Sibling Relationship Quality and Future Planning among Siblings of Adolescents with Developmental Disabilities: A Mixed Methods Approach

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SIBLING RELATIONSHIP QUALITY AND FUTURE PLANNING AMONG SIBLINGS OF ADOLESCENTS WITH DEVELOPMENTAL DISABILITIES: A MIXED METHODS APPROACH

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This study involves secondary analysis of data from the Early Intervention Collaborative Study (EICS; Hauser-Cram, Warfield, Shonkoff, & Krauss, 2001), a longitudinal investigation of children with disabilities and their families. Presented is a mixed methods investigation of the relationship between future planning issues and sibling relationship quality when the teen with a disability (DD) was in adolescence (15 and 18 years old). First, future planning issues were examined contemporaneously with sibling relationship quality using hierarchical regression. Second, future planning issues from when the teen with DD was 15 years old were investigated in their relation to change in sibling relationship quality from ages 15 to 18 using lagged OLS regression. Third, qualitative content analysis was used to analyze sibling responses to a series of open-ended questions concerning the future at age 15 (1 question) and age 18 (4 questions). Siblings were asked “what have you learned by living with your brother or sister?” at both time points. In the first set of analyses, discussion of the teen’s needs with parents, teen functional skills, sibling gender match, and sibling expectation of future roles were found to significantly relate to sibling relationship cooperation when the teen was 18. Additionally, sibling birth order was related to sibling conflict at age 18. In the second set of analyses, sibling relationship closeness was found to decrease over adolescence and sibling pessimism at age 15 was found to negatively relate this decrease. Finally, in the results for the qualitative analysis, various themes in sibling responses are discussed. More specifically, patterns arose in the change of sibling responses: trends reflecting a decrease in sibling relationship closeness, trends reflecting increasing role asymmetry in the sibling relationship, and trends reflecting sibling development. Future research must further examine the sibling relationship by using a developmental perspective and by taking into account the dynamic nature of sibling roles. The findings support the design of family-based interventions that address future planning explicitly with siblings and parents. Finally, improving the current resources and support for siblings may potentially increase siblings' perception of sibling relationship quality in these sibling pairs.

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Chapter 1: Statement of the Problem

The bioecological model of child development asserts that development occurs in the context of the child's environment, which encompasses multiple mutually dependent levels. The most proximal context for a child's development is the family. Therefore, family is considered to exert the most immediate and direct influence on the child and represents a critical developmental factor (Bronfenbrenner, 1986). In addition, Family Systems Theory (Minuchin, 1988) emphasizes the importance of the dyadic relationships within the family system separately from each other, as well as the significance of studying transition points for families (Minuchin, 1988; Wachs, 2000).

Research investigating families of a child with a developmental disability ("DD") has overwhelmingly focused on relationships with the parents, although the sibling relationship has been of increasing interest (Seltzer, Greenberg, Orsmond, & Lounds, 2005). This is a critical shift, as the sibling relationship is considered to be the longest-lasting and most influential relationship an individual will have in his or her lifetime (Seligman & Darling, 1989). This relationship becomes especially important for individuals with DD, as they often rely on their siblings rather than peers for social support (Guralnick, 1997). When compared to typically developing sibling pairs, sibling pairs where one child has DD report more cooperation and positivity within their relationship, as well as lower levels of conflict, quarrelling and competition (Brody, Stoneman, Davis & Crapps, 1991; Kaminsky & Dewey, 2001; Rivers & Stoneman, 2003; Roeyers & Mycke, 1995). The sibling relationship has been found to have great value in terms of impacting emotional, cognitive, and social well-being outcomes for both the siblings and the individuals with DD (e.g., East & Rook, 1992; Stocker, Burwell, & Briggs, 2002).

An important aspect of sibling relationships in which one individual has DD is the role asymmetry that characterizes the relationship (Knott, Lewis, & Williams, 1995). The typically developing sibling often takes on manager, caregiver or teacher roles in this relationship (Stoneman, Brody, Davis, & Crapps, 1989). This dynamic can extend throughout his or her lifetime (Griffiths & Unger, 1994).

Additionally, the individuals with DD are living longer now than ever before, resulting in the need for families to look forward and plan for the future (Seltzer & Krauss, 1989). This is compounded by an aging population and a shift toward community care (Lefley & Hatfield, 1999). It has been found that most families look to siblings of the individual with DD to take over caregiving when the parents themselves are no longer able to maintain the same level of support they once were (Davys & Haigh, 2008). Indeed, it has been shown that siblings of individuals with DD may be socialized to expect a caregiving role as part of their future family responsibility (Begun, 1989; Grossman, 1972; Stoneman & Berman, 1993). If this is true, it is important to understand how future planning impacts the sibling relationship as siblings and their brothers or sisters with DD mature.

Focusing on adolescence would allow for examination of future planning aspects and how they may impact the quality of the sibling relationship during a period of potential change and stress. Until now, all of the research on future planning has looked strictly at siblings of adults with DD. Nothing is known about the very beginnings of this process. However, in the United States, legal guardianship should be established, if needed, by the time the teen with a disability is 18 years of age. This is when the teen legally reaches adulthood. At age 18, all persons are presumed to be competent, meaning that they are assumed to be responsible to make their own decisions regarding finances, health care, and all other important life decisions (Baum, Cohen, & Nussenbaum, 2009). Therefore, it is likely that future planning begins well before the individual with a disability is in adulthood.

The future planning process coincides with siblings feeling stress and anxiety around the teen's future and their role in that process (Harris & Glasberg, 2003). Furthermore, if families begin a legal guardianship process during the child with a disability's adolescence, it prompts the sibling's realization of the long-term implications of the teen's disability (Eisenberg, Baker, & Blacher, 1998). Many siblings expect that their level of caregiving and commitment to the child with a disability will increase in the future (Greenberg, Seltzer, Orsmond, & Krauss, 1999). Additionally, research has shown that, because parents are reluctant to include the typically developing sibling in the process of family planning, there is a discrepancy between what parents expect and believe about the future, and what the sibling is aware of (Davys, Mitchell, & Haigh, 2010).

Little is known regarding the effect the future planning process has on the sibling relationship. Some studies found that siblings who had more negative relationships with their brother or sister with DD were less likely to be expected by parents to take on future caregiving roles (Bigby, 1997; Griffiths & Unger, 1994). However, these studies did not take into account the sibling's perspective of the teen's future and his or her expected role in it. Given the importance that the sibling relationship can have on the cognitive, emotional and social well-being of the individual with DD, as well as the sibling, it is critical to examine how something so salient and malleable – the future planning process – impacts this relationship. Finally, it is important to understand this relationship over time, as it is not a static relationship, but a dynamic one. Since the future planning process occurs over time, the sibling relationship is likely to change, along with the experiences of the sibling, in relation to future planning issues. A much fuller understanding is needed in order to appropriately and effectively support siblings and families of children with disabilities in this process and in healthy family functioning.

For the purposes of this investigation, the term "teen" will be used to refer to the adolescent with a developmental disability while "sibling" will refer to his or her typically developing brother or sister.

Chapter 2: Literature Review

In this chapter I will present three theoretical models: bioecological systems theory (Bronfenbrenner, 1979; Bronfenbrenner & Morris, 2003), the developmental contextual model (Lerner, 1984; 1986; 1991), and family systems theory (Minuchin, 1988). These models will serve as the basis upon which this dissertation is based. Next, the literature on sibling relationships and future planning in families with children with developmental disabilities will be reviewed. Finally, the above-mentioned theories will be used to illustrate how future planning might impact the sibling relationship.

Theoretical Overview

Bioecological Theory. The bioecological model of child development (Bronfenbrenner, 1979; 1986; Bronfenbrenner & Morris, 2003) posits that the developing child is situated in successive interdependent levels of context. These levels range from the most proximal, the microsystem, to the most distal, the macrosystem. The microsystem contains the child's immediate environment and includes family, schools, and peers. The mesosystem is the next level, which consists of the connection, or interrelation, between microsystems. The exosystem consists of systems that do not directly contain the child, but indirectly affect the child nonetheless through impacting the child's microsystem. Finally, the macrosystem represents society at large and refers to political, cultural, or institutional patterns that can be expressed in the microsystem, mesosystem, or exosystem (Bronfenbrenner, 1979). Child development occurs in each of these developmental contexts. The most proximal context for a child's development is the family. Therefore, family is considered to exert the most immediate and direct influence and represents a critical developmental factor (Bronfenbrenner, 1986; Lerner, 1991). The current dissertation will focus on the microsystem of the child's family.

