblings in his family who had bonded through their communal experiences with Tim. He also
believed that his family’s experiences with Tim, both the rewarding and challenging ones, had ultimately strengthened their faith. Edward shared that while some individuals sometimes fall away from their faith, neither he nor his other siblings had. He attributed this largely to Tim and the ways that his family had come together to support him.

On a personal level, Edward also noted that he had matured because of his relationship with Tim. Edward shared that he had gained a greater empathy for other individuals with disabilities, and that he had grown more sympathetic to the unique needs that others have. Because Edward sometimes helped feed his brother and take care of him, Edward believed that his relationship with Tim had taught him how to care for others.

There was a wistfulness in Edward’s voice as we neared the end of our interview, possibly because of the memories and experiences that had been evoked throughout our interview. Edward appeared especially thoughtful about his past experiences with Tim and aware of the possible memories they would create in the future. His advice to others who have siblings with disabilities was to be present: “They’re there, they’re your siblings, so, like, so be with them and cherish your moments with them. Because you only have so many moments. Because you only, you only have so many memories you can create with them.”

**Paige**

I don’t see him as somebody different. I just see him as my little brother. --Paige

Throughout my interview with Paige, she described her younger brother Ray as having a substantial amount of energy and sometimes acting wildly. This was not difficult for me to imagine, as I had known Ray for five years and had just witnessed one
of his frenetic bursts of energy. As I was preparing to set up the materials needed for our interview in their family dining room, I was interrupted by a sound behind me. Ray had just clamored into the kitchen, and, surveying the scene around him, had knocked an empty plastic cup off the kitchen counter. Moving into the living room, Ray next reached up for the canvas photos of his family hanging throughout the living room and knocked these to the floor. When Ray was eventually veered from his destructive path by the distracting glow of a cartoon on the television, Paige and her mother laughed and restored the living room to the way it had been. Almost as if to testify that these types of unpredictable and spontaneous occurrences had happened before, I noticed that fragile items were conspicuously absent from their living room decor.

I had known Paige’s family for six of Paige’s 14 years and Ray’s 11 years. Paige’s family had consistently treated me with the utmost kindness, and throughout the years I had enjoyed getting to know their family through my interactions with them. They had been especially supportive of my desire to become a school psychologist, and had frequently checked in with me throughout my studies to see how I was doing. Because of my friendship with them, they were one the first families that I thought of as I began this study. Despite previously knowing Paige, I was nevertheless surprised by the amount I learned about Paige and her relationship with Ray through my interview with her. Sometimes this required me to challenge my previous assumptions about Paige and her family as her actual perspective emerged during our interview

I interviewed Paige at her home where she resided with her parents and Ray. With her blonde locks, freckles, and her laid-back presence, Paige had always reminded me of the type of person that I imagined would live near a beach. Slouching in her chair as we
met, Paige spoke candidly throughout our interview. I appreciated her honesty in describing both the challenges and joys she experienced in her relationship with Ray.

At a young age, Ray was diagnosed with both Trisomy 21 (also referred to as Down’s syndrome) and autism spectrum disorders. Although he was able to intone some sounds, Ray was nonverbal and had difficulty learning new concepts. Because of his needs, Ray also needed substantial support with daily routines such as getting ready in the morning, toileting, and eating. Physically, Paige also noted that Ray was shorter in stature than his classmates. Because Paige was only a few years older than Ray, she did not recall the particular moment when her family learned about Ray’s significant needs. Paige did not remember any specific conversations that she had with her family about Ray’s disability, recalling instead that she “just figured it out” as she got older. Still, she remembered not being sure what to expect in the future as Ray got older. She noted that at first there was some distance between she and her younger brother, and initially she treated him as if she didn’t want a younger brother. She described having feelings that many siblings do adjusting to having a new member in their family. However, as time went on Paige began to spend considerable time interacting with Ray and getting to know him.

There was a playful thread to Paige and Ray’s relationship that Paige recalled sharing with her brother even from an early age. As Paige reflected, Ray preferred “attention that is play” compared to affectionate attention. She remembered watching movies with Ray when he was young, and roughhousing and wrestling with him as well. Paige also shared that there were times when Ray became physically aggressive towards her and others. She remembered instances when Ray would unexpectedly hit her or pull...
her hair. Although this aggression could be substantial when he was younger, Paige shared that it had decreased as Ray matured.

Much of Paige and Ray’s current sibling relationship was defined by their frequent, playful interactions with each other. Paige described her brother as often “really hyper and giggly,” with many of their interactions involving physical activity of some sort. One primary way that Paige and Ray interacted with each other was by playing with one of Ray’s favorite toys, an oversized peanut-shaped aerobic ball. When I first met with Paige and her family to discuss my study, they demonstrated the ways that they played on the ball with Ray. Displaying his seemingly endless energy, I watched as Ray ran up to the ball and bounded onto it, gleefully giggling as he levitated through the air. Sometimes for Paige, playing with Ray and the oversized ball meant allowing Ray to roll the ball on top of her as she lay down. In her daily check-in journal Paige also mentioned other instances throughout the week when she and Ray were active together, such as when they had gone swimming together at the local pool and Ray kept his eyes open underwater. Paige indicated that Ray’s need for physical activity crescendos in the summer, when he can be found “either swimming or on the [trampoline].”

Their interactions were not only activity-based as Paige described that teasing each other was a hallmark of her sibling relationship with Ray. This teasing was sometimes initiated by Paige, who would hide from Ray and then unexpectedly surprise him. This teasing could take different forms when initiated by Ray, which usually entailed Paige noticing that items were missing from her room. Paige described that Ray had a propensity for sneaking into her room while she was gone and hiding personal items like her makeup or stuffed animals around the house. On more than one occasion,
the family dog had successfully found and chewed these items before Paige had realized that they were missing.

Although there were many instances when Paige described Ray’s high level of energy and teasing personality as entertaining or humorous, she also noted that at times it was disruptive for her and her family. When Ray was in one of his wild moods, it could be difficult for Paige’s family to contain him or calm him down. Paige shared that when Ray was in one of these excitable states, “sometimes he’ll like walk around the entire house scraping the walls with something. And he’ll bang on the walls, and he’ll hit people! And he’ll talk, well, really loudly. And he’ll throw things.” Paige also shared challenges she had faced when she was trying to do something alone in her room, such as playing a video game. Ray would open her bedroom door and peek his head into the room. Paige described that even when Ray found out where she was, he would continue this progression of opening and closing her door repeatedly.

Paige noted that getting restful sleep was particularly challenging because of Ray’s exuberant energy. She shared that her brother woke her up “like every morning.” Contributing to this difficulty was the drastic difference in their sleep schedules, with Ray waking early in the morning and Paige preferring to sleep in when possible. In the mornings, Paige described that she was often shaken from her sleep by the sound of her brother hitting the shared wall between their rooms. Paige’s difficulty in staying asleep was especially prevalent when her family traveled and she was required to share a room with Ray. Recalling a trip that her family had taken to visit her uncle, Paige remembered clearly the difficulty she had falling asleep. Paige noted that, “me and my mom wanted to
go to sleep and he would just keep walking around the room, and he kept coming up to me and like messing with my mouth, my nose, and poking my eye. It was so annoying!”

Paige noted that Ray’s high level of movement also made it difficult for her entire family to go out in public together. Paige described that seemingly ordinary routines, such as going out for dinner, could become complicated ordeals for her family. Recalling times in the past when her family had gone to eat a restaurant, Paige described her brother as reaching across the table and knocking plates and food onto the floor. To get him to sit still at a table, Paige noted that someone in her family needed to sit with Ray and hold his hands down. Although this might be temporarily effective, Ray would sometimes become frustrated and bang on the table instead. Because of the difficulties that this could create, Paige noted that her family had only attempted to take Ray to eat at restaurants, “a couple of times.”

As Ray was typically in motion and on the move, he needed frequent supervision to make sure that he was being safe. Because of this, Paige noted that her parents sometimes relied on her to watch Ray if they needed to get something done. For example, Paige shared that she would sometimes watch Ray in the mornings to allow her mother a chance to work out. When her family did bring Ray with them to run errands, Paige was often responsible for helping her parents contain him. Often times, this meant that Paige must take Ray somewhere else if he was “wound up” so that her parents could complete their needed tasks.

When discussing the family’s public outings, Paige noted the frustration that she experienced when she felt like other people were judging her brother. At times when she perceived that this happened, Paige could become protective of her younger brother.
During our interview, she shared a frustrating experience she recently had when her family went shopping with Ray:

And I think it was like a month ago, and we went to Target, and he was being really wild. And so we were checking out, and so I just took him out of the basket, and I went to go sit down at a bench. And there were people staring at us, like this girl maybe a little bit younger than me. And I gave her a death stare, and I didn’t mean to! It kind of just happened! I was really mad, though. She was judging because Ray was running around.

In contrast to the ways that others sometimes judged Ray, Paige was resolute in not defining her younger brother by his disabilities. Instead of defining Ray by the characteristics of his disabilities or by the things that he could not do, Paige was more inclined to describe Ray based on his boundless energy or his frequent “goofy” moods. As Paige worded it, “I don’t see him as somebody different. I just see him as my little brother.” Even in the areas where Ray’s disability affected him, such as in his ability to use words to communicate, Paige was quick to note that Ray had learned other ways to get his needs met. She noted that when Ray wanted something like a piece of toast, he would go to the toaster and make noise to indicate his needs. To Paige, Ray’s unique needs were less defining of him than his standing as her younger brother was.

Paige had found the experience of being the older sister to a child with a disability to be both challenging and rewarding. Although Paige admitted that it was “harder” having a sibling with significant needs, she also acknowledged that she had come to view it as normal and had gotten used to many of the challenges she faced in relating to Ray. Throughout our interview, Paige identified several protective processes that had helped her and her family maintain a sense of normalcy. Paige had her own bedroom so she had a personal space to engage in her own preferred activities. She also noted that because Ray typically woke her up early in the morning, her family had begun the process of
remodeling their basement with the intention of moving her down there so she could
sleep in and have more privacy.

Paige noted the importance of an organization her brother attended in providing
her family with respite and a chance to get things done. In the parent questionnaire,
Paige’s mother shared that they had received support from two local organizations in
their county. Paige also noted the importance of agency support and shared that because
Ray could receive care and supervision from this agency, it had provided her a chance to
spend much needed time alone with her parents. Paige noted that this time alone with her
mother and father had provided them with an opportunity to engage in routines that were
difficult to do with Ray, such as going out for dinner as a family or going to shop at the
mall with her mother.

Paige also shared that her relationship with Ray had benefited from her family’s
decision to own a dog. Paige stated that Ray and their family dog made an almost
instantaneous connection, and that this strong bond had persisted as Ray had gotten older.
Paige noted that their dog “treats Ray like her own,” and had provided another
companion for Ray to play with when Paige needed a break. She shared that their dog
was protective of her younger brother, and in the past had interceded when Ray had
gotten too close to the neighbor dog. Paige noted that sometimes she had caught Ray and
their dog walking out of a room together, only to walk into the room herself and find it
disheveled. According to Paige, “If something happens bad [sic] it’s both of them!”

Although Ray’s substantial energy had created challenges for Paige and her
family, she also shared that she often found Ray’s unique sense of humor entertaining.
She noted that she found humor in many of Ray’s routines and preferences, such as in his
unquenchable appetite for bacon or when he asked for toast by repeatedly pressing the lever on the toaster. When sharing the photographs she had selected during the photo elicitation interview, Paige recalled how her brother was able to make “dreadful” events like taking family photographs more palatable because of his unpredictable tendencies when he was hyper. Additionally, Paige also noted that her experiences being the older sibling to a child with a disability had taught her many things. As she had seen other people judge her younger brother, Paige indicated that she had learned not to judge others based on outward appearances. To gain an understanding of others, Paige mentioned that one must gain an understanding of where they had come from. Partially because of her relationship with her younger brother, Paige noted that, “you can’t judge people because you don’t know their past. You don’t know what they’ve been through.”

**Phoebe**

She’s kind of unpredictable. You never really know what’s going to happen until you get there!

--Phoebe

It was a snowy Saint Patrick’s Day weekend when I met Phoebe, her sister Ruby, and her mother at their household for our interviews. Before conducting our interviews, Phoebe suggested that our group should first attend the local Saint Patrick’s Day parade downtown. Bundling up in our winter jackets and preparing for the snow that gently fell outside, we waited patiently while Phoebe’s younger sister Ruby got ready for the parade. As our group was preparing to exit the living room and depart for the parade, Phoebe noticed that her younger sister had chosen to wear sandals. Explaining that it was snowing outside and that she would become cold quickly, Phoebe and her mother gently asked Ruby to find a pair of shoes to wear instead. Although I had assumed that it would
be a relatively quick process for Ruby to switch shoes, I was surprised by Ruby’s adamancy that she was going to wear sandals to the parade. After asking politely and waiting to see if Ruby would put on shoes, Phoebe suggested that we should instead wait in the car in hopes of accelerating Ruby’s timeline for putting on her shoes. As the minutes passed and Ruby still had not put on her shoes, it became clear that we would not be going to the parade as originally planned. This experience demonstrated the concepts of stubbornness and patience that would emerge during my later interview with Phoebe.

As much as any of the participants, 14 year-old Phoebe seemed especially enthusiastic to have the opportunity to share her experiences with me. She spoke in a gregarious manner, often twirling a strand of her golden hair as she shared with me humorous anecdotes about her sister. While I found it very easy to talk with her, initially Phoebe seemed hesitant to discuss the challenges she had faced in her relationship with her sister. At first, she tended to focus on her sister’s strengths or the things that they enjoyed doing together. However, as our time together progressed I noticed that Phoebe became more willing to also discuss the difficult parts of her relationship with her 13 year-old sister.