Furthermore, the model builds on these four contexts and highlights four important processes as well as the interactions among them. First, this model includes the person, or the individual's dispositions, demand characteristics, and biological competencies. Next, it involves process; specifically, the processes that occur between the individual and his or her environment on a fairly regular basis, over enough time to become increasingly complex (proximal processes). This model includes environmental context, which refers to the interdependent levels of context described above (microsystem, mesosystem, exosystem, macrosystem). Finally, this model includes time, which is further specified as microtime, mesotime, or macrotime. This is referred to as the person-process-context-time framework (PPCT; Bronfenbrenner & Morris, 2003).

When examining sibling dyads in which one individual has a developmental disability, the most important components of this model are person, process, time and the microsystem. Characteristics of the person can encompass factors such as gender and age, which are relevant to all sibling pairs, as well as disability level, behavior problems, and cognitive functioning. All these characteristics impact the child's interactions or relationships. The bioecological systems theory posits that children contribute their individual characteristics to their interactions with their environment. In terms of the person, this theory has implications for research involving populations of children and adolescents with DD because these children are typically born with biological impairments (e.g., low cognitive abilities or poor motor skills) that have the ability to impact the interaction they have with their environment as well as how the environment responds to the child with DD.

The processes, or interactions, involved in the sibling relationship occur in the child's microsystem, which consists of the child's interaction with his or her immediate surroundings, including family. Again, this theory emphasizes the significance of the interactions between the child and the family, as these interactions create the primary context for the child's development. Finally, all developmental processes and contexts are assumed to be taking place over a chronosystem, or across time. Therefore, based on the bioecological model, to understand any aspect of child development, it is critical to look at the processes and contexts of interest longitudinally.

Developmental Contextual Model. The developmental contextual model posits that there are multiple levels of the organism, as well as multiple levels of the context, that are both qualitatively distinct and dynamically intertwined (Lerner, 1991). This model places a heavy emphasis on the multidirectional interactions between levels of context. The broadest implication of this model is that research should include intraorganism-context relations and interorganism-context relationships in a longitudinal, multivariate, integrated, and multidisciplinary way (Lerner 1991). However, it is recognized that the entirety of the developmental contextual model cannot be studied in one research endeavor. Therefore, for purposes of this dissertation, the model serves as a guide to the formulation of person-context relational questions and a general template from which to derive a more empirically testable model. The entirety of the model can be found in Figure 1.1.

The current study will encompass child factors such as gender and age, which are relevant to all sibling pairs, as well as disability level, behavior problems, and cognitive functioning and how these characteristics impact the sibling relationship (interorganism-context relationships). In terms of child characteristics, this theory also has implications for research involving populations of children and adolescents with DD because these children are typically born with biological impairments (intraorganism-context relationships; e.g., low cognitive abilities or poor motor skills) which have the ability to impact the interaction they have with their environment as well as how the environment responds to the child with DD. Both the bioecological model and the developmental contextual model posit that children contribute their individual characteristics to their interactions with their environment.

Again, this theory emphasizes the significance of the interactions between the child and the family, as these are interorganism-context relationships. Therefore, this model stresses the importance of examining the child within the context of family processes, which, in this investigation, include the sibling relationship and the family future planning process. Finally, all developmental processes and contexts are assumed to be taking place across time in this model, as well. Therefore, to gain a fuller understanding of any aspect of child development, it is critical to look at the processes and contexts of interest longitudinally. It is noted that there are many aspects of this model that are not within the scope of the current study. However, this model, in conjunction with the bioecological model and Family Systems Theory, provided a framework for the development of the research questions to be addressed.

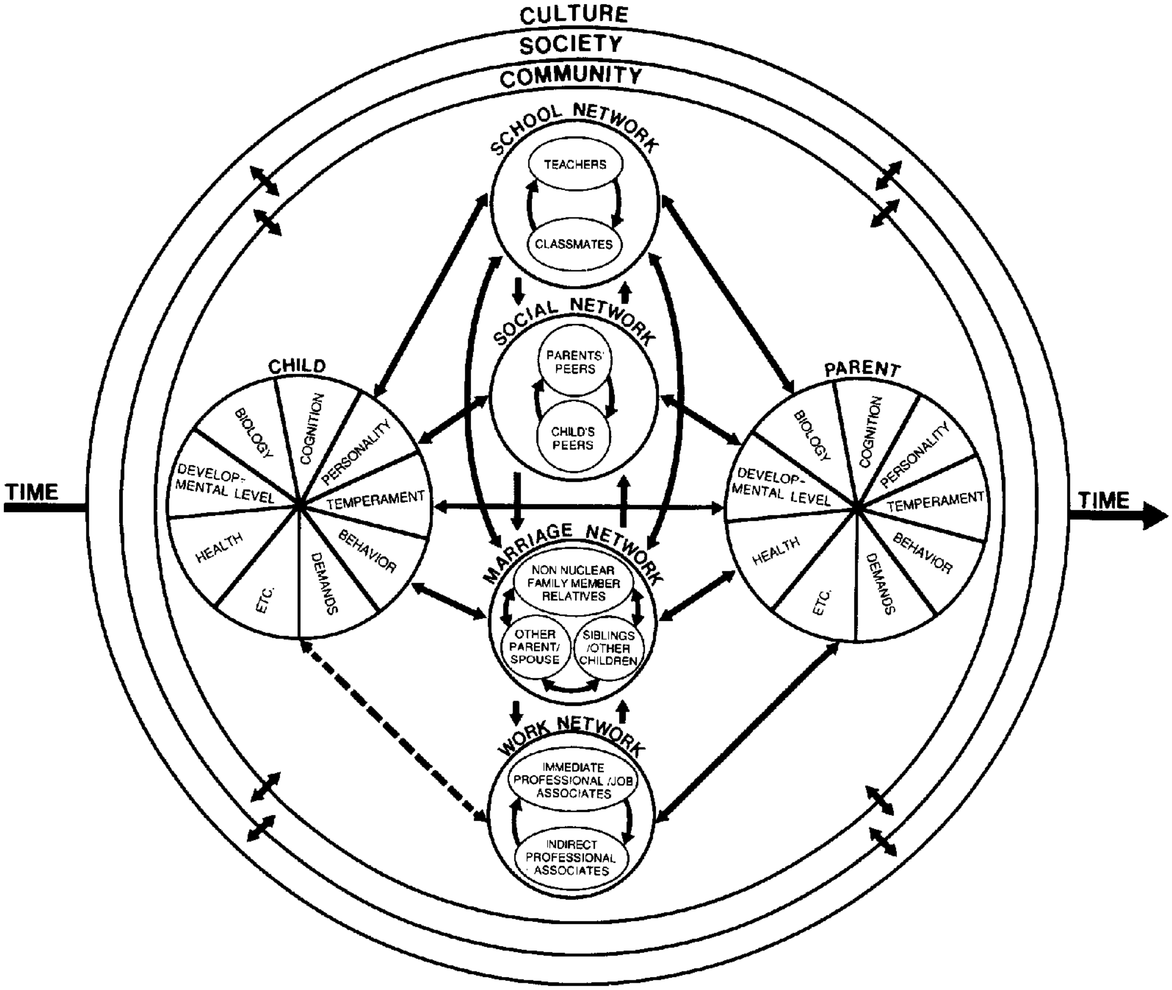


Figure 1.1. *A Developmental Contextual Model of Person-context Interaction (Lerner, 1984; 1986; 1991)*

Family Systems Theory. The final central theory to studying sibling pairs is family systems theory (Minchin, 1988). This theory focuses on four aspects within the family system: 1) the specificity and locus of relationships (i.e., the mother-child relationship is unique from the sibling-child relationship); 2) the individual's regulatory role in the system (how roles of individuals differ at various points in time); 3) the system in the larger context (all individuals are also part of other dyads that can buffer or stress the system); 4) and the working model (individuals develop a working model that is carried with him or her to other contexts). This theory highlights three important points that are critical for sibling dyad research and for the current dissertation. First, it emphasizes the importance of studying the sibling relationship as its own entity. Although the sibling relationship exists within the family system, it is separate and unique from the other relationships in the family. Second, this theory highlights the importance of studying transition points for families, as a challenge to one member of the family necessarily presents a challenge for the system as a whole. As a result, this theory emphasizes transition points, or points of great change, as important areas for research to illuminate family and dyad functioning. This is particularly important for the current investigation as the sibling relationship is examined within a context of sibling and teen development, as well as within the context of planning for the future. Such challenges require a restructuring of system components. Finally, similar to the bioecological and developmental contextual theories, family systems theory highlights the importance of the pattern of interactions between the child and the family, as these patterns exert a considerable force on child development.

Sibling Relationship

Siblings as a Social Context. The sibling relationship is often considered to be the longest lasting and most complex relationship an individual will experience in his or her lifetime (Seligman & Darling, 1989; Seltzer et al., 2005). By the time a child is one year of age, they spend as much time with their siblings as they do with their mothers, and more time than they do with their fathers. Additionally, sibling lifespans overlap more with each other than with parents, resulting in relationship longevity that cannot be matched in any other relationship (Lobato, Faust, & Spirito, 1988). Given that it is estimated that 80 to 90% of individuals grow up with one or more siblings (Cicirelli, 1995), this relationship exerts considerable influence throughout an individual's lifetime. The sibling relationship provides a unique context in which children develop emotional, social, and behavioral competencies (Dunn, 1999). As children move into adolescence, sibling interaction generally becomes less intensive (Dunn, Slomkowski, Beardsall, & Rende, 1994); however, adolescents still spend approximately 13% of their time with their sibling (Csikszentmihalyi & Larson, 1984). Therefore, although an overwhelming emphasis in sibling literature has been placed on early to middle childhood sibling pairs, siblings remain a considerable potential influence on development, continuing through adolescence. Moreover, the influence of siblings may be even greater for individuals with a developmental disability, as they have limited opportunity for friendships and regular interactions with peers (Gresham & MacMillan, 1997). Due to these limited peer networks, siblings are the most consistent and primary interactions for adolescents with DD (Guralnick, 1997), and these adolescents often rely on their siblings for support rather than their peers (Coleby, 1995; Stoneman, Brody, Davis, & Craps, 1988; Wenz-Gross & Siperstein, 1996). In fact, Krauss, Seltzer, and Goodman (1992) conducted a study of informal social networks of individuals with DD and found that siblings composed one-quarter of their entire social network.

Importance of the Sibling Relationship. The value of the sibling relationship for social-emotional, cognitive, behavioral, and overall psychological well-being has been well-documented (Dunn, 1999). However, siblings of children with DD are often investigated in their unique role as caretakers of their brothers and sisters (Cuskelly & Gunn, 2003; McHale & Gamble, 1989; Stoneman, Brody, Davis, Crapps, & Malone, 1991) and, consequently, the overwhelming emphasis in this research has presumed they are at risk for poor psychological outcomes. The research has thus focused on their psychological adjustment to having a brother or sister with a disability. Much of this research emphasizes the stress (Lobato, 1983) and psychological difficulties (Breslau & Prabucki, 1987) of the typically developing siblings. The relationship between these siblings has received some contemporary attention. Nevertheless, much of this research has been predominantly descriptive in nature, and/or has compared siblings of children with disabilities to siblings of typically developing children (Stoneman, 2001).

More recently, the quality of the sibling relationship has been examined in its role in outcomes related to well-being. In typically developing populations, a supportive sibling has been associated with lower immaturity levels (East & Rook, 1992), lower internalizing and externalizing of behavior problems (Branje, van Lieshout, van Aken, & Haselager, 2004), better peer competence (Kim, McHale, Crouter, & Osgood, 2007) and positive self-worth (Stocker, 1994). Conversely, sibling conflict has been linked to anxiety, delinquent behavior, and depressed mood (Stocker et al., 2002). Research on individuals who have a sibling with a disability reflects similar patterns; when conflict between siblings increases, risk for poor behavioral and psychological functioning in the typically developing sibling increases as well (Verte, Hebbrecht, & Roeyers, 2006). In contrast, increases in sibling warmth are associated with positive ratings of psychological well-being (Seltzer, Greenberg, Krauss, Gordon, & Judge, 1997), social competence, and prosocial behavior (Ferrari, 1984) for the typically developing sibling. Additionally, positive sibling relationships have been shown to improve outcomes for the sibling with a disability, as well. Floyd, Richardson, and Kupersmidt (2009) reported that high levels of both sibling warmth and conflict were related to higher social competence and fewer behavior problems in the sibling with a disability. The authors argued that while warmth created a spillover effect, so that positive relationship skills transferred to relationships outside of the sibling relationship, conflict socialized the sibling for more effective interactions with peers.

The unique role experiences of siblings of a child with a disability have been found to have an impact on various aspects of the typically developing sibling's life. The vast majority of studies examining siblings of a child with a disability take the perspective that having a sibling with a disability is detrimental for these individuals. Although these relationships have been shown to be positive in their interactions overall, many studies indicate that typically developing siblings tend to have more negative personal adjustment (Sharpe & Rossiter, 2002). Research examining pairs where one individual has a developmental disability shows the typically developing sibling to have difficulty in school functioning and internalizing behavior (Hannah & Midlarsky, 1999), lower social competence and cognitive development scores (Sharpe & Rossiter, 2002), higher depressive symptoms (in a sample of children with ASD; Gold, 1993), and higher overall problem behavior (Cuskelly & Dadds, 1992). Despite a history of focusing on negative outcomes for siblings of children with a developmental disability, several more positive research trends have emerged. First, research is recognizing that having a sibling with a developmental disability can have positive, as well as negative, effects (Fisman, Wolf, Ellison, & Freeman, 2000; Stoneman, 2005). Second, there has been a new concentration on contextual differences affecting siblings' outcomes.

The experience of learning to fulfill various roles may augment the sibling's ability to understand the thoughts and feelings of others (Flavell, Botkin, Fry, Wright, & Jarvis, 1968). Cuskelly and Gunn (2003) found that, in a sample of siblings of children with Down syndrome, increased childcare behavior was associated with higher levels of empathy. Likewise, in a sample of siblings of children with and without intellectual disabilities, siblings of a child with an intellectual disability were found to have increased maturity compared to their peers, increased awareness and tolerance of differences, and an improved appreciation of their own abilities and health (Dyke, Mulroy, & Leonard, 2009). In addition, compared to siblings of typically developing children, siblings of children with disabilities have been shown to display higher levels of cooperation and self-control (Mandleco, Olsen, Dyches, & Marshall, 2003). Given these findings, more emphasis is needed on possible factors and mechanisms that may lead to findings of both positive and negative adjustment for siblings of children with disabilities.

Increasingly, research is focusing on contextual differences affecting the typically developing sibling's adjustment, rather than on making general comparisons of siblings of children with developmental disabilities versus siblings of typically developing children. Research examining the impact of contextual differences has focused almost exclusively on the family context. For example, siblings of children with developmental disabilities tend to perceive more maternal partiality toward their brothers or sisters than siblings of typically developing children (Bischoff & Tingstrom, 1991). However, when the sibling's family is cohesive and supportive, the partiality is perceived as an appropriate response to the other child's needs and, thus, has no impact on the sibling's adjustment. If the sibling's family is high in disorganization and conflict, on the other hand, the perceived partiality has been shown to lead to poor school functioning, depressive symptoms, and anxiety (Stoneman, 1998). Indeed, family characteristics have been of increasing interest in recent inquiries regarding the adjustment of siblings of a child with a disability. In a sample of siblings of children with Down syndrome, family demands, resources, coping style, and communication style were found to relate to sibling social competence, behavior problems, and self-concept (Van Riper, 2000). Likewise, in a sample of siblings of children with severe disabilities, socio-economic status, parent stress, family time and routines, family problem-solving and communication, and family hardiness were found to predict sibling daily stressors and coping (Giallo & Gavidia-Payne, 2006). Examination of more varied contextual differences, including peer, school, and neighborhood characteristics, is needed to further unpack influences on sibling adjustment in these sibling pairs.