From an early age, Phoebe was required to demonstrate patience as her family worked to address Ruby’s significant health concerns. As Phoebe is only a year older than her younger sister Ruby, she mentioned that as a child she did not fully understand her sister’s unique needs or the serious risks Ruby faced as an infant. Because of these health concerns, Ruby spent much of her infancy in the hospital receiving specialized treatment. Although Ruby was able to be at home immediately following her birth, she required hospitalization at around six months because she was sick and had begun to
vomit multiple times a day. An extensive physical exam revealed that Ruby had a
duodenal web in her intestine that was inhibiting her ability to completely digest food.
Because Ruby was such a young child and developmentally fragile, Phoebe noted that
removing the duodenal web from her younger sister’s intestine was a “really hard
procedure.” During this time, Ruby stayed in the hospital for multiple months for the
surgery and subsequent recovery. Although this surgery was successful in removing the
blockage, Ruby again required lengthy hospitalization at around two years old for heart
surgery. During these surgeries, Phoebe often stayed with her aunt and grandmother, only
rarely getting to see her younger sister. As Phoebe recalled, her sister and parents “were
just like in and out” during much of her early childhood as they worked to meet Ruby’s
complex medical needs.

Phoebe and Ruby’s relationship began to blossom when Ruby was able to return
home and her health stabilized. Phoebe noted that although her sister was hospitalized for
much of her infancy, they “caught up really fast.” Initially Ruby could not be in public
because of her fragile health, meaning Phoebe spent a significant amount of time at home
with her younger sister. From watching home videos, Phoebe knew that many of her
early interactions with Ruby involved playing games like hide-and-seek together. She
recalled that because her sister was not able to talk at first, communication with Ruby
was initially difficult. In order to communicate with her sister, Phoebe learned a few
different sign language signs that she could use when with Ruby.

For Phoebe, learning that her sister had Down syndrome was a realization that
gradually occurred as she got older. While her parents knew from birth, Phoebe only
“knew there was something different” about her sister early on. Although she didn’t
recall exactly when, Phoebe speculated that her parents specifically mentioned Down syndrome to her around kindergarten. When recalling how she learned about her sister’s needs, Ruby remembered that it, “was never a big shocker or something.” However, Phoebe noted that she truly began to comprehend what this entailed once she met other individuals who had Down syndrome in her community and by comparing them to her younger sister. She noted that her parents helped educate her about Down syndrome, and previewed the types of challenges that Phoebe might have relating to Ruby as they both got older.

Phoebe shared that their current relationship was marked by the significant amount of time they spent together and by the large amount of activities that they did together. Phoebe described that she and Ruby were “best friends” who participated in many communal activities together like playing basketball, riding bicycles, and watching television shows together. Phoebe noted that because her younger sister often did not enjoy the same types of shows that she did, she usually deferred to Ruby’s preferences when they were together. Much of their present relationship was marked by Ruby’s colorful, spontaneous personality. She shared that many of her conversations with her sister were unique because her sister said “stuff that probably shouldn’t be said out loud.” Phoebe noted that her sister’s personality was “hilarious,” and shared during the interview and in her daily check-in journal the extravagant shows that her younger sister liked to put on for her. Although she admitted that these impromptu shows often did not make sense, Phoebe also noted that it was “really entertaining” when her sister dressed in costume for these shows and decided to perform for her family.
As part of their sibling relationship, Phoebe had assumed a number of roles with her young sister. She noted that part of her relationship with Ruby involved teaching her new concepts and helping her learn. When helping her sister on homework, Phoebe noted that she had learned to adapt specific strategies to help Ruby understand the concepts that she was working on. Phoebe noted that teaching her younger sister often involved explaining concepts to Ruby at a slower pace, and repeating directions when necessary. As her sister could become easily distracted, Phoebe noted that she had to be patient when working on homework with her younger sister to ensure that she stayed on task and completed her work. Teaching Ruby extended not only to helping her with academic tasks, but also to helping her sister learn how to do other activities like play the piano, or paint her fingernails.

Phoebe shared that her younger sister’s stubbornness could often be challenging for her family. Phoebe noted that her sister would often not do what others asked her to do, and could be steadfast in continuing to do things her own way. These bouts of stubbornness happened daily, often beginning in the morning when Ruby resisted brushing her hair or picking out an outfit for the day. Phoebe admitted that her sister’s stubbornness could make getting to places in a timely manner difficult, and that “it wastes a lot of time that we could be doing something else.” During the photo-elicitation interview, Phoebe shared a photograph demonstrating how difficult it was to get her sister to follow directions when she was being stubborn. While she and her mother had asked Ruby to smile for the camera, in the photograph Ruby had instead chosen to make a “really weird face.” Related to this, Phoebe confided that it usually took her family many attempts before they arrived at a successful photograph where Ruby was actually smiling.
Ruby’s stubbornness often became evident when she was asked to do something different than what she was used to or anticipating. Ruby had a very specific routine that she typically followed each day; she could easily upset if that routine was disrupted or changed. Phoebe also noted that her sister could become especially stubborn if she felt tired, particularly when she was away from the comfort of her house or if it was near the end of the day. Phoebe mentioned that trips outside of the house, such as to go shopping or for entertainment, were often impacted by Ruby’s stubbornness. Because Ruby’s behavior could decline quickly when she felt tired, her family had been forced to prematurely end some trips that were planned. Phoebe shared how her sister’s stubbornness could present when her family went shopping together:

Shopping is always like the hard thing, because she wants everything. And so she like insists on getting it, carries it around with her, and she won’t leave until she gets it. So we could be like leaving and she’ll stay in the store, and like sit in the middle of the store, and just sit there with the item that she wants.

Because of Ruby’s difficulty with activities that fell outside of her typical routines, Phoebe noted that her family would take proactive steps to prepare for these difficulties. Her family had learned to plan for trips away from home beforehand, beginning with previewing the upcoming trip to Ruby so that the changes to her schedule would not be surprising and to ensure she got ample rest the night before. Additionally, Phoebe mentioned that her family had learned to bring items to keep Ruby entertained on trips.

Ruby’s stubbornness not only impacted trips that her family made outside of their house, but could also impact her family’s ability to engage in their normal routines at home. Ruby was often insistent on deciding which activities her family should do together, which created challenges if her family did not have the time to do that activity.
Sometimes when Ruby was being stubborn, Phoebe had difficulty redirecting her sister’s behavior. Phoebe noted feeling frustration after she had asked her younger sister to do something, often because Ruby did the opposite of what she was asked. For example, Phoebe mentioned that if she asked her sister to turn down the volume on her computer, Ruby often responded by turning up the volume. In addition, Phoebe also noted feeling frustrated by her sister’s sometimes volatile reactions to seemingly small events. She noted moments when she had been working on homework or engaging in leisure activities, only to be interrupted by the sound of Ruby screaming because their cat had jumped up on the table.

When her sister felt upset, Phoebe mentioned how difficult it was to calm her down. If Ruby felt especially exhausted or angry, she would sometimes hit others or become physically aggressive towards Phoebe. Even so, Phoebe noted that she would often jump in to address these outbursts when their mother felt overwhelmed. Phoebe shared that “she seems to be the one that stops the stubbornness,” and acknowledged that her sister sometimes needed to hear a new voice or “a different perspective to help her see something.” Phoebe mentioned that she had learned a variety of different strategies to help her sister when she was being stubborn, such as repackaging directions given to Ruby into a game or some type of competition. Phoebe had also learned that it was sometimes best just to ignore her sister’s behavior and “walk away from the situation.” Phoebe admitted that this could be frustrating, especially if she or her mother were forced to stop what they were doing because of Ruby’s disruptive behavior. As Phoebe worded it, “I try be as patient as I can but sometimes that patience goes out the window!”
Phoebe noted a number of protective processes that helped her adjust to having a family member with a disability. Phoebe noted that people in her town were “really accepting of her (Ruby) and everyone knows her.” She also shared that local services available to Ruby had been beneficial for her and her sister. Although her sister participated in some sporting activities at school, Ruby could “sometimes notice that she’s different than other people” and become frustrated. Phoebe shared that her sister had benefited from participating in the Special Olympics, and that she had personally enjoyed partnering alongside Ruby for these activities. At home, Phoebe’s mother had helped her by teaching her how to interact with Ruby, while also educating her about Down syndrome and helping her understand the root cause of her sister’s frustration. In addition, Phoebe shared that both she and her sister had jointly benefited from the efforts that her parents have made to treat both children fairly. She mentioned that her parents chose not to treat Ruby “like a baby,” and that her sister was not “given the easier stuff just because she has a disability.” Phoebe mentioned that she and Ruby shared similar household responsibilities, and both completed similar chores as part of these responsibilities. Phoebe shared that these high expectations that her parents held for Ruby had taught her that Ruby’s disability “doesn’t get in her way. And she can do what she wants.” She noted that she also tried to challenge her sister when they worked together, and by doing so hoped to increase Ruby’s ability to live independently one day.

Phoebe noted that her experiences alongside Ruby had also personally benefited her. Specifically, Phoebe shared that dealing with her sister’s stubborn tendencies required that she learn patience, and mentioned feeling “a lot more mature than some people my age because of it.” Having a younger sister with a disability, Phoebe also had
developed a desire to work alongside other individuals with special needs. At the time of our interview, Phoebe was volunteering regularly at an agency that provided services to individuals with intellectual disabilities, and was using skills there that she had learned from her interactions with Ruby.

Although mentioning that having a younger sister with a disability is “just really different,” overall Phoebe had found that “the experience is really fun,” noting that “living with Ruby is just a blast!” As evidenced throughout my interview with her, there was clearly a deep love and appreciation shared between Phoebe and her younger sister. As Phoebe shared, this depth of love also extended to embracing Ruby’s special needs:

Which is, it all goes back to loving like her disability and like loving her. I just think people with disabilities are so different and fun, because you never really know what’s going to come out of their mouth and that’s always kind of a fun thing. It’s always a new experience.

Carrie

There’s some days when you go and just sit at a traffic light all day. That’s fun! --Carrie

Late last summer, I was surprised to receive a message from my friend Miranda. I had known Miranda and her children Carrie and Luke for six years, largely through my previous employment at an agency providing services to children with developmental disabilities. Her son Luke had received services at this agency from a young age, and his regular presence at the agency was a fixture of my time there. In the message, Miranda shared that while she would still retain parental rights over Luke, he would be transitioning towards primarily living with a family in the Denver metro area. The message detailed the background that Luke’s new placement family had working with children with similar physical and cognitive needs, and how Miranda and Carrie had
painstakingly vetted a supportive family with whom they felt comfortable to care for their beloved Luke. Although Luke would be residing primarily with this family in Denver during the week, he would still be traveling to visit Miranda, Carrie, and his grandparents every other weekend.

It was clear that this had been a difficult decision for the family to make. It was also apparent that the family had gone through a thorough and methodical process to find a family that would be able to meet Luke’s unique needs. Knowing Luke and the significance of his medical concerns, I was also well aware of the daily sacrifices that Miranda and Carrie had made for him throughout his childhood, including providing daily in-home medical care for him. Still, the revelation that Luke would now be primarily living with a family in Denver completely surprised me. As my interview with Carrie would later reveal, several significant events transpired that prompted Carrie’s family to make this difficult decision. As Miranda noted to me, her family had reached a point where it was “pretty clear that there was a pretty serious crisis, and nobody was going to survive.” As became very evident during my interview with Carrie, factors related both to Luke’s individual needs and to the needs of other members of Carrie’s family prompted their family to arrive at this decision. I found Carrie’s story especially powerful in demonstrating how protective processes and risk factors can change, and that the resilience process is dynamic depending on contexts and supports.

Throughout my interview with the then 14 year-old Carrie at their household, there was a gentleness in her voice whenever she spoke about her younger brother Luke (11 years-old). When Luke was first born, there were no concerns detected in utero or at birth, but he would later face significant health concerns related to intractable epilepsy,
hypotonia, and developmental delays. Although she was young, Carrie recalled her initial excitement about having a younger brother. Luke’s health was stable at the beginning of his infancy, but his family began to have concerns about his health when he was four months old. Carrie detailed this to me by sharing a photograph that was taken around the same time. Posing in a park together in this photograph, I noticed that even from a young age Carrie and Luke resembled each other with their brown hair and freckled faces. Although it was unclear if this was the same park, Carrie shared that her family first began to have concerns about her younger brother on a walk there one day. Miranda and Carrie’s father noted that Luke began breathing irregularly, which prompted them to put Luke on oxygen and closely monitor his breathing. Although Carrie recalled not being very concerned initially, she noted that she began to worry soon after when Luke’s health concerns became substantial. What had started as irregular breathing quickly escalated into seizures -- life threatening episodes that often happened multiple times a day. When Luke had a seizure, he stopped breathing and had to be immediately resuscitated by his parents. Carrie recalled one instance when she noticed that her young brother was shaking and that his lips were purple, and calling to her parents for help. She noted that the first few seizures she witnessed were frightening, but because of their high frequency, they became more “normal” over time.

Carrie noted that this was “a time of crisis” for her family. Initially, it was not clear to medical professionals what the cause of the seizures was. As her parents scrambled to address Luke’s frequent seizure episodes, Carrie remembered hearing her parents talking about the problems confronting them and deliberating about how to pay for the medical expenses that were accruing. She overheard tense conversations where
her parents argued about what steps they should take to meet Luke’s needs. In spite of the stress her family experienced, Carrie noted that her family remained as prepared as they could any time that Luke had a seizure. Often times after a seizure had occurred, Carrie recalled that ambulances would come to her house and take Luke. She remembered seeing her parents cry as they worried about Luke’s health, and watching as her parents would leave to go to the hospital to be with Luke. At other times, Carrie would only realize that her brother had a seizure upon waking up in the morning and finding her grandparents at her house in place of her parents. During our interview, Carrie shared the uncertainty she and her family experienced when Luke first began to have seizures:

It was scary because I loved and still love both of my parents and my brother, and I saw them go to the hospital and I didn’t like know what was going to happen. And I’d have to stay with whoever. And some nights they would go in the middle of the night, and then I’d wake up and come downstairs and my grandparents or somebody would be there and my parents would be at the hospital with Luke. And I’d still have to get ready for school and stuff, which is hard.

Because Carrie’s parents were often at the hospital with Luke when he was young, Carrie spent significant amounts of her childhood with her grandparents and with her aunt and uncle. She recalled wondering if she would be moving in with her grandparents on a permanent basis as Luke’s seizures continued. With Luke’s seizures showing no signs of improvement, his family worked diligently with medical professionals in the Denver area to identify the cause of his seizures. During this time, Carrie primarily stayed with her grandparents for nine months to allow her parents to focus on getting help for Luke.

After extensive testing, doctors identified that a severe seizure focus in Luke’s left temporal lobe was responsible for the sudden onset of seizures. Without surgery to remove the seizure focus, it was unlikely that Luke would survive through his infancy.
While Carrie’s family hoped and prayed that Luke would be able to make it to his scheduled surgery date, an epileptologist was identified who could conduct the specialized operation that could potentially remove the focus of the seizure. At eighteen months, brain mapping and surgery were successful in resecting the seizure focus from Luke’s left temporal lobe. Unfortunately, while Luke was recovering from the surgery in the hospital, he developed a staph infection at the site of surgical invasion that required him to remain in an Intensive Care Unit for an extended period while he recovered.

With the staph infection forcing Luke to remain in the hospital longer than the originally prognosticated week-and-a-half recovery period, Carrie wondered when her brother would be able to leave the hospital. She believed that her early bond with Luke was strengthened by the visits she would make to the hospital to see him. Because one of her parents usually needed to be nearby Luke in case of an emergency, Carrie recalled that she rarely saw both of her parents at the same time. Even though her parents were busy, she mentioned that each of her parents independently set aside time to spend with her. Carrie also noted that her grandparents were an especially powerful presence in her life during this time, and that their reassurance and support helped her navigate the changing dynamics of her family as they collectively worked to address Luke’s needs.

When Luke was finally released from the hospital, Carrie and her family had to adjust again to the aftereffects of the surgery. While the brain mapping and surgery had been successful in removing the seizure focus from Luke’s developing brain, after the surgery Luke experienced significant delays on the right side of his body that greatly impacted his fine and gross motor abilities. Carrie noted that as a young child, Luke needed to be fed by hand as he was unable to feed himself. One of the photographs
Carrie shared with me during the photo-elicitation interview also highlighted the ways that the surgery had impacted Luke’s gross motor abilities. In the professionally shot sibling photo Carrie shared with me, Carrie had her arm around Luke as he sat in a wicker chair. Although I had assumed that Carrie had placed her arm around Luke for cosmetic purposes, she noted that in actuality this had been done to stabilize Luke’s upper body. Without the support of her arm, Carrie stated that Luke would not have had the strength to remain upright and would have fallen out of the chair.

Although Luke had made progress throughout his childhood, he was still impacted both physically and verbally. Because of his diagnosed hypotonia and low muscle strength, Luke could not walk independently beyond a few steps. The intractable epilepsy that contributed to so many seizures during Luke’s infancy negatively impacted his ability to verbally communicate with others. The post-surgical staph infection caused Luke’s left ear to rupture and consequently he experienced unilateral hearing loss in that ear. Because of the complex nature of Luke’s needs, his family had taken considerable steps during his childhood to provide him the best care. Carrie mentioned that her family moved to a new town in order to be eligible to utilize a non-profit agency specializing in providing short-term care for children with developmental disabilities. Carrie’s family was also proactive in enrolling Luke from an early age in speech therapy, physical therapy, occupational therapy, and behavioral therapy. Because many of his needs were medical, Carrie’s mother worked diligently to provide intensive in-home care to Luke through nurses in the community. Carrie noted how this in-home support, as well as the short term care facility, were especially beneficial to her family. Carrie recalled the relief her family felt in finding a community agency that could meet Luke’s intricate needs, and
noted how using this community support allowed her and her mother to run errands and occasionally have a night out together.

As the older sister, Carrie noted taking on a number of different roles with her sibling. Carrie credited her parents for helping her better understand Luke, and helping her learn how to interact with her younger brother. She noted that she had taken on a partnering role with her mother by helping Luke with daily activities like eating and practicing walking. Although a large part of Carrie’s relationship involved helping provide for his needs, another primary component of their sibling relationship centered on their playful interactions with each other. Often times, these interactions were colored by Luke’s cheerful disposition and singular interests, such as with traffic lights, water, and musical toys. Carrie mentioned that when she was with Luke, they often played with his beloved musical toy “cube” together, or went somewhere together where Luke could watch traffic lights change. As Carrie noted, every day with Luke could be uniquely entertaining and there are “some days when you go and just sit at a traffic light all day. That’s fun!”

Carrie noted there were some challenges she had faced in interacting with Luke. While Luke could often be cheerful, Carrie noted that he became frustrated when he wasn’t able to express himself or wanted something. Luke could also be very “demanding” sometimes, and could become upset when he was unable to fully communicate what he wanted. Carrie noted that when Luke became very frustrated he would, “cry, and he’ll scream, and he’ll hit people. And his pinches hurt because he’s very strong.” Mentioning that there was always a “good reason” for why Luke became upset, Carrie had learned how to communicate with Luke differently than she would with
others. She noted that sometimes her interactions with Luke required extra patience, as well as finding ways to redirect him when he was upset beyond just telling him what to do.

Carrie also described instances when routines in her day were disrupted by Luke. Because of his hearing loss, Carrie noted that Luke often did not realize how loud he could become. She mentioned that watching television could be difficult when Luke was home because he would often “smack the TV” and excitedly make loud noises when the television was on. When Luke was at home, there were many people who came to the house to provide in-home care. Carrie noted that the noisiness in her house made concentrating on homework especially challenging. She remembered having to wear headphones or play classical music to block out the noise coming from her living room. Additionally, Luke’s limited mobility and the significance of his health needs made leaving the house difficult for Carrie and her mother. Although their family was able to receive assistance from the local short-term care facility and from the in-home care, Carrie recalled how challenging it was to run errands with Luke:

Like, I know like if I’ve been really wanting to do something, go to a store or something, but Luke’s been here and it’s been too much because he freaks out in stores! And he pulls things off shelves. And I know, we went to Hobby Lobby once and they have like those glass shelf things. And he pulled one off and shattered it in the store!

While her family had already overcome one crisis in adapting to Luke’s life-threatening seizures in infancy, Carrie and her family had recently experienced another cascade of unanticipated stressors. As Luke got older, Carrie noted that it became more difficult for her family to take care of him and provide for his needs. Because Luke grew stronger and larger with age, transporting Luke and walking with him became especially
difficult for Carrie and her mother. The medical attention that Luke needed, which was often provided in-home until 9:30 in the evening by a rotating ensemble of up to 30 different nurses a month, also made it challenging for Carrie and her mother to maintain a sense of family life. Carrie admitted that it could be “awkward” waking up on a weekend to find unfamiliar people in her living room, and that eventually she “became really annoyed with the people” constantly coming in and out of her household.

Around this time, other stressors beyond caring for Luke impacted Carrie and her family. Carrie’s grandfather, who had played a central role in supporting Carrie’s mother and shared “a special bond that no one else has” with Luke, was suddenly diagnosed with stage four melanoma and at its early onset given only six to eight weeks to live. Carrie noted the significant impact this news had on both she and her mother, especially considering the invaluable ways he had helped Carrie’s family care for Luke. She noticed her grandfather, who was usually a “happy man”, becoming more tired and irritable as his health deteriorated and caring for Luke became more difficult. Carrie “could just tell that people were stressed more”, and realized that she and her mother were arguing with each other with greater frequency. Around this time, Carrie also experienced serious health concerns of her own that required her to be hospitalized for two months. It was a time of significant stress not only for Carrie, but also for her entire family.

As Carrie, Luke, and their grandfather were all facing serious medical concerns, Carrie’s family arrived at the difficult conclusion that something needed to change for everyone’s needs to be fully met. Carrie’s family began to start exploring different options to address Luke’s needs, before ultimately deciding that a foster placement would serve him best. Carried noted that “it took a long time to find a place would work for
him,” and that the process of finding a suitable family for Luke was strenuous. Her family was methodical in finding a family with whom they believed they could entrust their son. Carrie’s family began to do trials with this family who had provided foster care to children with similar needs to Luke. They began with having Luke visit the family in for two hours at a time for a couple of times a week. When Luke and his family became more comfortable with that arrangement, they then completed an overnight trial with the foster family at their household. These trials were gradually increased in duration until Luke appeared acclimated to living with the foster family and Carrie’s family was comfortable with this being a long-term arrangement. Carrie’s mother still maintained parental rights and Luke spent every other weekend at their personal residence. Carrie noted that the pairing had been a “good match,” and that Luke had built close relationships with his new foster parents.

Thankfully, both Carrie and her grandfather recovered from the medical concerns that they experienced. While finding solace in having found a placement that could meet Luke’s needs. Carrie noted that it was “a big change” when Luke first left. Recalling the summer when Luke first moved to his new placement, Carrie suddenly noticed that her house felt different. Because the in-home care for Luke was no longer necessary, she found that her house felt strangely quiet and empty without the entourage of nurses and other professionals. Even though it was a difficult decision for her family to make, Carrie shared that she ultimately believed it was a healthy choice for her family. She noted how her family had experienced less stress because of the respite, and that they were “not as tired and burnt out” anymore. Additionally, her family had found it easier to provide for his needs when Luke was with them. Despite not seeing her younger brother
as often, Carrie noted their strong bond with each other had endured and had actually been strengthened. When Luke did come back to visit every other weekend, Carrie could tell that he was happy to see her when he came through the front door.

Attributing it to her special relationship with Luke, Carrie had developed a deeper understanding and appreciation for people with disabilities. Her experiences with Luke had shown her that everyone faces their own unique challenges, and fostered within her a worldview to “appreciate everyone for who they are.” Being the older sibling to Luke, Carrie also described developing a special interest in working alongside other children with special needs. At high school, she noted being able to interact and connect with her classmates with special needs. Carrie also began to volunteer at the short-term care facility where her brother received services and also with a local group that providing equine-based activities for individuals with special needs.

While Carrie and her family had encountered significant stress related to Luke’s health and his needs, Carrie noted that she and her family had grown together through their experiences of having a family member with a disability. For every crisis that they faced, Carrie noted that she and her family had to demonstrate strength to persevere. Largely because of these challenges, she perceived that she had forged closer bonds with both her mother and Luke. As Carrie noted, she and her mother had “both been through a lot together. And I don’t know, we had to stick with each other through all of it.” She described interacting with Luke had gained added specialness because they no longer saw each other as much. Recalling the journey that she and her family had been on together, Carrie noted that, “In a way I think we’ve all gotten strong, or like we’ve all bonded. But
like we’ve also gotten stronger, and that was a big hurdle and stuff. But we got through it
together and now we’re here.”

Summary

These stories detailed the personal experiences that each participant shared about
being the older sibling to a child with a disability. Framed within the context of a
psychological resilience framework, each sibling courageously shared both the risks they
had experienced and the ways that protective processes had helped them adapt to having
a family member with a disability. The experiences shared in this chapter not only
describe the personal journey of each older sibling, but also encapsulate the unique
perspectives and meaning that each individual had derived from his or her experiences.
From a social-constructivist perspective, these individual accounts were based not only
on participants’ direct interactions with their siblings, but were also shaped by their
unique family environment. These personal accounts and stories were collectively used in
the next chapter to arrive at a tentative manifestation of what it was like for these
individuals to be the older sibling to a child with a disability.
CHAPTER V

DISCUSSION

Experience is not always the kindest of teachers, but it is surely the best. 
---Spanish proverb

As is evident through the personal stories of each participant, being the older sibling to a child with a disability is a unique experience. It is one that is shaped not only by the needs of the child with a disability but also by the ways that families adjust to this reality. Each participant had followed a path throughout their childhood and adolescence that included both valleys and peaks; adolescent participants noted both significant stressors and sources of risk, as well as wonder, fun, and personal growth experiences. They viewed themselves as having benefitted from having a sibling with a disability and each participant shared stories of perseverance and strength in the face of this challenge. In fact, participants noted ways that they had grown as a person from their unique status of having a sibling family member with special needs.

Although each participant’s story was distinct, similar themes emerged throughout their accounts. Taken together, these themes were used to arrive at a common narrative describing the phenomenon of being the older sibling to a child with a disability. Their journeys can be viewed through a psychological resilience framework which integrates risk, vulnerability, and protective processes. Specifically, the Double ABCX Model of Family Adjustment and Adaptation was utilized in the development of the interview materials to understand the process of adaptation for these older siblings.
within the context of their families. Particular emphasis in this model is placed on the relationship between stressors \( (aA) \), resources \( (bB) \), and perceptions of the stressor \( (cC) \) both before and after a family experiences a crisis (McCubbin & Patterson, 1983).

Although using such a model might suggest a straightforward path towards adaptation for each older sibling after encountering an isolated crisis, the narratives of each participant suggested otherwise. Instead, participants described being faced with multiple, sometimes shifting barriers that challenged their adaptation.

To better understand the experiences of these siblings, three research questions guided my study: first, what challenges and risks do older siblings identify in adjusting to living with a sibling with an intellectual disability; secondly, how do older siblings perceive their adaption; and finally, what meaning do older siblings of children with disabilities make of their experiences? Based on the narrative of each participant, five primary themes emerged that answer these research questions: (a) “I Didn’t Really Know What to Expect”: Learning about the Disability and Early Challenges, (b) “You’ll Create a Special Bond with Them”: Roles, Responsibilities, and the Nature of the Sibling Relationship; (c) “It’s Going to be a Lot Harder Sometimes”: Disruptions, Changes, and Establishing New Routines, (d) “I’ve Learned to Love It”: Changing Perceptions and Creating Meaning, and (e) “I Feel Like he’s Brought us Closer Together”: Personal Growth and Perceived Benefits. Recognizing these themes may be helpful to understanding the unique stressors that these older siblings can face and might possibly assist in generating specific supports for these siblings and their families.
Naturally, the entrance of a new child created immediate changes to each participants’ family. In any family, the birth of a newborn will produce a certain level of normative stress as the family adjusts to its new circumstances. I was surprised, however, by the types of exceptional, non-normative stressors that participants noted their families encountered early in the life of their younger sibling. In fact, the early years of the younger sibling seemed to be a time of considerable stress and confusion for each family. Participants used words like “challenging” and “tough” to describe this initial process of adaptation for both themselves and their families. Paige seemed to speak for every participant when she acknowledged that she “didn’t really know what to expect” during this time.