Sibling Relationship Quality. Having a sibling with a disability, as previously noted, has a significant impact on the sibling relationship. Overall, research has found that siblings of children with a developmental disability rate their sibling relationship as rewarding, positive, and nurturing (Rivers & Stoneman, 2003). Indeed, some lines of inquiry have even found siblings in this population to report their relationship as being more positive than that of typically developing sibling pairs (Cuskelly & Gunn, 2003; Fisman et al., 2000). Siblings of children with an intellectual disability report lower levels of conflict with their brothers and sisters, as well as higher levels of positive affect, warmth, and fewer negative behaviors when compared to siblings of typically developing children. This trend to rate the sibling relationship as more positive in this population has been linked to fewer behavior problems and higher social competence at school for the child with a disability (Floyd et al., 2009; Roeyers & Mycke, 1995). Siblings of children with ASD or Down syndrome have reported greater admiration of their sibling, as well as less quarreling and competition in their relationships compared to siblings of typically developing children (Kaminsky & Dewey, 2001).

To date, very little is known about the mechanisms that influence sibling relationship quality in sibling pairs in which one individual has a developmental disability (Hodapp, Glidden, & Kaiser, 2005). The sibling relationship is most often measured using parent-report and is examined as a predictor of a psychological well-being outcome. As a result, there is a dearth of information concerning how the typically developing sibling views the relationship. Furthermore, although it is generally agreed upon that the sibling relationship is complex and multifaceted (Seltzer et al., 2005; Griffiths & Unger, 1994; Stoneman & Berman, 1993), the current literature does not reflect intricacies, but instead focuses on either sibling conflict or warmth. This seems to be a result of the connection conflict and warmth have with developmental outcomes (Sherman, Lansford, & Volling, 2006). This overwhelming concentration has provided invaluable information regarding the impact of sibling relationship quality on development, but has not addressed what mechanisms impact the quality of the sibling relationship. In order to utilize the sibling relationship to improve psychological outcomes in this population, more knowledge is needed pertaining to the factors on which the sibling relationship depends.

Although many parallels have been found between typically developing sibling pairs and sibling pairs in which one individual has a disability, some important differences have been discovered that highlight the significance of investigating these relationships further. These relationships have been found to be less competitive and intimate (Begun, 1989), involve less reciprocal interaction (Dallas, Stevenson, & McGurk, 1993), and have larger role asymmetries (Brody et al., 1991). Among sibling pairs in which one individual has a disability, typically developing siblings are more likely to report less admiration for the sibling, less nurturance by their sibling and more nurturance for their sibling, and more dominance over their sibling (Begun, 1989). Despite these seemingly glaring differences, however, when compared to typically developing sibling pairs, typically developing siblings of brothers or sisters with a disability report a more positive relationship overall (Rossiter & Sharpe, 2001).

Sibling Roles. Sibling pairs in which one child has a disability have been characterized by role asymmetry (Knott et al., 1995). Though the sibling relationship in typically developing sibling pairs generally becomes reciprocal and egalitarian, the research examining the sibling relationship in pairs in which one individual has a developmental disability has focused heavily on the power differential between the two siblings (Abramovitch, Stanhope, Pepler, & Corter, 1987; Stoneman et al., 1989). This asymmetry seems to become more marked when the child with a disability has fewer functional and language abilities (Dallas et al., 1993; Stoneman et al., 1989). In addition, as these children age, the relationship becomes more asymmetrical over time, whereas the relationship between two typically developing siblings becomes more symmetrical as children grow older (Orsmond & Seltzer, 2000; Stoneman et al., 1989). The sibling of a child with a disability often takes a more dominant role as they teach and assist their sibling. Indeed, role relationships between children with intellectual disabilities and older siblings have been found to be especially asymmetrical, with older siblings assuming frequent teacher, manager, and helper roles, whereas siblings of typically developing children are more likely to engage their brothers and sisters as playmates (Stoneman et al., 1989). Both older and younger siblings of children with disabilities have been found to take on more extensive caregiving roles when compared to their peers who have a typically developing sibling (Cuskelly & Gunn, 2003). This role dominance is especially salient for younger siblings who begin as the less dominant sibling and, as time progresses, eventually surpass their older sibling developmentally (Farber & Jenné, 1963). This experience, known as role cross-over, contrasts to that found in typically developing sibling pairs, which follows a pattern of older sibling dominance (Dallas et al., 1993).

Sibling Involvement & Future Planning

Need for Future Planning. Individuals with DD are living longer now than ever before. As a result, it has become necessary for families to think about the future in ways they may not have had to before. This has only been compounded by the aging of the population and a country-wide shift from institutionalization toward community care (Lefley & Hatfield, 1999; Seltzer & Krauss, 1989). It has been found that individuals with DD live with a parent well into their adulthood (Emerson & Hatton, 2008). In fact, the most dominant residential arrangement for individuals with intellectual disabilities is family-based care (Grosser & Conley, 1995). This is complicated by the fact that more than one quarter of the individuals living with family are residing in households headed by aging parents (Braddock, Emerson, Felce, & Stancliff, 2001; Fujiura, 1998).

Surprisingly, in spite of the clear growing need for future planning, researchers have reported that only between 25% and 50% of families have made plans regarding future living arrangements for their child with DD, and approximately 50% of families want their child to live with another family member (Freedman, Krauss, & Seltzer, 1997; Heller & Factor 1991).

Sibling Involvement. Despite this growing need to think about future planning, many parents show reluctance in involving their typically developing children in this process (Heller & Caldwell, 2006). Griffiths and Unger (1994) conducted a study of families of individuals with DD and found that 78% of parents reported having discussed the issues of placement with their typically developing children, but 64% of those children were unsure as to what their parents' future plans for their siblings were after their parents could no longer fulfill the caregiving role. Without satisfactory future planning, individuals with DD are more likely to end up in emergency placements, often in inappropriate settings, when their parents can no longer care for them (Freedman et al., 1997; Heller & Factor, 1993). Even more importantly, it has been suggested that siblings may be less effective in their caretaking roles if they have not been included in the future planning process (Heller & Kramer, 2009).

When individuals with DD do leave the parental home, studies show that the responsibility for these individuals continues to remain in the family. Furthermore, siblings are most often named as next of kin when parents die or are no longer capable of maintaining previous levels of care; in fact, this is often the expectation (Davys & Haigh, 2008). Some studies have examined what has predicted sibling level of involvement in caretaking when their brother or sister has a disability. For example, some studies show sibling age, gender, birth order (Richardson, 2009) and family climate have been shown to impact sibling involvement (Greenberg et al., 1999; Rimmerman & Raif, 2001). In addition, parent expectations of involvement and caregiving have also been found to significantly affect sibling involvement (Greenberg et al, 1999; Zetlin, 1986). Other findings have indicated that siblings of individuals with intellectual disabilities are socialized to anticipate a caregiving role as part of their future family responsibilities (Begun, 1989; Grossman, 1972; Stoneman & Berman, 1993).

Regardless, parents most often name siblings as potential future caregivers (Bigby, 1997; Griffiths & Unger, 1994), including advocate, co-resident, guardian, or trustee (Heller & Kramer, 2009). Research has revealed that, among siblings of adults with DD who are highly involved, 19% expected to co-reside with their sibling with DD in the future (Krauss, Seltzer, Gordon, & Friedman, 1996), 44% were willing to be future caregivers (Griffiths & Unger, 1994), and 60% expected to be a future caregiver (Greenberg et al., 1999).