I noticed that participants appeared to draw from several sources when constructing these early experiences for me. Participants spoke frequently from their personal memories, recollections, and encounters. At times, participants also appeared to have drawn from the narrative of their parents and other family members. Because many participants were also relatively young when their sibling was born, it seemed that they also relied on the accounts of their parents to piece together the times immediately after the birth of their younger sibling. Hearing participants talk about these early times, I thought back to a figure I had seen in a research article about family resilience. In the figure, Patterson (2002) had conceptualized adjustment as acting similarly to a weighing scale. On one end of the scale were the demands placed on the family, while on the other end were the capabilities and resources of the family to meet these demands. Figuratively, adjustment and adaptation is facilitated when the scale is balanced between
the demands and capabilities of the family (Patterson, 2002). What seemed to have happened for each family was a redistribution of the scales, with the demands of the child suddenly overwhelming their capabilities and resources. Each family was faced with a new and unexpected reality: the entry of a child with a disability into the family with specific, significant needs. I conceptualized this time of identifying the disability and addressing the needs of the younger sibling as a crisis period. Carrie shared a similar sentiment, directly identifying this as “a time of crisis” for her family.

One of the first challenges each family faced was in correctly identifying the existence of a disability. Between participants, the path each family took to finding answers varied considerably. While Phoebe and Paige’s families knew from an early age that their child had a disability, for others this realization was not immediate or sudden. For these families, learning about their child’s disability was a much more gradual process that began with specific identified concerns. For example, Edward’s family became concerned when Tim abruptly began to “disconnect” from others beginning around his second birthday. For Carrie’s family, Luke’s irregular breathing pattern was the first unusual sign that their family detected. These significant unknowns appeared to contribute to feelings of ambiguity and tension within the family unit. Acknowledging this time as particularly challenging for his family, Edward noted that, “It was just something brand new and unknown, and I think that weighed down on my parents and some of my older siblings.” To learn more, parents sought testing and professional opinions about their younger children that led to a formal diagnosis of a disability.

I recognized that older siblings’ paths to identifying that their sibling had a disability seemed to follow a longer timeline than those of their parents. Probably
because the participants were young, they appeared to have difficulty recalling a specific moment when they personally learned that their younger sibling had a disability. Instead, they commonly described this knowledge as having been procured across time and through their experiences with their younger sibling. Instead of explicitly knowing that their sibling had a disability, or even being cognizant of what a disability was, at first participants described feeling that there was something “different” about their younger sibling. For some participants, they noted comparing their younger sibling to other children and noticing divergences in their development. This appeared especially true for Rachel, who already had a younger sister before Madeline was born. She remembered how her other sister had learned to start talking at a young age, and had expected Madeline to act similarly. Instead, Rachel noted feeling confused when Madeline had difficulty making intonations or talking when expected. Phoebe said, “I was little, so, like, I didn’t really understand what she like had. But I knew there was something different.”

For Carrie and Phoebe, the precarious health of their siblings early in their development appeared to be the strongest indicators that something was not normal. In their interviews both shared frightening moments that occurred during their younger siblings’ infancies. Carrie remembered the moments immediately after her brother had one of his daily seizures, and recalled seeing her “mom or whoever like crying and like them doing CPR.” Phoebe also mentioned that her sister was frequently sick when she was young and remembered that her younger sister “was always, like, throwing up and stuff.” I was amazed at how vivid and clear these moments still seemed for them years after the events had taken place.
I noticed a dichotomy in the narratives of participants; although they detected differences in their sibling, they eventually came to perceive these differences as normal. Over time, participants described a process of becoming more accustomed to the differences that they had observed in their sibling. For her youngest sister, Rachel eventually noted that things “weren’t exactly the same.” Still, she remembered accepting this reality “pretty quickly.” Carrie also discussed a shift in how she reacted to her brother’s frequent seizures. While acknowledging how scary they could be, she also came to view them as “kind of normal in a way.” It seemed that this shift towards normality extended to when participants became aware that their sibling had a specific disability. Because they had detected that something was different, participants indicated not feeling completely surprised to learn that their sibling had a disability. For Edward, having a younger brother with autism was something he “grew up with, so it was normal.”

Still, these early encounters with their younger sibling often appeared to elicit feelings of confusion and worry for participants. Often, these feelings appeared to be related to the uncertainty of the future and what it might hold. Rachel recalled wondering, and worrying, about what the future would look like specifically for her younger sibling. She wondered how Madeline’s disability would impact her as she got older, and feared that her sister would not be able to make friends. Participants also sometimes indicated that they were worried about what the future held for their families. Carrie recalled that as Luke, “got more sick and stuff I was starting to worry. Like what would our life, like our family life and situations turn out to be and just be like in the future.”

For participants, there was a distinction between identifying a disability and truly understanding what it meant to their lives. As participants grew older, they described
becoming more aware of their siblings’ disabilities and their impact. I recognized that this added knowledge appeared to be a natural consequence of age and maturity. For Paige and every participant, they each gained a specific understanding “as it went along.” For example, they appeared to gain insight from their experiences across childhood interacting and playing with their siblings. Still, parents and other adults also took specific steps to help inform each older sibling about the nature of the disability. Participants described their parents educating them about the disability, answering what questions they could, and helping explain the behaviors and frustrations of their younger siblings. These types of early conversations with parents appeared to help provide a sense of clarity for older siblings.

Beyond the challenge of identifying the disability, families still faced significant decisions about how to best meet their child’s needs. McCubbin and Patterson (1983) identified that when families experience significant stressors, the stability of the family as a functional unit is challenged. To restore stability to the system, families must access new resources while also making internal adjustments within the family unit (McCubbin & Patterson, 1983). The narratives of participants similarly suggested that their families went through a similar process of change. Externally, families were proactive in seeking disability-related resources to meet the needs of their child. Edward mentioned that his family traveled across the country to attend a training about autism and to better learn “how to help Tim.” In the demographics questionnaire, parents also indicated seeking out supports like physical therapy and occupational therapy for their young child. For Carrie and Edward, their families eventually relocated to new towns to access specific programs for their child.
Internal adjustments within the family were also necessary to ensure that the needs of other members could be met. Especially for Carrie and Phoebe, the early health concerns of their younger siblings required a significant amount of their parents’ time and attention. For both, their parents spent considerable time with their younger sibling while they were hospitalized. Still, Carrie recalled the effort that her parents made to spend quality time independently with her. While noting that one of her parents would stay at the hospital with her younger brother, her parents would alternate making time to spend with her. She noted that her parents “knew I still need, like, a parent.” Extended family members like grandparents also stepped in to provide additional support for families and respite for parents. Grandparents often serve an important function in families of children with disabilities by providing physical and emotional support to other members of the family (Lee & Gardner, 2010).

“You’ll Create a Special Bond With Them”: Roles, Responsibilities, and the Nature of the Sibling Relationship

The relationship shared between siblings was an influential component of the ways that participants described their process of adaptation. Throughout our interviews, I sensed that participants were eager to describe their relationships with their younger siblings to me. When discussing these relationships, they often appeared to speak with a heightened energy and enthusiasm. It was easy for me to visualize these sibling relationships from the rich, detailed anecdotes that each participant provided.

I noticed that participants described a shift in their relationships with their younger siblings. This shift was noticeable in how participants described both the content and quality of their relationship with their younger sibling. Participants often described
having difficulty initially connecting with their sibling. For Carrie and Phoebe, part of the challenge in building relationships with their siblings came from the significant amounts of time their siblings spent at the hospital from an early age. Thinking back to her initial thoughts about having a sibling, Paige confided, “I just treated him like I didn’t want a sibling.” Similarly, Edward perceived that he and his younger brothers were “enemies” at first. Both initially and presently, every participant described facing unique stressors in their relationship with their sibling.

While facing challenges in their relationships, participants described that their relationship had improved. This was especially evident in Edward and Phoebe’s interviews, who both stated that their younger sibling had become their “best friend.” There seemed to be a variety of factors that contributed to these gains. In some cases, difficult or rigid behaviors of the younger sibling were noted to have improved across time. For example, Paige perceived that her brother’s level of physical aggression had decreased and that, “he’s getting better with hitting.” Both Edward and Rachel also noted that their siblings’ communicative abilities had also progressed as they got older. However, I also noted that participants described making gains in their own abilities to understand, relate to, and interact with their siblings. In fact, each participant seemed to have forged a unique, singular relationship with his or her sibling. Carrie’s words describing her own relationship with her younger sibling seemed to capture the sentiments of the group; they had each learned to “create a special bond” even during the difficult moments.

Previous research by Walton and Ingersoll (2015) suggested that sibling relationships are typically more avoidant when one of the individuals has a disability.
Although I sometimes detected this distance when participants described their early relationship with their sibling, most participants described spending significant amounts of time voluntarily interacting with their sibling. Phoebe observed that she and her sister “do a lot of stuff together” and “like to spend time together.” Similarly, Edward noted that he had sometimes forgotten to do tasks that he needs to do because he and his brother are “caught up in hanging out.” Indeed, the ways participants described spending time with their siblings was through the roles they described assuming with them. Participants described encountering both challenges and joys in these roles.

One central role participants described sharing with their younger sibling was a companion role akin to many sibling relationships. A hallmark of this companion role was participants engaging in play-based activities with their younger sibling. This appeared to be the most enduring role assumed by older siblings, with many participants sharing both early and present recollections of playing alongside their sibling. The importance of play appeared to be an especially significant component of Paige’s relationship with her younger brother Ray, who preferred “attention that is play.” What I found particularly interesting was the content of this play. Participants generally appeared to cater to the interests of their siblings when interacting with them. They described play-based activities like dressing up dolls, playing with a musical “cube”, playing the “microphone game,” and playing on an aerobic exercise ball. While these activities appeared more developmentally targeted to their siblings, participants still professed to enjoying this time together. Reflecting this, Rachel remarked that she and Madeline, “like to play games together…that’s something we like to do.” Being a companion to their
younger sibling and engaging in fun activities together appeared to strengthen the bond shared between siblings.

While play was a central component of each sibling dyad, participants also noted that playing alongside their sibling could be challenging. Some participants faced difficulty in finding common ground with their younger siblings because of marked differences in hobbies and interests. Often, there appeared to be considerable differences in the preferred activities of older siblings and younger siblings. Participants regularly professed that there were certain activities that they would like to engage in alongside their sibling that were infeasible. I could sense that this was disappointing for siblings, who wanted to share certain types of communal experiences alongside their siblings. Rachel noted, “it’s a little bit hard because she has all this stuff and I wish that sometimes she didn’t because we want to go like hiking or something but she can’t.” Engaging in particular activities alongside their sibling, such as playing video games or board games, was often described as challenging. Edward described the difficulties he faces in playing video games with his brother. While Edward preferred to “goof off” while playing video games, he noted that his brother could become upset when the gameplay was not predictable. Because of this, Edward admitted that his brother, “kicks me off…we never get any video game time together. It’s very, very, hard to do.”

Additional roles that siblings assumed appeared to be more directly related to the needs of their younger sibling. Each narrative illustrated a caregiving role that participants eventually assumed. As part of this caregiving, siblings of children with disabilities often take on responsibilities parallel to what their parents do (Damiani, 1999), including supervisory roles (Stoneman et al., 1989). This caretaking role appeared
to serve an important function for participants’ families by providing support and respite for their parents. Older siblings frequently shared with me that they watched over their brothers or sisters while their parents were away or needed to get something done. The responsibilities associated with this role varied based on the specific needs of the younger sibling and sometimes varied considerably between participants. The responsibilities seemed to range between normative (e.g., helping their younger sibling get ready in the morning or helping to prepare meals), to tasks that might be considered highly specific to helping a child with a disability (e.g., toileting an adolescent sibling, spoon feeding a sibling so that he does not choke).

Related to this caregiving role, I noticed that siblings were often tasked with addressing the emotional and behavioral needs of their younger siblings. Stories of emotional outbursts and “fits” were frequently laced throughout the accounts of participants. Often, stubbornness and rigidity appeared to be antecedents to the tantrums that younger siblings could eventually throw. These tantrums often resulted from younger siblings being denied something that they wanted, or when transitioning away from preferred activities. Consistent with the findings of Ross and Cuskelly (2006), participants also noted that the emotional outbursts of their siblings could escalate into physical aggression. Carrie used the phrase “two-year-old temper tantrum” to describe her younger brother’s physical and emotional outbursts. She stated that when he became especially distraught Luke would “cry, and he’ll scream, and he’ll pinch people. And his pinches hurt because he’s very strong.” Paige similarly shared that her brother Ray would hit her, throw objects, and scrape the walls of their house when feeling worked up.
Participants described partnering with their parents to address these challenges when they arose. Paige, for example, noted that she would walk around in stores with her brother when he was upset so that her parents could quickly finish shopping. Rachel and Phoebe also shared that they would attempt to calm down their sisters when their parents needed a break. I could sense that it could be exhausting for participants to interact with their siblings when they were emotionally or behaviorally dysregulated. Edward noted that because his brother could be sensitive to the emotions of others, he was careful to become neutral with his emotions when interacting with his brother so that there would not be a strong reaction. Rachel also shared that when her younger sister was distraught, “it annoys all of us… she cries and she won’t stop and she’ll be, like, talking about something, and we all just kind of want to go on with our day.” Phoebe similarly reflected on how her sister’s stubbornness made it challenging to calm her down:

Yeah, I think she just kind of calms herself down. But it’s hard to calm her down. She just needs time, which is always a thing, because she doesn’t really. We always tell her to breathe, but going back to the stubbornness, she won’t do it. She doesn’t do anything we tell her to do, usually!

Another role that many participants (Rachel, Edward, Phoebe, Carrie) indicated taking on was that of acting as a teacher to their younger sibling. As part of this role, participants provided instruction to their sibling in both academic and functional areas. Both Phoebe and Rachel shared that they often helped their younger sisters with their homework. Phoebe noted that she needed to take a different approach while helping her sister by noting that she had to “explain stuff in more detail, and maybe a couple more times” for repetition. In her photo-elicitation interview, Rachel shared a photograph of her working on homework alongside her younger sister. While noting that she often taught her younger sister, she mentioned that her younger sister had also taught her how
to be “happy” and “funny.” The instruction provided to younger siblings also extended to assistance with daily-living activities and skills. Related to this, Edward viewed one of his responsibilities as helping to guide his brother through adolescence and into adulthood. He described sharing a master/apprentice dynamic with his brother by acknowledging that Tim was “kind of learning the ways of the world. And, like, I am still too, but I’m kind of teaching, kind of guiding him through. Kind of like a mentor.” Indeed, participants often described serving as a guide to their older siblings, helping them to navigate and understand the world around them.

Challenges in communication were especially apparent when participants described teaching or guiding their younger siblings. As conversations play an important role in family functioning, difficulties in communication can negatively impact the sibling relationship when one sibling has deficits in verbal communication (Cate & Loots, 2000). A portion of these issues in communication related to the difficulty participants noted in personally expressing themselves to their younger sibling. Participants frequently described needing to communicate with their siblings differently than they would with others. Carrie learned over time that “with Luke, you need to find a certain way to communicate things with him other than just telling him.” Often, participants shared that communicating with their younger sibling required patience to comprehend what they were saying. Paige described her younger brother as nonverbal and noted that he would often state his needs by making physical gestures. Similarly, Carrie also noted the difficulty inherent in understanding what her brother needed because of his inability to use words.
Of all the narratives, Edward’s narrative was most centered on challenges specifically related to communication. Because his younger brother, Tim, spoke primarily through scripting, Edward and his family had learned to communicate with him by using quotes. In his interview, Edward noted that difficulties in communication had created barriers in his ability to know his brother fully. Edward noted that, “I feel the autism limits his communication because I think he has an amazing mind. He knows, he knows what’s going on, he’s very, very, aware. But I feel like I don’t think we realize nearly how much they know, you know?” His quote represented the challenges communication difficulties created for participants in fully knowing and being able to understand their siblings.

A final role that participants took on in their sibling relationship was that of a protector to their younger sibling. When hearing participants describe this role, I clearly sensed their sense of responsibility to look out for their younger sibling. Rachel and Edward specifically used the words “protective” and “protectors” to describe their positions with their younger sibling. This protective aspect of their sibling relationship was sometimes expressed through specific instances when participants perceived that others had judged their younger siblings. Paige admitted feeling frustrated when she felt like others were looking down on her younger brother, especially when she was out in public and her brother was acting wildly. The protective nature of the sibling relationship was also related to concerns or worries that participants had for their younger sibling. Rachel shared a specific photograph of her hugging her sister that she felt encapsulated her role as a protector. Although she noted that she was also protective of her other sister, she mentioned that she was specifically concerned about the ways that others would treat
her sister at school. These concerns were closely echoed by Edward who described times when he had, “always thought of, like, children making fun of him. And I would just tackle them and just, like, defend him in any way I can.”

Siblings of children with disabilities can experience stress because of the increased roles and responsibilities they typically assume to help their parents (McHale & Gamble, 1989). While participants described approaching some of these responsibilities with a willing enthusiasm, I noticed that some of these responsibilities associated with particular roles appeared stressful for siblings. When helping with homework, Rachel acknowledged sometimes feeling exasperated when her sister was having difficulty understanding concepts. Similarly, Phoebe shared that while she has attempted to teach her sister many things, sometimes it “didn’t work out very well.” Edward also noted feeling mixed emotions about the responsibilities he held. He confided that while he liked watching his brother while his parents are away, he did not enjoy assisting with helping his brother with toileting.

“It’s Going to be a Lot Harder Sometimes”: Disruptions, Changes, and Establishing New Routines

Having a younger brother or sister with a disability contributed to unique obstacles to adaption for each older sibling and their family. Participants described being impacted at both the individual and family level. At times, I observed that participants had difficulties overtly detecting these changes. “Nothing’s really changed,” Paige suggested at first. “I don’t really know the difference.” However, the accounts of participants revealed that each individual and each family encountered disruptions in their abilities to complete activities both at home and in the community. For each, previous routines and patterns of functioning were significantly challenged by the needs
of the younger sibling. To restore a semblance of order, each family engaged in a process of modifying old routines and establishing new ones. The ability of siblings and their families to adapt to these disruptions was buffered both by characteristics of the family unit, and by the ability of families to access resources within the community.

A common challenge created by the needs and behaviors of the younger siblings was that tending to these behaviors created barriers for the rest of the family to engage in everyday tasks. The often-unpredictable behaviors of younger siblings frequently led to disruptions in daily activities at home. Children who have disabilities that are characterized by high levels of externalizing behaviors can negatively impact family functioning and contribute to added familial stress (Rao & Biedel, 2009). Disruptions to participants’ routines occurred early in the day, with most participants (Paige, Phoebe, Rachel, and Carrie) indicating that their sleep schedule could be disturbed by their younger sibling. Challenges to getting restful sleep were exacerbated by differences in the sleep schedules of participants and their younger siblings. While participants relished opportunities to sleep in, their younger siblings often awoke early in the morning. Participants shared frustrating moments where they had been awoken to the sound of their sibling screaming, waking up in the middle of the night to the sound of their sibling playing, or being roused by the physical touch of their sibling. Paige noted shared that, “If I’m trying to sleep…then he’ll like come in my room and peek around the door. Like, he’ll open the door and peek in, and then he’ll shut it. And then he’ll keep like opening it up and just completely repeating that.” Previous research has also identified family members of children with disabilities face unique challenges to getting restful sleep. Children with disabilities such as autism may sleep less than typically developing
children, and often wake up in the middle of the night and early in the morning (Meltzer, 2008; Richdale, Francis, Gavidia-Payne, & Cotton, 2000). As Richdale et al. (2000) determined, difficulties in sleeping for children with disabilities can contribute to both increased parental stress and heightened behavior problems for the child.

I also identified that participants faced disruptions that could threaten their ability to engage in certain types of activities that are typical for many adolescents. It was striking for me to hear participants describe how the behaviors of their younger sibling could dictate the entire atmosphere of their household. The peace and quietness each household experienced could be ephemeral, quickly fleeting as the sibling’s behavior changed. In fact, participants described how noisy and chaotic their household could quickly become when their younger sibling became either upset or excited. These shifts in the household ambience created challenges for each participant to engage in leisure, recreational activities. Even seemingly simple domestic rituals that participants enjoyed, such as playing the piano, playing games, and watching movies as a family, could be interrupted by the behavior of the younger sibling. Sometimes, these sudden shifts forced families to end certain activities prematurely. Phoebe mentioned that she and her mother had sometimes been forced to stop what they were doing and leave the room when her sister had difficulty calming down. In his interview, Edward confided that his family must “be very careful” not to scratch movies because of the way his brother would react. Apparently, when movies skip or freeze, Edward’s brother runs out of the room and yells until the problem is fixed. Because of this, Edward had learned that, “there’s certain things that I can’t do when he’s around that annoys him, that he tells me to stop very forcedly.”
Beyond leisure activities, the narrative of participants also suggested that they sometimes faced risk in completing necessary daily activities. Working on school assignments in this type of frenetic environment was reported as a particular challenge for some participants (Carrie, Edward, and Phoebe). Because of her brother’s unilateral hearing loss, Carrie’s brother is not able to accurately gauge the loudness of his voice or actions. She noted needing to wear headphones when working on homework to block out the sound of her brother. Additionally, she also discussed how the large number of in-home health care providers had made it challenging for her to establish a sense of normalcy in her own house. Phoebe also described her sister’s stubbornness as creating a loud atmosphere that was not conducive to completing essential work. She shared that when she asked her younger sister to turn down the volume while she is on the computer, her sister often had the opposite response.

Outside of the house, the needs of the younger siblings also presented challenges to each family’s functioning. Each family faced unique barriers and significant risk to completing both practical and recreational activities in the community, a theme that emerged in participants’ daily check-in journals. I was surprised by how difficult even common trips could become for each family. Actually, even getting out of the front door was described as a considerable challenge. Younger siblings, who needed predictability and routine, appeared to have difficulty adjusting to the changes that naturally arose from leaving the household. Describing how it could take her sister significant time to prepare for trips, Phoebe lamented that, “It wastes a lot of time that we could be doing something else.” The behavioral and physical needs of siblings often required strategic planning and preparation for families, even for seemingly routine trips.
Away from the structure and routine of home, participants noted how the behavior of their younger sibling could confound whole family outings in public. While younger siblings could demonstrate appropriate behavior early in a trip, often their behavior deteriorated as they became more tired. For families, this could make longer trips with the younger sibling either especially difficult or completely implausible. It was apparent that these difficulties in going out in public could be disappointing for older siblings. This was especially noticeable when these challenges arose during activities that participants had been looking forward to. Participants shared stories of their siblings knocking over items in stores, throwing tantrums in store aisles, and breaking items by the end of a long trip. While participants could find these situations frustrating, they also appeared to be considerate of how their younger siblings might have been feeling. I was impressed by the level of insight, and empathy, Rachel had for her younger sister when she described a shopping trip in her daily check-in journal:

Sometimes as the older sibling, it is hard to go shopping with two younger sisters. Madeline is especially hard sometimes when she is tired. Today, Madeline got upset a few times while we were at the store, when she was nervous. It was a bit of extra stress at times. However, when we were at home, Madeline was very kind and sweet to me (she hugged me at unexpected times). And we played for a bit together…Madeline tends to have a lot of anxiety when we go shopping, or when the routine changes.

The needs of younger siblings limited the ability of families to engage in some types of communal activities as a whole unit. In her interview, Paige noted that her brother’s physical behaviors made eating in public together challenging. Because her brother often reached across the table for food and plates, she acknowledged that her entire family was rarely able to eat in public together. Similar results were found by Maul and Singer (2009), who found that these types of families often are not able to attend
public outings together. Because of the needs of the child with a disability, frequently one family member is required to stay at home with the child to care for him or her (Maul & Singer, 2009). In some cases, the needs of a child with a disability may cause families to adapt a pattern of withdrawing from public interactions and isolating from others (Gray, 1994).

Taken together, these types of difficulties posed threats to the cohesiveness of each family. Participants noted that these types of disruptions still occurred, but also described ways that their family had adjusted to these sources of risk. As Rachel worded it, her family had, “learned how to fit her needs and all of our needs too.” Between participants, each noted specific ways that their families had ensured that the needs of each family member, and not just those of the younger sibling, could be met.

Flexibility was an important characteristic of each family. As noted by Walsh (2003), families who are flexible can proactively confront stressors, often through fluid reorganization of assets, and by making changes when necessary. Participants described the ways that their families worked together to meet the needs of the younger siblings. Each participant’s narrative underscored that caring for the younger sibling was a responsibility of the entire family, with each member providing assistance when needed. Distribution of responsibilities between family members created time for individuals to engage in other activities. Older siblings appeared to support their families by helping to care for and supervise their younger siblings, allowing their parents to complete other tasks such as preparing dinner and attend to their other children. Conversely, parents and other family members also assumed responsibilities so that older siblings could have time to themselves.
This fluid pattern of family members “taking turns” providing care for the younger sibling was evident in the ways that families modified and adjusted their public routines. While out with their family in public, participants often noted alternating who would supervise the younger sibling. I noticed that this was a process of give-and-take for older siblings, who sometimes had to make sacrifices and set aside their own self-interests. In her interview, Rachel described a process that her family had adopted on a recent trip to ensure that everyone would have fun:

Well last year at Atlantis…my dad and his girlfriend and me went on this slide together while Sally stayed in the baby pool with Madeline. And then they did the same thing, like they switched out, so that felt pretty good because then I could still do some of the things that I want to.

Participants also described benefiting from their families establishing new routines, which seemed to anchor the family as a unit. Even though parents appeared to spend significant time tending to the needs of the younger sibling, they also found time to spend alone with participants. Most participants (Paige, Phoebe, Rachel, and Carrie) noted that this time alone with parents was important. Often, older siblings described spending this time engaging in preferred recreational activities that would not have been possible if their younger sibling was present. For example, Paige mentioned that her family had created a new routine where she and her parents go out to dinner together once a month. Similarly, Paige and Phoebe also noted enjoying having the opportunity to shop alone with their mothers. As Dodd, Zabriskie, Widmer, and Eggett (2009) found, engaging in leisure activities are significantly associated with improved family functioning for families of children with disabilities. As such, it appears that older siblings directly benefited from the attention of their parents, and that the identity of the whole family was strengthened by this time together.
To create this time, families often relied on resources within their community that could provide short-term supervision for the younger sibling. Noting how her younger sister often preferred the familiarity of home, Phoebe mentioned how her family utilized a trusted babysitter so that she and her mother could travel into town together. Carrie and Paige also noted that their families had found a non-profit organization that specialized in providing care for children with disabilities. Carrie, whose family relocated to utilize this organization, described the reprieve her family experienced when they discovered it. She acknowledged that, “It was like a big relief when we knew that would work out for him and stuff. Because it gave us time to go out and I don’t know, just get stuff done.”