Research shows that siblings of individuals with disabilities display concerns about the future. Some siblings express reluctance in accepting responsibility for their brother or sister with DD in their adult life, and those who are willing to accept these responsibilities experience anxieties surrounding added undertakings in their lives (Meyer & Vadasy, 1997; Powell & Gallagher, 1993). In addition, many siblings feel a particular sense of responsibility for when the time comes that their parents will no longer be able to maintain the previous level of support for the individual with a disability (Orsmond & Seltzer, 2007). Indeed, many siblings have expectations that their level of caregiving and commitment to their brother or sister will increase in the future (Greenberg et al., 1999). For brothers or sisters of children with disabilities, the sibling relationship may take on additional importance. Although many individuals with developmental disabilities mature into independent adults, many others require supervision and care throughout their lifetime. By the adolescent with a disability's eighteenth birthday, many families have begun the guardianship process or have begun to think about guardianship in some way (Baum et al., 2009). In the United States, legal guardianship should be established, if needed, by the time the teen with a disability is 18 years of age. This is when the teen legally reaches adulthood. At age 18, all persons are presumed to be competent, meaning that they are assumed to be responsible to make their own decisions regarding finances, health care, and all other important life decisions (Baum et al., 2009). Therefore, it is likely that future planning begins well before the individual with a disability is in adulthood. The guardianship process prompts the sibling's realization of the long-term implications of the adolescent's disability (Eisenberg, Baker, & Blacher, 1998). Consequently, around this time, siblings have been shown to exhibit concern and stress regarding their role in this process (Harris & Glasberg, 2003).

Future Planning & the Sibling Relationship

Little is known regarding the effect that future planning has on the sibling relationship. Some studies have found that siblings who were found to have more negative relationships with their brother or sister with DD were less likely to be expected to take on a future caregiving role (Bigby, 1997; Griffiths & Unger, 1994). In addition, all of the aforementioned studies examining future planning examined siblings of adults with DD. Nothing is known about the very beginnings of this process. Taking into consideration the salience that determining legal guardianship may have when the individual with DD is in adolescence, it stands to reason that future planning may be beginning around this time. Finally, given the importance that the sibling relationship can have on the well-being of the individual with DD, as well as the sibling, it is important to examine how something so significant and malleable – the future planning process – impacts this relationship.

Based on the state of the current literature, an important aim of this dissertation is to address the impact of future planning on the sibling relationship as, during the teen's adolescence, siblings have been shown to exhibit concern and stress regarding their role in the teen's future (Harris & Glasberg, 2003). The second critical aim of this investigation is to identify the experiences of siblings of individuals with DD over the teen's adolescence. The current study will examine various aspects of future planning and the impact these have on the sibling relationship when the teen with DD is 15 and 18 years of age. To do this, three aspects of sibling relationship quality (cooperation, conflict, and relationship closeness), as rated by the typically developing sibling, will be examined in a mixed methods study. These aspects will be examined in relation to how much parents discuss the adolescent with a disability's needs and future with the sibling, the sibling's concern for the future of their brother or sister with a disability, and the future roles that the sibling expects to play in the teen with DD's life. In addition, how the siblings describe their pride in the adolescent with DD (age 18), their concerns about the adolescent with DD (age 18), their hopes for the adolescent with DD (age 18), and what they have learned from their brother or sister with DD (age 15 & 18) will be examined. The responses regarding lessons learned from living with a brother or sister with DD will be examined from when the teen was 15 and 18 years old, while the remained questions will only be examined from when the teen was 18 years old. The goal of this study is to explore the typically developing siblings' perceptions of the sibling relationship quality during a period of potential future planning to examine the predictors of these perceptions. This is especially important given the research indicating the impact that sibling relationship quality can have on future adjustment for these sibling pairs.

These particular aspects were selected for investigation based on the age of the individual with a developmental disability in the current sample. As these individuals were 18 years of age by the second time point used in this study, this is a critical time point in terms of the salience of the adolescent's capabilities. By age 18, most typically developing adolescents are becoming independent young adults. In contrast, families with a child with a disability may be thinking about their adolescent's dependence, functional skills and future legal guardianship issues. As a result, this is a time of concern for these families, and it offers a unique opportunity for examining the sibling relationship under conditions of some stress related to planning for the future.

Research Questions

Question 1: How do future planning issues impact the sibling relationship quality when the teen is 18 years of age? (Quantitative analysis)

> Question 1a: Are concurrent concerns for the teen, discussion of teen needs and sibling future roles predictive of sibling cooperation above and beyond family SES and teen functional skills at T18?
>
> Question 1b: Are concurrent concerns for the teen, discussion of teen needs and sibling future roles predictive of sibling conflict above and beyond family SES and teen functional skills at T18?

Research Question 2. Is there a change in sibling relationship closeness from when the teen is age 15 to when the teen is age 18? (Quantitative analysis)

Question 2a: Is the change predicted by sibling expectations or pessimism for the teen with a disability?

Question 2b: Is the change predicted by how often siblings talk to parents about the teen's needs at T15?

Research Question 3: What are the siblings' feelings about their brother or sister with a disability in the present, and about the future of their brother or sister with a disability? (Qualitative analysis)

Research Question 3a. What makes siblings proud of their brother or sister when the teen is 18?

Research Question 3b. What are the siblings' concerns about their brother or sister's future when the teen is 18?

Research Question 3c. What are the siblings' hopes for their brother or sister's future when the teen is 18?

Research Question 3d. What are the siblings' lessons learned from living with the teen when the teen is 18?

Research Question 4: Do the lessons learned from the teen at T15 look different than the lessons learned from the teen at T18?

Chapter 3: Methodology

This chapter details the design of the current study. This investigation examined the predictors of changes in and perceptions of sibling relationship quality among pairs of siblings where one individual has a developmental disability using a mixed methods approach. This study is a secondary analysis of data from the Early Intervention Collaborative Study (EICS), a longitudinal, non-experimental study of families with children diagnosed with early identified developmental disabilities (DD) extending from infancy to young adulthood (Hauser-Cram et al., 2001). Participants entered the study at the time of enrollment into a publicly funded early intervention program in Massachusetts or New Hampshire during the infant or toddler years.

Constructs

The following section will detail the constructs being analyzed in the proposed study. First, sibling relationship quality will be introduced, as this will be the main dependent variable for the quantitative analysis. Next, I will introduce sibling future planning, as aspects of this will be analyzed as predictors. Finally, sibling experience will be addressed, as this will be the focus of the qualitative analysis in the current study.

Within both typically developing sibling dyads and sibling dyads in which one child has DD, sibling relationship quality has not been well-studied. As a result, there has been no universal agreement as to how to define sibling relationship quality. Some studies have used amount of time siblings spend together as a measure of relationship quality (Heller, Gallagher, & Fredrick, 1999; Knott et al., 1995; Strain & Danko, 1995), while others have used observations of sibling interactions (Brody, Stoneman, & Burke, 1987). However, in conceptualizing this construct more recently, many studies have used the Sibling Relationship Questionnaire (SRQ; Furman & Buhrmester, 1985; Eisenberg et al., 1998; Kaminsky & Dewey, 2001; Lardieri, Blacher & Swanson, 2000). This measure has been used due to its ability to capture 4 facets of the sibling relationship: warmth/closeness, conflict, power, and rivalry as perceived by the sibling. The current study only collected data on three of these subscales: warmth/closeness, conflict and power. Previous studies have found that all three subscales effectively measure sibling relationship quality in sibling dyads in which one child has DD. The current study will use the items from the three subscales, but has re-conceptualized the subscales after performing a factor analysis on the items for this sample (see measures section of this chapter). Therefore, in this dissertation, sibling relationship quality will be measured using two new subscales referred to as cooperation and conflict. In addition, for the change models used to address research question 1, sibling relationship closeness will be used to measure sibling relationship quality. The positive affect, or relationship closeness, has been used as one of the dimensions of sibling relationship in many studies (e.g., Seltzer, Orsmond, & Esbersen, 2009). Relationship closeness will be measured in the current study using the Positive Affect Index (Bengtson & Black, 1973). This particular measure defines a close sibling relationship as one characterized by mutual feelings of understanding, respect, affection, trust, and fairness (Bengtson & Black, 1973). Sibling relationship quality will be conceptualized as relationship closeness for the change models, as it was collected from siblings both when the teen with DD was 15 and 18 years of age.