As adolescents, it also seemed developmentally important for participants to have time to themselves and to develop their own unique identities. For Rachel, she noted the importance of having time to herself at school. Also acknowledging the importance of her life at school, Carrie noted the “conscious effort” her mother had made to keep her on course in school. Maintaining friendships, and still having time to spend with friends, also appeared to be significant for older siblings. Beyond the enjoyment that came from spending time together, some participants (Paige, Edward, and Rachel) specifically shared that they had been supported by their friends. Previous research has suggested that adolescent siblings of children with disabilities typically report receiving support from at least one to two different friends (Opperman & Allant, 2003). This peer support may be especially important for adolescent as they begin to form identities outside their families (Opperman & Allant, 2003). For participants, having time with their friends and time alone at school appeared to meet their needs to form and maintain an identity outside of their roles and responsibilities within the family (Grant, Ramcharan, & Flynn, 2007).
Of all the narratives, Carrie’s provided the most striking example of a family making structural and organizational changes to meet the needs of each family member. Because her brother’s health required substantial attention at birth, often one parent would spend time with her while the other would spend time with Luke in the hospital. As her brother grew up, Carrie also mentioned that her family relied on community organizations and in-home care to provide her and her mother with time together. Unfortunately, her family experienced a cascade of stressors that prompted them to make more drastic changes. As Luke’s needs became more pronounced and other members of her family faced individual concerns, Carrie’s family made the difficult decision to provide foster care for Luke during most weeks. While acknowledging how tough this decision had been for her family, Carrie noted that her family was “not as tired and burnt out” anymore. She also believed that Luke’s new foster family was in a better position to provide regular care for him.

The importance of maintaining, adjusting, and establishing routines appears especially important for families that have a child with a disability. Routines can help families of children with a disability maintain an overall sense of normality, and can ensure that the needs of each individual family members are met (Breitkruz, Wunderli, Savage, & McConnell, 2014). In fact, Grant et al. (2007) suggested that routines may be related to a sense of control over the stressors that families who have children with disabilities face. For each older sibling, established routines also appeared to provide a sense of normalcy while also solidifying the cohesiveness of the entire family unit.
Throughout their childhoods and into adolescence, each older sibling arrived at an individual conceptualization of what it was like to be the older sibling to a child with a disability. Participants described feeling predominantly confused and worried at first, but within this context their perceptions included a variety of beliefs and values. To some degree, these perceptions were uniquely colored by the relationship shared between siblings, although I also noticed similarities in their views. In fact, the perceptions of each participant contained many common elements.

Acknowledgement appeared to be a central component of the way that participants perceived their process of adapting to having a sibling with a disability. As I read through their interviews, this acknowledgment seemed to be a common sentiment among older siblings. At some level, each participant acknowledged that being the older sibling to a child with a disability was often “harder.” Paige was forthright in her assessment, acknowledging that “it’s definitely harder” having a younger sibling with a disability. At times, it seemed difficult for participants to discuss their own needs or the ways that they had personally been impacted by having a sibling with a disability. This seemed especially evident for Phoebe, who early in her interview tended to illustrate her experiences using optimistic brushstrokes. However, the challenges and sources of risk that each participant faced could be traced through their narratives. Their accounts indicated that they experienced hardships within their sibling relationship, while their families had also experienced unexpected difficulties because of the needs of the sibling. Acknowledgement also extended to the needs of the younger siblings and to identifying the limitations associated with their siblings’ disabilities.
Related to acknowledging these difficulties and limitations, the narratives of participants sometimes contained a sense of bereavement. Participants often appeared to have had mourned, or were still mourning, some of the realities that came with having a sibling with a disability. Sometimes, this sadness appeared related to seemingly lost opportunities. For Rachel, she still seemed to be processing the reality that family trips requiring extensive physical activity were unlikely because of her sister’s low muscle tone. She described how a family trip to Disneyland would be difficult because of how much walking it would require. Participants also lamented some of the challenges they faced in their relationship with their sibling. Edward described feeling “sad” that there were certain things he could not do with his brother or when his brother was home. Each participant appeared to have experienced sorrow, or a longing that things could be easier, related to some aspects of their current circumstances.

Despite their hardships, many participants seemed to have arrived at a state of acceptance. Frequently, participants used the word “different” to describe their experiences having a sibling with a disability. When asked what she would like others to know about her experience, Carrie noted that the experience of having a sibling with a disability will, “be different than…anyone else who has a normal sibling.” Similarly, Phoebe related that “it’s just really different having a sister with a disability.” I viewed this acceptance as an active state, with participants understanding that they would sometimes have to make sacrifices and accommodations for their younger sibling. In her interview, Rachel described accepting the fact she would sometimes have to care for her sister so that her family could do other things. She noted that “sometimes I don’t get to do things” that her other sister did when she had to supervise Madeline. While participants
seemed to mourn some aspects of their circumstances, they also appeared to have accepted many of these differences. Coming to terms with their life circumstances appears to be a common element for many families of children with disabilities. Families of children with disabilities can come to accept their child’s disability, while also accepting the challenges associated with the disability (King, Baxter, Rosenbaum, Zwaigenbaum, & Bates, 2009).

Participants also perceived that there were elements of their sibling relationship that were akin to many sibling relationships. This appeared especially true for Paige and Phoebe, who were quick to identify the similarities to typical sibling relationships. They noted that their fights and arguments were all part of any sibling relationship. I also noticed that participants did not describe their siblings by their disabilities, or solely by what made them different. Rather, they seemed more apt to describe their sibling based on qualities of their personality (e.g., stubborn, playful). They seemed to both accept what was different while also bringing forth what was typical.

Beyond acknowledgment and acceptance, participants also appeared to embrace many aspects of their experience. They seemed to perceive that being the sibling to a child with special needs could at many times be a wondrous, remarkable experience. I sensed that older siblings often had difficulty pinpointing exactly what it was that made their sibling so dear to them. “He’s amazing.” Edward said about his brother Tim. “It’s hard to describe him simply.” Participants appeared to view their siblings as *sui generis* individuals, special and unlike anybody else. Similarly, participants also appeared to embrace that being the sibling with a child could be a rewarding experience. Describing what it is like to having a sibling with a disability, Phoebe shared that, “It’s fun to have,
like, that experience.” She described a process of learning to love her sister’s disability, which allowed her to love her sister at a greater depth. Although it could be harder and much different from the typical sibling relationship, each participant seemed to indicate that it could also be special.

With embrace came a sense of hope in the narratives of participants. Edward, Phoebe, and Rachel all described feeling hope for the future of their younger sibling. Rachel described feeling more hopeful about her sister’s ability to make friends and learn at school, and Phoebe began to imagine a future where her sister could live independently. Even Carrie, whose family was experiencing so many challenges and changes, appeared to have hope for the future of her family. Although a part of her wondered what the future would hold for her and her parents, she perceived that her family had made adjustments so that each individual’s needs would be met.

Embracing the sibling, and his or her disability, was evident when participants mentioned who their friends were and what they liked about them. In a previous qualitative study of siblings of children with disabilities, Petalas, Hastings, Nash, Dowey, and Reilly (2009) reported that siblings of children with disabilities often feel embarrassed by the needs of their siblings. Because of this, they may be hesitant to have their friends interact with their siblings (Petals et al., 2009). I sensed this might have been initially true for Rachel, who described that early on she “didn’t want to tell anyone” that her younger sister had a disability. However, in general, participants expressed a strong desire for their friends to know their siblings. Describing the way her friends related to Ray, Paige stated that, “a lot of my friends get it, and a lot of my friends like my brother.”
Edward, who had grown up watching friends of his older siblings interact with Tim, also expressed his desire for his friends to forge a similar connection:

And just how, you know, and I’ve never really had that. Not even in my home school group back in Oregon. It was mainly my siblings’ friends who went in the playroom and he, he had a really good relationship with them. And I’m, like, it’s kind of like a really nice treat. Or like something really exciting that you love and you want to share with the world kind of thing.

Participants often had difficulty answering me when I asked what meaning they had derived from their experiences. When I later reflected on why this might be, I suspected that the question may have been too abstract to easily be answered. I also wondered if meaning, and creating meaning, were thoughts that participants had actively contemplated. Instead, the meaning participants ascribed to their experiences appeared to be largely influenced by the larger worldviews and beliefs of their families. Reflecting this familial influence, I noticed that participants often used the word “we” when describing what they had learned from having a family member with a disability. In fact, the meaning participants ascribed had appeared to become a part of the fabric for each family.

Patterson and Garwick (1994) identified that families can derive meaning from hardships by attaching specific meanings both to the stressors they face and the identity of their families. Similarly, part of the identity of each family appeared to encapsulate caring for the needs of the younger sibling. From this identity, participants appeared to find meaning in helping and supporting their younger siblings. Their narratives suggested that their families had found purpose, and calling, in understanding and providing care for the younger sibling. Rachel shared that her family had learned that, “it’s going to be a lot harder sometimes, but we, since we’re used to it, it’s not that bad. But we know that
when we she has her hard days we’re there to help her.” As Bayat (2007) found, conceptualizations of family meaning often change when a child with a disability enters into the family system. Often, the emphasis on what is important can change for these families (Bayat, 2007). For participants’ families, it appeared that their meanings may have also shifted as they attached importance to providing for the sibling with a disability.

In addition to this, families can derive meaning from connecting these perceptions to their larger worldviews and belief systems (Patterson & Garwick, 1994). The meaning Edward derived from having a younger brother with a disability was also shaped by the spiritual belief system of his family. As previous research by Tarakeshwar & Pargmanet (2001) demonstrated, spirituality can help families derive hope as they adapt to stressors associated with having a child with a disability. Spiritual beliefs can benefit families of children with disabilities by helping them conceptualize and frame the challenges they face (Poston & Turnbull, 2004). For Edward, belief in a higher power provided him with a sense that his brother was “sent” to his family for a particular purpose. He shared the belief that he was called to help his younger brother, and that his younger brother had been sent to help his family. His faith also provided Edward with a sense of hope and peace when trying circumstances arose. He mentioned his steadfast hope for a future day when his family would be able to see Edward’s “personality to the fullest.”
“I Feel Like He’s Brought Us Closer Together”: Personal Growth and Perceived Benefits

While participants acknowledged facing challenges, they also perceived that they had uniquely benefited from having a younger sibling with a disability. In fact, I frequently sensed that it was natural for older siblings to identify the rewarding, positive aspects related to having a sibling with a disability. Potential benefits that older siblings identified were related to their own personal growth and development, a greater understanding and appreciation of individuals who have disabilities, unique experiences of joy and entertainment within the sibling relationship, and strengthened family bonds.

Participants described having personally grown through their relationship with their younger sibling. These gains in personal development often appeared attributable to the roles and responsibilities that participants assumed in their sibling relationships. For Edward, he perceived that he had learned how to provide for others through his relationship with Tim. He noted that, “I’ve learned kind of how to take care of someone. At least to a level… I’ve had to help around with feeding him, and just hanging out with him and stuff.” Similarly, each participant described a process of finding ways to help their families meet the needs of their younger sibling. Each appeared to have learned about caring for others through the responsibilities that they had taken on, and to have developed an important role within their families.

Participants also perceived that they had developed patience through their interactions with their siblings. In her interview, Carrie identified the contradictory nature of this accrued patience; the frequent impatience of the younger sibling often necessitated participants to practice considerable forbearance. I noticed that patience and perseverance were integral to proactively solving conflicts with their sibling. Sometimes, participants
admitted that their patience waned when their siblings were stubborn. When feeling frustrated, Rachel, Edward, and Phoebe each mentioned the importance of taking a break. Rachel shared that when she argues with her sister, she needed to remind herself that Madeline can have a, “hard time with the little stuff.” Participants also described that helping their siblings with daily tasks, such as homework, often required patience. Because of the caregiving roles they assume, siblings of children with disabilities may display heightened levels of maturity and responsibility than siblings of typically developing peers (Cuskelly & Gunn, 2003; Hastings, 2002). Similarly, Phoebe viewed that she had gained maturity through her relationship with Phoebe. She shared that, “it’s given me so much patience…I feel like I’m a lot more mature than some people my age because of it.” Their patience seemed related to an individual efficacy that problems could be solved, and persistence in actively addressing challenges when they arose (Burton & Parks, 1994; Rivers & Stoneman, 2003).

Another benefit that participants noted was having gained an increased understanding of other individuals with disabilities. Related to this, both Paige and Rachel shared that they had learned not to judge others with disabilities. Rachel noticed that her classmates would sometimes look down on their peers that had special needs, but she was resolute in choosing to “treat them the same as everyone else. Because I know with Madeline, that I don’t think she likes being treated differently than anyone.” Because she believed that others had judged Ray in the past, Paige had learned not to do this herself: “I’ve just learned this over time…you can’t judge people because you don’t know their past. You don’t know what they’ve been through.” To understand others,
participants noted needing to extend their view beyond the needs of others to truly embrace who they were as individuals.

It seemed that this increased understanding helped foster compassion for other individuals with disabilities. Carrie, Paige, and Rachel each specifically mentioned to me students at their schools who had disabilities. Through the insight gained from their own younger sibling, they perceived that could better relate to and interact with these particular classmates. Previous research by Mulroy et al. (2008) also suggested that these types of siblings might gain a greater compassion for individuals with disabilities through their own sibling relationship. In their study of parent perceptions, parents commonly perceived that their typically developing children had gained increased tolerance and understanding because of having a sibling with a disability (Mulroy et al., 2008).

For Carrie and Phoebe, this tolerance and understanding had flourished into an interest in working with individuals with disabilities. They had voluntarily taken the additional step of serving at local agencies that provided services to individuals with intellectual disabilities. Carrie’s acknowledged that her interest in working with individuals with special needs was rooted in the special relationship that she had forged with her younger brother. She shared that her and her brother’s personal story had allowed her to meaningfully connect with individuals who have disabilities. Phoebe also mentioned that she felt especially equipped to work effectively alongside others with significant needs. She identified that she was able to use many of the strategies she used with her sister Ruby when she volunteers. For some siblings of children with disabilities, their passion for working with individuals that have disabilities may eventually lead to career choices in special education or related fields, as many individuals who choose
these careers cite their experiences working alongside individuals with disabilities (Marks, Maston, & Barraza, 2005).

Participants also described that they enjoyed many aspects of their relationship with their sibling. In fact, the opportunity to share in the exchanges and interactions alongside their sibling appeared to be particularly valuable for participants. They described that their younger siblings had contributed something unique and precious to the culture of their family. Most frequently, participants cited the fun and entertainment that their siblings often provided through their exceptional senses of humor. Consistent with the findings of Petalas and colleagues (2009), participants embraced many of the distinctive characteristics and tendencies of their younger siblings. Older siblings shared cherished memories of their younger siblings putting on extravagant shows for them, telling them interesting stories, and recording humorous personal videos of themselves talking into the camera. Paige noted that even dull, routine activities could be brightened by her brother’s gregarious personality. Carrie shared that it’s, “kind of fun how every day’s just, like, different because you never know what’s going to happen!” Participants enjoyed interacting with their younger siblings and appreciated the ways that they vibrantly contributed to the essence of their families.

A final benefit that participants described was in strengthened bonds within their families. Because of the significant needs that children with disabilities often have, their families are required to work together to successfully address these needs. Although this can create strain and tension within the family, some families actually perceive that these challenges can bring them closer together (Bayat, 2007; Maul & Singer, 2009). Similarly, the narratives of participants suggested that families had been strengthened and had
united around the sibling with significant needs. Reflecting this, participants often described their adaptation in terms of how their families had gone through this process collectively. Carrie perceived that, “In a way we’ve all gotten strong, or like we’ve all bonded. But like we’ve also gotten stronger, and that was like a big hurdle…but we got through it together and now we’re here.” Through the challenges they faced, Carrie specifically mentioned how the bond between her and her mother had been fortified. Edward similarly perceived that he and his other siblings that are close in age became closer to each other since Tim was born. He described how his entire family’s faith had been tested and refined because of the challenges that his family had endured. For each family, it seemed as if their fortitude had been tested and refined through the challenges that they had faced.

**Implications and Recommendations**

The focus of this study was to understand resilience processes in older siblings of children with disabilities. The narratives of participants provided details about how this pattern of positive adaptation can unfold for older siblings across their childhood and into adolescence. Their ability to adapt to the stressors associated with having a sibling with a disability were influenced by the specific stressors they faced, the resources they utilized, and the meaning that participants ascribed to their circumstances. An understanding of these factors may provide guidance on supports for these individuals that can promote resilience processes for both the younger and older siblings, as well as their families.

The results of this study indicate the importance of families in providing a context for sibling resilience processes to occur. Families, and specifically parents, engaged in a variety of practices to promote positive adaption for their children. One way that they can
help their children is by being cognizant of the sources of stress for older siblings. An area in which older siblings encountered stress was within the context of their sibling relationship. Specifically, they encountered stress related to the behaviors of the younger sibling and because of the roles that they assumed in helping provide care for their brother or sister. In addition, they also encountered stress related to disruptions to their daily routines and family activities. Based on this, parents might try to minimize the stress their children experience by ensuring that older siblings do not assume too many responsibilities or roles within the sibling relationship. As findings by Cate and Loots (2000) indicated, open conversations between parents and siblings of children with disabilities can help siblings feel supported. Parents can benefit these siblings by encouraging them to candidly discuss the challenges they face, while also showing appreciation for the contributions that siblings make to their families (Cate & Loots, 2000). As participants in this study also indicated, parents can also help educate siblings about the nature of the disability and guide them in their interactions with their siblings.

Additionally, in this study parents met the individual needs of older siblings by making specific organizational changes to the structure of the family. One type of organizational change that appears to benefit families of children with disabilities is to establish, or re-establish, family routines. Leisure family routines are associated with many positive outcomes for these families including increased family cohesion, and strengthened bonds between family members (Dodd et al., 2009; Giallo & Gavidia-Payne, 2006; Spagnola & Fiese, 2007). As Grant and colleagues (2007) recognized, it is also important for parents to protect the individual identities of each family member. In her interview, Rachel mentioned the importance of having time with her friends and
having her own identity at school. Parents might also promote the individual identities of their children by encouraging them to be involved in extracurricular activities and clubs, and by ensuring that they have time to spend with their friends.

Participants also frequently noted the importance of disability-related resources that were available within their communities. However, families can often experience stress in navigating and locating services that might be available for their child (Resch et al., 2010). As previous research has suggested, both formal and informal forms of social support can be important in reducing the stress that families of children with disabilities encounter (Breitkreuz et al., 2014; Boyd, 2002). Through their interactions with these families, professionals like school psychologists can support families by helping them to locate and forge meaningful connections with resources in the community (National Association of School Psychologists, 2010). Because both parents and siblings in these types of families may be at greater risk for mental health concerns (Rossiter & Sharpe, 2001; Singer, 2006) school psychologists might also provide outside referrals for individual family members when appropriate.

While professionals such as school psychologists may be uniquely situated to work directly with these siblings, it appears that the roles these school professionals take with this population of students are often underdeveloped. Supporting this notion, participants in this study noted no specific supports at school that had helped them adapt to having a sibling with a disability. The results of this study suggest that siblings of children with disabilities may benefit from receiving individualized or group support from mental health professionals at school. As participants in this study experienced feelings of confusion and worry when they first learned about their siblings’ disabilities,
this support may be especially important from an early stage. While a few services have been developed to provide support for these siblings, most of the time these programs have been offered to siblings outside of school (Evans, Jones, & Mansel, 2001; Naylor & Prescott, 2004). To improve the accessibility of these resources, school practitioners might consider offering similar types of support groups that siblings can readily access within their school schedule. In a study conducted by McLinden, Miller, and Deprey (1991), siblings who attended a support group run by school psychologists reported feeling more social support from their peers after attending group meetings. School psychologists consider running similar support groups, such as Sibshops, which promote educating siblings, building peer support, and providing an avenue for siblings to discuss their experiences (Conway & Meyer, 2008; D’Arcy, Flynn, McCarthy, O’Connor, & Tierney, 2005)

Limitations

While the results of this study can be used to guide our understanding of resilience processes in older siblings of children with disabilities, there are several limitations to this study that warrant attention. The decision to use a qualitative methodology in this study provided both advantages and disadvantages. While qualitative information can provide a wealth of information about the phenomenon being studied, its specificity limits the transferability of the findings. All participants currently lived in midsized towns and reported currently utilizing at least one disability-related service in the community. Additionally, all participants were identified as Caucasian by their parents in the demographic questionnaires that were completed. As such, participants in this study represent a very small section of the strata of the population.
A number of different methods were utilized in this study, and semi-structured interviews were the primary source of data collection. It is possible that the response of participants during these interviews may have been influenced by the presence of the interviewer. While each participant appeared candid in sharing their difficulties and challenges, it is possible that participants may have been more likely to positively appraise aspects of their experiences because of my outside influence. Additionally, it must be noted that I shared a personal acquaintance with three of the participating families before beginning in this study. This familiarity not only may have had an unforeseen influence on participants, but also on my interpretation of their accounts.

It should also be noted that each of the five families who were approached in this study agreed to participate in this study, and made up the entire sampling pool. However, there may be differences in the accounts of the older siblings who did participate when compared to potential older siblings who theoretically would have declined to participate. It is possible that the older siblings participating in this study engaged in patterns of positive adaptation that had reduced the stress and risk that they experienced; because of this, they may have been more willing to speak openly about their experiences than other siblings who may have potentially been encountering significantly more stress. As such, the narratives detailed in this study may not be representative of the experiences and perspectives of some siblings who may feel less comfortable to describe their circumstances.

Finally, the pre-established criteria that participants were required to meet to participate in this study were somewhat broad. While each participant was required to be the older sibling to a child with an intellectual disability, there were also variances
between each participating family. The specific intellectual disabilities of the younger siblings varied between families, with some younger siblings having one identified disability and others having multiple disabilities. As such, these differences in disabilities appeared to contribute to unique challenges and stressors between each participant. For example, siblings of children with autism may encounter more relational problems with their siblings when compared to siblings of children with Down syndrome (Hodapp & Urbano, 2007; Kaminsky and Dewey, 2001). In addition, there were other differences between participating families including the marital status of the parents and the size of the immediate family (i.e., number of other siblings). While I have attempted to highlight both the similarities and differences in the experiences of each sibling, it is possible that the influence of some of these differences may have been masked by the decision to group families with these differing characteristics together in this study.

**Future Research**

In describing post-intentional phenomenological research, Mark Vagle (2014) writes that the phenomenon should be explored in its “multiple, partial, and varied contexts” (p.121). Future studies can continue to strengthen an understanding of older siblings of children with disabilities by studying siblings from other “varied” types of contexts. Related to this, there is a paucity of research related to the unique experiences of families of children with disabilities from diverse backgrounds. Families from diverse backgrounds may hold different beliefs about disabilities, face additional barriers to accessing services, and engage in different types of resilience processes (Harry, 2002). For example, Latino families may experience pronounced difficulties in obtaining accurate information about their child’s disability and in accessing needed health
supports (Bailey et al., 1999; Cohen, 2013). Additionally, these families may be more likely to rely on familial support to help meet the needs of the child with a disability (Bailey et al., 1999; Cohen, 2013). A more recent study by John and Roblyer (2017) focused on the perceptions of mothers of children with disabilities living in India. Interestingly, parents in this study frequently noted the importance of their child’s school in providing them with information about the disability and emotional support (John & Roblyer, 2017). While studies such as these have clarified the unique experiences of these families, further scholarship is needed to understand specifically how children from diverse backgrounds adapt to having a sibling with a disability.

In their interviews, Phoebe, Rachel, and Edward alluded to what the future might hold for their siblings. In her interview, Phoebe emphasized the importance of setting high standards in case Ruby “ever wanted to live on her own.” In this study, the phenomenon of being an older sibling to a child with a disability was examined through childhood and parts of adolescence. Future research should continue to focus on how these older siblings continue to positively adapt throughout their adulthood. Recent estimates suggest that around 60 percent of individuals with disabilities continue to live in their parents’ homes during their adulthood (Hodapp & Urbano, 2007). Siblings appear to often take on additional caregiving roles in their adulthood, especially those siblings who are female or do not have additional brothers or sisters in their families to help support them (Burke, Taylor, Urbano, & Hodapp, 2012; Saxena, 2015). These changes in roles appear to contribute to additional barriers to adaptation for older siblings in adulthood. Additional studies are needed to understand the nature of risks, protective
processes, and adaptation for these siblings across different periods of their life (Meadan, Stoner, & Angell, 2010).

Finally, additional qualitative and quantitative studies in this area may provide us with additional insight about how older siblings adjust to having a sibling with a disability. While many studies of siblings have featured combinations of older and younger siblings in their participant pool, additional studies are needed exploring the similarities and differences between their experiences. While siblings in this study perceived that they had benefited in some ways from being the older sibling to a child with a disability, in general there is still a lack of research investigating the positive aspects of this relationship. Future studies may contribute to our understanding of this by directly comparing the ways that the experiences of siblings of children with disabilities are different and similar to those of siblings of typically developing children.

**Post-Reflexivity Statement**

While writing this fifth chapter, I frequently found myself reflecting to my early interest in researching older siblings of children with disabilities. Admittedly, I began this undertaking with many preconceived notions about what I would research find. My previous experience working alongside families of children with disabilities instilled in me a deep respect and admiration for these families. I was and continue to be amazed by these families and by the ways that many of these families are able to positively adapt to the significant stressors that they encounter. Still, my understanding of older siblings of children with disabilities and their families has changed throughout this study. As I reflect back about my initial beliefs and assumptions, I realize the process of loosening
these thoughts has been a continual progression as the phenomenon became more apparent.

As Mark Vagle (2014) writes, in post-intentional phenomenological methodologies the researcher is reflexive to uncovering “underlying, shifting, changing knowledges” (p.132). As the personal narratives of participants emerged, I noticed gradual shifts in my own thinking. Hearing about the stressors that older siblings had experienced was a remarkable and sometimes poignant experience for both the participants and me. Each of their stories resonated with me, and I found myself amazed by both the stressors they faced and the ways they described confronting these. While I have read significant amounts of research about the stressors that siblings of children with disabilities face, hearing these themes relayed through personal stories was especially impactful. These stories of adversity added significantly to my appreciation of how significant the challenges are for these siblings. After these interviews, I often compared these siblings to myself at that age; I wondered to myself how I would I have personally responded to these types of stressors as an adolescent.

My greater insight into the significance of these risk factors also shifted my understanding of how these older siblings were able to adapt to the challenges they faced. Their narratives clearly demonstrated that resilience is a pattern of adaptation across development, shaped by each individual environment and each specific context. In many ways, each participant was in a constant process of adapting to having a younger sibling with a disability. That process of adaptation for each older sibling will continue beyond this study. Similarly, my personal understanding of these older siblings will continue to expand as I work alongside these families in my professional practice.
Conclusion

The personal narratives of participants provided insight into their perceptions about having a younger sibling with a disability. Participants encountered stressors from an early age that challenged their ability to positively adapt to having a family member with a disability. Their stories were sometimes punctuated with worries, confusion, and frustrations. The needs of the younger sibling required families to make changes, and often necessitated younger siblings making difficult personal sacrifices. They experienced unique challenges that are not typically encountered by most individuals in their childhood. Still, the accounts of siblings also revealed an ability to be resilient and to proactively confront the stressors that they faced. Their experiences testified to a capability to persevere, be steadfast, and to endure through the challenges that they faced. In fact, participants often appeared to thrive and derive benefit from being the sister or brother to an individual with a disability.

The accounts that participants shared allows us a glimpse into their worlds and helps us to better understand what it is like for these individuals to be the older sibling to a child with a disability. However, their journeys alongside their younger siblings are still in their infancy; positive adaptation for these siblings will be a lifelong process. Throughout their lives, the essence of what it is like to be the older sibling to a child with a disability will continue to emerge and shape the actions, decisions, and perspectives of these youth. In the future, participants will conceivably encounter new stressors and strains in their sibling relationship. As both they and their younger sibling grow older, they may take on new roles and assume new responsibilities to provide for their younger siblings. While it is impossible to predict the future of these older siblings, what is clear
is that these siblings have formed a foundation of resilience in their childhood to build upon. It is my hope that these older siblings will draw from this deep well of support and individual strength as they and their younger siblings continue to journey through life together.
REFERENCES


Colorado Department of Education (2013). Guidelines for the determination of eligibility for a child with an intellectual disability or multiple disabilities. Retrieved from https://www.cde.state.co.us/cdesped/guideliensfordeterminationeligibility_id_md


developmental disability. *Journal of Intellectual & Developmental
Disability, 27*(3), 149-160. doi:10.1080/1366825021000008657

Havighurst, R. J. (1980). Social and developmental psychology: Trends influencing the

Retrieved from https://www.researchgate.net/profile/Laraine_Glidden/publication

syndrome versus with autism: findings from a large-scale US survey. *Journal Of
Intellectual Disability Research, 51*(12), 1018-1029. doi:10.1111/j.1365-
2788.2007.00994.x

& J. M. Price (Eds.), *Vulnerability to psychopathology* (pp. 3-16). New York:
Guilford Press.

in urban India: An application of the stress and resilience framework. *Intellectual

doi:10.1023/A:1010664603039


Vagle, M. D. (2014). Crafting phenomenological research. Walnut Creek, California: Left Coast Press.