Sibling future planning refers to the ways in which siblings think about the teen with DD's future. This will be measured through a variety of sibling self-report measures. First, to address question 1, the future planning involves looking at concurrent measures at T18. Perhaps even more so at this time than when the teen is 15 years of age, the legal guardianship process is a potentially salient issue for these families (Hauser-Cram, Krauss, & Kersh, 2009; Harris & Glasberg, 2003). The legal guardianship process is a potentially complicated process in a family of a teen with DD's life. Many studies have conceptualized this process by asking families if they have established a legal guardian (Heller & Kramer, 2009; Hong, Seltzer, & Krauss, 2004). In the current dissertation, a similar approach was taken; siblings were asked within a list of future roles how certain they were they would be a legal guardian in the future. In addition, a series of questions was asked of the siblings specifically to illustrate the issues around legal guardianship. Each question was an item developed by EICS. First, siblings were asked to rate how concerned they were for the teen in five areas when the teen was 18 years of age: 1) what happens when parents can no longer care for the teen; 2) the teen's ability to get a job; 3) the teen's ability to have a social life; 4) the teen's ability to live independently; and 5) the amount that the teen will depend on the sibling. These items were summed to arrive at a total score for concerns. Second, siblings were asked to rate how sure they felt that they would be involved in certain roles in the teen's life in the future: legal guardianship, assistance with transportation, support with medical needs, assistance with shopping, daily caregiving, socializing with teen, providing emotional support, and living together. These items were summed to arrive at a score for total roles. Finally, siblings were asked to rate how often they discussed the teen's needs with their parents. Each of these measures taps into the siblings' thoughts around the future in different ways. These issues surrounding legal guardianship will be examined in relation to sibling relationship quality to address question 1.

To address question 2, future planning will be conceptualized differently from the constructs used to address question 1 discussed above. Sibling future expectations for the teen with DD (EICS measure) will be examined. This consists of 12 items that ask the sibling to rate if they believe each accomplishment is likely for their brother or sister in the future. These items yield a total future expectation score used for these analyses. The accomplishments addressed in this measure include things like having a job and having a social life in the future. In addition, sibling future planning will be measured using the Questionnaire on Resources and Stress – Short Form (QRS-SF; Friedrich, Greenberg, & Crnic, 1983). Although the full measure contains 4 subscales examining both resources and stress in families of children with DD, only the pessimism scale was collected from the siblings for the current study. This self-report measure examines siblings' pessimistic beliefs about the teen with DD's future. Both sibling future expectations and pessimism will be used to examine question 2 as aspects of their future planning in relation to their brother or sister with a disability.

Finally, the concept of sibling experiences with the teen with DD could be conceptualized many ways. Many studies address this issue using descriptive statistics (e.g.,Van Riper, 2003). However, to address this construct, the current dissertation will use a series of open-ended questions asked of the siblings when the teen with DD was 15 and 18 years of age. At both time points, siblings were asked what they had learned from living with their brother or sister with DD. At T18, siblings were also asked what their hopes were for the teen, what their concerns were for the teen, and what made them proud of the teen. The answers to these questions will be analyzed using qualitative content analysis analysis to determine how siblings experience having a brother or sister with a disability during a time when thinking about the future may be especially salient (adolescence).

Data

Data for this study were drawn from the Early Intervention Collaborative Study (EICS) (Hauser-Cram et al., 2001). EICS is an ongoing longitudinal investigation of children with DD and their families extending from infancy to young adulthood. EICS was initiated in 1985 to study the diverse developmental pathway illustrated by children with DD and the adaptation of their parents. Siblings were later included in the study when they emerged as primary sources of social support for the children in the study during middle childhood. All families were recruited between their child's birth and age three at their time of enrollment in one of 29 state- or federally-supported early intervention programs in Massachusetts or New Hampshire. Participants were categorized into three diagnostic groups: Down syndrome, motor impairment, or developmental delay. The disability groups utilized in the proposed analyses when the child with DD is in adolescence are: Down syndrome, motor impairment, and unknown etiology. Type of disability was confirmed at study entry through the child's medical records and again at age three through independent child assessment.

Procedures for Data Collection

Home visits were used as the primary means of data collection and were conducted by research assistants who were blind to study hypotheses. These visits took place when the children with DD were 1, 2, 3, 5, 10, 15, 18, and 23 years of age. The current study uses data collected when the individual with DD was age 15 and 18 only (henceforth referred to as T15 and T18). During these home visits, child and parent demographic information was collected, such as years of education, family income, race, and gender. Additionally, visits included multidimensional child assessments, parent interviews, and questionnaire booklets completed independently by both parents, as well as the siblings. Data were collected by trained research assistants in the participants' homes within 6 months of the teen's 15th and 18th birthdays. Semi-structured interviews with mothers (approximately 2.5 hours in length) and fathers (approximately 1 hour in length) were completed, as well as a structured multidimensional assessment with the target adolescents (approximately 1 hour in length). Siblings, as well as mothers and fathers, were asked to fill out a self-report booklet. All sibling data were collected from the self-report booklets, as siblings were not interviewed in person.

Sample

The initial sample for the EICS study as the children were entering their first year of early intervention was 190 children and their families. Due to attrition, the sample size decreased approximately 10% per data collection point. For the purposes of this study, only adolescents with participating siblings were included in the study. If the target adolescent had more than one sibling, the sibling booklet was completed by whichever sibling the mother indicated was closest emotionally to the adolescent with a disability, with the restriction that only one sibling completed a booklet per family. The initial sample for this study was 89 families at T15. Three years later, at T18, the sample had decreased to 84 families. Therefore, for the analyses addressing research question 1, the 84 families at T18 were included. However, to address research questions 2, 3, and 4, only cases in which the same sibling participated at both time points were included in the study for a final sample of 49 sibling pairs.

Measures

Measures of child, sibling, and family characteristics were conducted at each data collection point. The variables of interest include: sibling characteristics, teen disability type, family socioeconomic status, teen functional skills, teen behavior problems, future planning (pessimism, future roles, expectations), discussion of teen's needs and future, sibling relationship quality (relationship closeness, cooperation, and conflict), and sibling experience.

Sibling Characteristics. Sibling characteristic variables included in these analyses were age of the sibling (in years), gender of the sibling (0=male, 1=female), sibling gender match (0=sibling and target adolescent are same gender, 1=sibling and target adolescent are opposite genders), and sibling order (0=sibling younger than target adolescent, 1=sibling older than target adolescent).

Disability type. There are three disability groups with the dataset that were used at both data collection points: Down syndrome, motor impairment, and developmental delay-unknown etiology. These groups were determined based on medical record review at entry to the study and again at age 3. These groups are combined for analyses (1=Down syndrome, 0=other developmental disability; 1=motor impairment, 0=other developmental disability).

Socioeconomic status. For family socioeconomic status, a composite score was computed using years of education completed by the teen's mother, as well as the approximate annual family income. Mothers reported the number of years of education they had completed at the time of data collection. In addition, they reported their average family annual income within a range of $5,000. To create the family socioeconomic status composite, maternal years of education and approximate annual family income were standardized and summed for each teen simultaneously at each time point (T15 and T18). The correlation between maternal years of education and approximate annual family income is $r = .48$ at T15 and $r = .60$ at T18.

Functional skills of teens. In this study, functional skills were measured using a composite of scores on the Vineland Adaptive Behavior Scales (VABS; Sparrow, Balla, & Cicchetti, 1984) and the Stanford-Binet Intelligence Scales (Roid, 2003). The VABS is a semi-structured assessment of skills that the child demonstrates regularly. These data were obtained through interviews with the primary caregiver (typically the mother). Three subscales were included in this assessment: communication, daily living skills, and socialization, for a total of 261 items. The Adaptive Standard score was used to determine the composite. The reliability for this measure has been reported to be $\alpha = .94$ (Sparrow et al., 1984) and the reliability for this sample was $\alpha = .98$ at both T15 and T18. The short version of the Stanford-Binet was used to measure IQ. This includes non-verbal and verbal routing questions. This measure has been found to be highly reliable (α = .95 - .98; Roid, 2003) and at T15 for this sample α = .98 and at T18 for this sample α = .96.To create the functional skills composite, the IQ and adaptive scores were standardized and summed for each target adolescent simultaneously at each time point (T15 and T18). In past analyses using the EICS sample, the correlation between these two scales has been found to be r=.70 or above. The correlation between these scales for the current sample at T15 is r = .84 and at T18 is r =74.

Teen behavior problems. At ages 15 and 18, internalizing and externalizing behavior problems of the target adolescents were measured using the developmentally appropriate version of the Child Behavior Checklist (CBCL; Achenbach & Edelbrock, 1983). This is a measure consisting of 112 problem behaviors assessing the presence or absence of certain problem behaviors. For example, "shy or timid" is an item that addresses an internalizing behavior, while "physically attacks people" is an item that addresses an externalizing behavior. The primary caregiver (typically the mother) completed the CBCL at both time points and was asked to rate the extent to which each statement was true about the target adolescent on a 3-point scale from 0-"Not true at all" to 2-"Very true". Internalizing and externalizing subscales were then summed to arrive at an overall behavior problems t-score, which will be used in these analyses. This is a widely used measure and its validity has been demonstrated in numerous empirical studies as well as through high correlations with similar psychological measures (e.g. DSM-IV Checklist, r=.80), indicating high concurrent validity. Any score above 60 is considered to be problematic; 25.5% and 24.4% of this sample scored above this cutoff at

T15 and T18, respectively. The average score was 54.55 at T15 and 53.68 at T18. Internal consistency has been found to be high with Cronbach's alphas ranging from .78 to .97 (Achenbach, 1991). Cronbach's alphas for the current sample at T15 and T18 are α=.91 and α=.89, respectively.

Sibling cooperation and conflict. Sibling cooperation and conflict will be measured using the Sibling Relationship Questionnaire (SRQ; EICS sample: α =.95; Furman & Buhrmester, 1985). Siblings were asked to rate the extent to which they participated in each interaction with the teen from 1-"Hardly at all" to 5-"Extremely much" when the teen with DD was 18. Buhrmester and Furman (1990) reported internal consistency coefficients for the SRQ that range from .71-.81 in a sample of siblings in 3rd, 6th, 9th, and 12th grades. A principal components analysis (PCA) with varimax rotation was performed, forcing 3 factors in accordance with the original SRQ subscales collected for this sample (relative power/status, warmth, conflict). It was established that items from the relative power/status subscale of the original SRQ were loading on the same factor as the items from the warmth/closeness subscale (e.g. "How much do you teach your brother or sister things he/she doesn't know?"). Therefore, a second PCA with varimax rotation was performed forcing two factors. The result was two discrete factors accounting for 57% of the variance. Factor 1 (eigenvalue=18.83, variance explained=44.84%) consisted of 29 items, and Factor 2 (eigenvalue=5.28, variance explained=12.57%) consisted of 13 items. Based on item content, it was determined that two types of items existed for this scale in this sample: those that described "cooperation" (Factor 1) between siblings, and those that described "conflict" (Factor 2) between siblings. Even the items that originated in the warmth/closeness subscale were decidedly more focused on interaction than affect. As a result, the term cooperation is used to distinguish the nature of this variable from that of relationship closeness (as measured by the Positive Affect Index, discussed below). Both subscales demonstrated high reliability ($\alpha_{cooperation}$ =.96, $\alpha_{conflict}$ =.94). Cooperation and conflict were treated as two separate outcomes for the remainder of the analyses.

Discussion of teens' needs and future. To assess the frequency that parents discussed the teen with DD's future and needs with the sibling, siblings were asked to respond to one item at T15 and one item at T18. At T15, siblings were asked "How much do you and your parents talk about your brother's or sister's needs?" and responded on a 3 point Likert scale from 0 ("Not at all") to 2 ("Very often"). At T18, siblings were asked "How often do you talk to you parents about your brother's or sister's needs?" and responded on a 5 point Likert scale from 1 ("Hardly at all") to 5 ("Extremely much").

Sibling relationship closeness. The closeness of the sibling relationship was measured using the Positive Affect Index (current sample: α_{T15} = .96, α_{T18} =.95; Bengtson & Black, 1973). Siblings were asked to report on 15 items rating the extent to which the relationship between the siblings was characterized by mutual affection, fairness, respect, understanding, and trust, and 5 items rating perception of overall relationship closeness. Siblings were asked to rate each item on a 5-point scale from 1 ("not at all") to 5 ("very much"). This was collected when the teen with DD was 15 and 18. At each time point, three subscales of relationship closeness as well as a total score were collected. The first subscale reflects how the sibling feels toward their brother or sister with a disability (teen). An example of this would be “How well do you understand your brother or sister?”. The second subscale reflects how the sibling perceives their brother or sister (teen) to feel toward them. An example of this would be “How well do you think your brother or sister understands you?”. The third subscale reflects the relationship between the sibling and the teen. An example of this would be “How well do you and your sibling get along together?”. Only the total score was used for the final analyses.

Sibling pessimism. Siblings’ pessimism regarding the teen’s future was assessed using the Questionnaire on Resources and Stress – Short Form (QRS-SF; normed sample: α =.93; Friedrich et al., 1983). The original measure includes four subscales: Parent and Family Problems, Pessimism, Child Characteristics, and Physical Incapacitation. Only the 11 items pertaining to the Pessimism subscale were collected from the siblings when the teen was 15 years of age. The original Questionnaire on Resources and Stress (Holroyd, 1974) was developed to measure the impact on the family of having a child with a disability or chronic illness. Examples of items from this modified Pessimism subscale are: “It bothers me that my brother or sister will always be this way” and “My brother or sister will always be a problem to us”. Siblings were asked to respond to each item with either “true” (coded as 1) or “false” (coded as 0). Items from this subscale were summed for a total pessimism score ranging from 0 to 11. Internal consistency for this measure overall has been found to be quite high, α = .99 (Friedrich et al., 1983). For this sample, the Cronbach’s alpha for the Pessimism subscale was found to be .70.

Sibling expectations. Siblings’ expectations regarding the future for the teen were assessed using 12 items developed by the EICS study. Each item asked siblings to respond based on their beliefs about the teen with DD's future. Examples of items from this measure include: "When an adult, my brother or sister will live in his/her own apartment or house" and "When an adult, my brother or sister will have a job". Siblings were asked to respond to each item with either "probably yes" (coded as 1) or "probably no" (coded as 0). Items were summed to create a total expectations score ranging from 0 to 12. Cronbach's alpha for this measure was .50. It was expected that the internal consistency for this measure would be low, because having the expectation that the teen with DD will accomplish one of these tasks does not necessarily indicate that the siblings would expect the teen with DD to accomplish the rest of these tasks. Consequently, an item analysis was run on the expectations measure. Results indicated that three items did not correlate with the overall scale score: "When your brother or sister is an adult, will they live with your parents?", "When your brother or sister is an adult, will they live with you?", and "When your brother or sister is an adult, will they need special services?". In other words, if siblings expected any of these three items, they did not expect the teen to accomplish the other items on the scale. Additionally, if any of these three items were deleted from the scale, it would increase the Cronbach's alpha for the expectations measure considerably. In light of these results, the aforementioned three items were dropped from the scale. The final scale used for analyses had 9 total items, for scores ranging from 0 to 9. The Cronbach's alpha for the final expectations scale was .86. Results from the item analysis can be found in Table 3.1.

Table 3.1. *Item Analysis for T15 Sibling Expectations.*

Item: When brother or sister is an adult, will he/she...	**Scale Mean if Item Deleted**	**Scale Variance if Item Deleted**	**Corrected Item-Total Correlation**	**Cronbach's Alpha if Item Deleted**
Have a job?	5.566	4.785	.508	.520
Live in his/her own apartment or house?	5.590	4.928	.414	.539
Have a lot of friends?	5.807	4.865	.393	.541
Go to college or vocational school?	5.773	4.544	.562	.501
Have money to pay his/her own bills?	5.771	4.496	.582	.495
Get married?	5.855	4.467	.604	.490
Drive a car?	5.807	4.499	.580	.496
Have children?	5.940	4.569	.580	.499
Have a social life?	5.506	5.131	.365	.553
Live with you?	*6.108*	*6.415*	*-2.94*	*.658*
Live with your parents?	*5.783*	*6.904*	*-.442*	*.706*
Need special services?	*5.773*	*7.008*	*-.480*	*.711*

Sibling future roles. Siblings' expected future roles were assessed when the teen was 18 years of age by asking siblings to what extent they believed they would be filling certain roles for the teen in the future. A total of 8 roles were presented and siblings were asked to rate the extent they believed they would fill those roles on a 4 point Likert scale from 0 ("Definitely no") to 3 ("Definitely yes"). The roles presented to the siblings were: legal guardianship, daily caregiving, assistance with transportation, assistance with medical needs, living with teen, providing emotional support, and socializing with teen. These items were then summed for a total future roles score ranging from 0 to 32. Higher scores indicate a higher expectation of involvement in the teen's life. Cronbach's alpha for this measure was .86. Frequencies for sibling future roles can be found in Table 3.2.