*the American Academy of Child and Adolescent Psychiatry, 37*, 1317-1325. doi:10.1097/00000458-199812000-00016
APPENDIX A

INSTITUTIONAL REVIEW BOARD APPROVAL FORM
DATE: August 16, 2016

TO: Brad Reimers, B.S.

FROM: University of Northern Colorado (UNCO) IRB

PROJECT TITLE: [907792-1] It's Different: Perceptions of Risk and Resilience in Older Siblings of Children with Disabilities

SUBMISSION TYPE: New Project

ACTION: APPROVAL/VERIFICATION OF EXEMPT STATUS

DECISION DATE: August 16, 2016

EXPIRATION DATE: August 16, 2020

Thank you for your submission of New Project materials for this project. The University of Northern Colorado (UNCO) IRB approves this project and verifies its status as EXEMPT according to federal IRB regulations.

Hello Brad,

As you know we consulted extensively prior to your submission so I am only passing on the first reviewer's suggestions. It is up to you and Dr. Hess if you wish to take them.

Best,

Maria

First Reviewer Comments

Brad,

Thank you for the well-written and thoughtful proposal. I only have a few minor suggestions. I won't need to see these after the changes are made, so it will be ready for the second reviewer once completed.

In discussing your dissertation (e.g., your recruitment letter and what gets read at the beginning of the interview), I would just use the word "research" or "study" as most won't know what a dissertation entails (especially the adolescents you are working with). Secondly, in the parental consent form, make sure to remain consistent with the language of you (or your child) since you are using this for the siblings that are over 18 and for parental consent (see example below). Best of luck with your research.

Regards,

Michael Phillips, Ph.D.
Examples

Recruitment Letter: For my dissertation, I am interested in learning more?

Parental Consent: These daily entries can take many different forms depending on what your child chooses.

We will retain a copy of this correspondence within our records for a duration of 4 years.

If you have any questions, please contact Sherry May at 970-351-1910 or Sherry.May@unco.edu. Please include your project title and reference number in all correspondence with this committee.

This letter has been electronically signed in accordance with all applicable regulations, and a copy is retained within University of Northern Colorado (UNCO) IRB's records.
APPENDIX B

RECRUITMENT LETTER
Dear interested participant and family,

Thank you for your interest in participating in this study. My name is Brad Reimers, and I am currently a doctoral student in the school psychology program at the University of Northern Colorado. For my dissertation, I am interested in learning more about the unique experiences that older siblings of children with disabilities have. To do this, I am seeking to work with older siblings of children with disabilities that are between the ages of 12 and 19 still residing in the same household as their family. In order to understand their experiences, I will meet with each participant twice in a location of their choosing. During the first meeting, I will explain the nature of my study and ask each participant to complete a daily journal for a week. After this, I will then conduct interviews with each sibling which should take about an hour to complete.

If your family is interested in participating in this study or has any questions, please feel free to contact me by email at reim2110@bears.unco.edu or by phone at 970-553-0214.

Thank you again for your consideration!

Sincerely,

Brad Reimers, B.S.

Doctoral Student, School Psychology
APPENDIX C

CHILD ASSENT FORM
Hello!

My name is Brad Reimers, and I am a student at the University of Northern Colorado. I do research on families of children with disabilities, and specifically older siblings of children with disabilities. Through my research, I am interested in learning more about what it is like to be an older sibling of a child with a disability. To do this, I would like to ask older brother/sisters such as you to share your experiences and stories with me. If you want to, you can be one of the older children that I talk with.

If you would like to talk with me, we will meet one more time after today. I am guessing that this meeting will last around one hour. During it I’ll be asking you about what it is like to be an older sibling to a child with a disability. I will ask you questions about what is challenging about your relationship with your sibling, and what you may enjoy about it. We will do this through one interview.

I will ask you to bring in five photos for our next meeting that show me what your relationship with your sibling looks like.

Also, I will ask you to check-in once a day for a week to help me understand what a week in your life looks like. You can use this check-in to describe the ways you spent time with your sibling that day and how you felt being around them. You can have fun with these check-ins and be creative in how you choose to do these!

Some of the things we discuss may be tough to talk about. If you ever feel uncomfortable about anything I ask, it is okay not to answer it. However, you may actually enjoy talking to me about your relationship with your sibling. Your parent(s) have said it’s alright for you to talk to me, but it’s your choice. If you do agree today but change your mind, you can stop at any time. Also, what you share with me will stay between us unless you choose to share it with your family. Do you have any questions about my research?
If you are interested in helping me with my research and talking about your relationship with your sibling, sign your name below and put today’s date next to it. Thanks so much!

________________________
Signature

________________________
Today’s Date
APPENDIX D

ADULT CONSENT FORM
CONSENT FORM FOR HUMAN PARTICIPANTS IN RESEARCH
UNIVERSITY OF NORTHERN COLORADO

Project Title: It’s Different: Perceptions of Risk and Resilience in Older Siblings of Children with Disabilities
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         Phone: 970-351-1636
         Email: robyn.hess@unco.edu

Thank you for the taking time to meet with me and to learn more about my research. Previous research has recognized that siblings of children with disabilities have unique experiences. They often face unique challenges in relating to their sibling and adjusting to changes in their families that arise. Although these challenges can be significant, research also indicates that many children are able to positively adapt to having a sibling with a disability. Not only are these siblings able to adapt, some are able to derive unique meaning and benefit from their relationship with their sibling. My research seeks to understand these unique circumstances by focusing on the specific perspectives of older siblings of children with disabilities.

If you agree to let your child participate in this study and if they also agree, I will ask them to do three specific things.

1. After our meeting today, I will find a date that works to meet with your child a second time. Before we meet again, I will ask your child to bring in five photos that they feel like represents their relationship with their sibling. These can be photos that they personally take, or images that already exist.

2. I will also ask your child to complete a check-in journal once a day per a week. In this journal your child will be asked to describe any events or interactions that they had with their sibling that day. These daily entries can take many different forms depending on what your child chooses.

Page 1 of 3_____
(Parent’s Initials here)
During our second meeting, I will collect these journal entries and discuss the photos they have brought in.

3. At this time, I will also conduct an interview with your child focusing on their perspectives of being an older sibling to a child with a disability. For example, I will ask both about what is challenging about being an older sibling to a child with a disability and what they like about it. I anticipate that this second meeting will last around 60 minutes in total.

I will be digitally recording each interview so that I can later transcribe it into a written document. After transcribing your child’s interview, I will compare it to other interviews to arrive at common themes of what it is like to be an older sibling to a child with a disability. All data received will be stored in a secure, locked location. To protect you and your child’s confidentiality, I will be asking your child to come up with a pseudonym used that will be used to identify them. All transcripts and journal entries will be de-identified. When writing up what I have found, I will use these pseudonyms to protect your family’s confidentiality. Once this study is complete, I will destroy all the interview recordings and photographs related to your child and this study. Only my research advisor, Dr. Robyn Hess, and I will have access to any documentation containing your actual identity. These consent documents will be kept in a locked file cabinet on campus for three years and then shredded.

The anticipated risks associated with this study are minimal. Because I will be asking your child about what is challenging about their relationship with their sibling, it is possible that they may experience some discomfort. If your child experiences these feelings and would like to discuss them more, please contact the University of Northern Colorado Psychological Services Clinic (970-351-1645) or the Colorado State University Center for Family and Couples Therapy (970-491-5991).

Possible indirect benefits for your child participating include having the opportunity to share their experiences and perspectives. To thank your child for participating, I will also provide them with a $20.00 Amazon gift card.

Participation is voluntary. You may decide not to allow your child to participate in this study and if (s)he begins participation you may still decide to stop and withdraw at any time. Your decision will be respected and will not result in loss of benefits to which you are otherwise entitled. Having read the above and having had an opportunity to ask any questions, please sign below if you would like to participate in this research. A copy of this form will be given to you to retain for future reference.

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(Parent’s Initials here)
If you have any concerns about your selection or treatment as a research participant, please contact Sherry May, IRB Administrator, Office of Sponsored Programs, 25 Kepner Hall, University of Northern Colorado Greeley, CO 80639; 970-351-1910.

______________________________________________________
Child’s Full Name (Please Print) ______________________

______________________________________________________
Child’s Birth Date (month/day/year) ______________________

______________________________________________________
Parent/Guardian’s signature ______________________

______________________________________________________
Date ______________________

______________________________________________________
Researcher’s Signature ______________________

______________________________________________________
Date ______________________

(Parent’s Initials here)
APPENDIX E

DEMOGRAPHICS QUESTIONNAIRE
PARENT DEMOGRAPHICS QUESTIONNAIRE

1. Name:

2. Ethnicity:

3. Place of residency:

4. Relationship status (Circle one): Married       Divorced       Widowed
   In a relationship       Single

5. Level of Education (Circle twice for you and partner, if applicable):
   Did not complete high school
   Vocational training
   Completed high school
   Completed some undergraduate
   Completed undergraduate
   Completed some graduate school
   Completed Master’s/Doctorate

6. Annual household income:
   Less than $24,999       $25,000-$49,999       $50,000-$99,999       $100,000 or more

7. Occupation (for you and partner, if applicable):

8. Immediate family members (Please list name and age):

9. Child’s diagnosis: ____________

10. How does this disability impact your child?
11. Have any of your other children received services from an Individualized Education Plan (IEP)? If so, please explain:

12. Does your family currently utilize disability-support services? If so, please describe the nature of these services and how frequently they are used:
DAILY CHECK-IN JOURNAL

I want to learn more about what it is like to be an older sibling to __________. For the next week, I would like for you to complete a daily check-in journal describing your interactions and experiences with your younger brother or sister that day. You can use these daily entries to describe your feelings, what you did with your sibling, or to share your perspective about what it is like to be the older sibling in your family. Although I have provided you a paper journal with space that you can write in, each check-in can take whatever form you would like. For example, you might choose to record a voice memo for one entry, write a digital note for another, or create a video message. If you would like, you do not need to use this paper journal. If you decide to use one of these other formats, I have provided a flash drive where you can save your entries. Please complete one entry each day for a week and bring these to our next meeting. Thanks!

DAY 1:
DAY 2:

DAY 3:
DAY 4:

DAY 5:
DAY 6:

DAY 7:
APPENDIX G
PHOTO ELICITATION INTERVIEW PROTOCOL
PHOTO ELICITATION INTERVIEW PROTOCOL

Participant’s name (pseudonym):

Date:

Place:

Interviewer:

Length of interview:

At the initial interview, read this statement:

To learn more about your experiences being the older sibling to a child with a disability, I would also like for you to bring in five photos describing your relationship with your sibling. These photos can take a variety of different forms. You might personally choose to take new photos, or you can use pre-existing photographs that you or somebody else have already taken. You may also choose to find images not personally related to you or your sibling but that you think describes your relationship. You can bring in physical copies of these photos, or use the flash drive I have provided you with to bring in digital versions. Please bring these five photos to our next meeting, where you will have an opportunity to share these with me. Thank you!

At the second meeting, read this statement to introduce the interview:

If you remember from the last time that we met, I asked you to bring in five photos that describe your relationship with your brother or sister with a disability. Now I’d like for you to share these photos with me, one at a time. You can show them to me in any order that you’d like. We’ll discuss each photo as you show them to me. Now please show me the first photo.

Potential questions and prompts that can be used for each photo:

1. Please describe this photo to me.
2. What is happening in this photo?
3. Why did you choose this photo?
4. Who is in this photo?
5. What would you like to tell me about this photo?
6. What does this photo mean to you?
Researcher notes about each photo (include detail about themes, feelings described, and content for each):

PHOTO 1:

PHOTO 2:

PHOTO 3:

PHOTO 4:

PHOTO 5:
APPENDIX H

SEMI-STRUCTURED INTERVIEW PROTOCOL
SEMI-STRUCTURED INTERVIEW PROTOCOL

Participant’s name (pseudonym):

Date:

Place:

Interviewer:

Length of interview:

At the beginning of each interview read this statement:

Now I am going to ask you more specific questions about what it is like to be the sibling to a child with a disability. In this interview I will refer to this individual either as your sibling or by their specific name. Please let me know if you need me to repeat any questions, or if anything seems unclear. Are you ready to begin? Alright, then let’s begin!

1. Describe your younger sibling to me.
   a. What does his or her disability look like? That is, how does it affect him or her?

2. What initial feelings did you have about having a brother or sister with a disability?

3. Describe your early relationship with ________(name of sibling).

4. Describe the nature of your current relationship with _________.

5. How has your family changed since _________ entered into your family?
6. Describe ways in which your family has helped you adjust to having a sibling with a disability.

7. Describe ways in which you help your family take care of __________.

8. What have your parents done to help you adjust to having a sibling with a disability?

9. What challenges do you currently face in relating to __________?

10. At school or in the community, what has helped you adjust to having a sibling with a disability?

11. What meaning do you and your family place on having a younger sibling with a disability?

12. When you and ________ have an issue, how do you personally handle these?

13. Describe what you have personally learned from living with a sibling with a disability.

14. What are the positives to living with a sibling with a disability?

15. What do you enjoy the most about living with __________?

16. What would you like others to know about what it is like being the older sibling to a child with special needs?