Table 3.2. *Frequencies for siblings' expected future roles*

	Definitely No	**Probably No**	**Probably Yes**	**Definitely Yes**	**N/A**
Legal Guardianship	12	17	16	18	17
Assistance with Transportation	4	13	26	28	10
Support/Assistance with Medical Needs	3	19	29	19	12
Assistance with Shopping, Groceries, and Other Needs	4	15	30	19	13
Daily Caregiving	15	18	11	15	23
Socialize Together	2	12	21	42	4
Provide Emotional Support	0	7	23	47	4
Live Together	15	35	16	12	4

Sibling concerns. The concerns siblings held for the teen with DD were measured by another EICS created measure that presented five concerns to the sibling. Siblings were asked to rate the extent to which they worried about each issue for the teen on a 5 point Likert scale from 1 ("Hardly at all") to 5 ("Extremely much"). The issues presented were: what will happen to the teen when parents can no longer care for him/her, the ability of brother/sister to get a job, whether brother/sister will have a social life, the ability of brother/sister to live independently, and how much brother/sister will depend on the sibling in the future. Items were summed to create a total concerns score ranging from 5 to 25. Cronbach's alpha for this measure was .88. Frequencies for sibling concerns can be found in Table 3.3.

Table 3.3. *Frequencies for Sibling Concerns for the Teen's Future*

	Hardly At All	**Not Too Much**	**Somewhat**	**Very much**	**Extremely Much**
What happens to teen if parents can't care?	16	11	27	16	11
Will teen get a job?	23	14	27	7	9
Will teen have a social life?	21	12	22	20	6
Will teen live independently?	19	10	21	19	12
How much will teen depend on sibling?	19	17	24	11	10

Sibling Experience. When the teen with DD was both 15 and 18 years of age, siblings were asked a series of open-ended questions. At T15, siblings were asked what lessons they had learned from the teen. At T18, these questions assessed the siblings' hopes for the teen, concerns for the teen, lessons learned from the teen, and things that made them proud of the teen. To answer these questions, siblings were asked to write down their responses in a booklet. These questions will be used in the qualitative analyses.

Table 3.4. *Constructs and Associated Measures with Reporters*

Construct	Measures & Reporter
Teen type of disability	Down Syndrome Motor Impairment Unknown Etiology *Independent assessment at entry into study*
Family Socio-economic Status	Family Income + Maternal Years of Education Composite *Primary caregiver report at T15 and T18*
Sibling Characteristics	Sibling Gender Sibling Age Sibling-Teen Gender Match Sibling Order *Sibling report at T15 and T18*
Teen Functional Skills	Vineland Adaptive Behavior Scales (Sparrow, Balla & Cicchetti, 1983): Standard Adaptive Score *Maternal report at T15 and T18*
	Stanford-Binet Intelligence Scales (Roid, 2003) *Teen assessed at T15 and T18*
Teen Behavior Problems	Child Behavior Checklist (Achenbach & Edelbrock, 1983) total score *Maternal report at T15 and T18*
Sibling Cooperation and Conflict	Sibling Relationship Questionnaire (Furman & Buhrmester, 1985) – warmth, conflict, & power subscales *Sibling report at T18*
SiblingCRelationship closeness	Positive Affect Index (Bengtson & Black, 1973) *Sibling report at T15 and T18*
Sibling Pessimism	Questionnaire on Resources and Stress – Short Form (Friedrich, Greenberg, &Crnic, 1983) – Pessimism Subscale *Sibling report at T15*
Sibling Expectations	EICS Measure *Sibling report at T15*
Sibling Future Roles	EICS Measure *Sibling report at T18*
Sibling Concerns	EICS Measure *Sibling report at T18*
Sibling Experience	EICS Questions *Sibling report at T15 and T18*

Statistical Analyses

In this section I address the proposed statistical analyses for the research questions presented in the current study. First, the plan for missing data will be discussed, as well as how this issue were addressed. Next, I will discuss issues of statistical power. Finally, I will delineate the steps I took in the data analysis process. Data collection time points will heretofore be referred to as T15 and T18 for data collected when the adolescent with a developmental disability was 15 and 18 years of age, respectively.

Missing data. Missing data were examined. If fewer than 10% of the cases were missing, substitution for missing values were made using regression-based imputation. If cases were missing a significant amount of data across measures, the cases will be dropped. If cases were missing information on maternal years of education or approximate annual family income for one time point, the missing value was replaced with the respective value for the other time point (e.g. if T15 income was missing, it was replaced with the case's value for T18 income). Previous EICS samples have found the correlation for these two variables across time points to be quite high ($r > .89$). A total of 49 sibling dyads completed measures at both time points.

Power analyses. The power of the proposed analyses was tested for a regression equation. To do this, the sample size to achieve a large effect size (.7) was calculated, with a predetermined alpha set at .05. For power equal to .80 with a large effect size and an alpha of .05, a sample size of 45 is needed for a two-tailed test (Cohen, 1988; 1992).

Data Analysis. In this section, I outline process followed in data analyses.

Basic frequencies and checks. Descriptive statistics were conducted on the relevant variables in order to obtain means and standard deviations. Additionally, frequencies were examined so as to identify outliers as well as any coding errors in the data. Examining the distribution of the data also helped to identify outliers that may bias the results of the study. Furthermore, normality checks were conducted using a histogram as well as a normal probability plot to ensure the data met the normality assumption of regression. To address multi-collinearity concerns, correlations were run between all dependent and all independent variables. Any variables that were highly correlated ($r >$ .70) and also conceptually related were re-conceptualized as composite variables. Prior to running the full regression analyses required to examine the research questions, correlations were run between independent and dependent variables to illustrate the basic relationships among the variables in terms of both direction and magnitude. In these preliminary correlations, if any independent variable was found to not have a significant correlation with dependent variables of interest, they were be removed from the final analyses in order to preserve statistical power.

Preliminary analyses. Prior to running the final analyses, an analysis of variance (ANOVA) tested for differences between the three disability groups (Down syndrome, motor impairment, and unknown etiology), sibling order (sibling older or younger than teen), teen gender, sibling gender, sibling gender match (whether or not sibling and teen are same gender), and the criterion variables (relationship closeness, cooperation, and conflict) to see if there were statistically significant differences between these groups. If there were not, these variables were excluded from the final analyses and the data were analyzed in aggregate. Additionally, two-way ANOVAs were conducted on type of disability with sibling order, teen gender, sibling gender, and sibling gender match on each criterion variable in order to test if main effects or interaction effects were present. If any of these effects were found, the corresponding variables were included in the final analyses as dummy variables. If not, these variables were excluded from the final analyses and the data were analyzed in aggregate.

Analysis of research questions. This dissertation took a mixed methods approach to the analyses of the research question. In this section, I will discuss the analysis plan for each of the three main research questions I have presented. I used Ordinary Least Squares (OLS) regression as the general approach to the quantitative portions to this dissertation. This type of approach is appropriate for the data in that the dependent variables are continuous. Regression analyses were run to examine the unique contribution of sibling factors to sibling relationship quality at T18, above and beyond the contribution of demographic variables.

Section 1: Quantitative Analyses. In order to address questions 1 and 2, two unique variables were created. First, a composite variable was made using the teen's cognitive performance at both time points and the teen's Vineland adaptive score at both time points. To do this, the *z* scores from each variable were calculated, then the respective *z* scores were summed in order to create a composite variable. This composite variable will be referred to henceforth as "teen functional skills". Second, a composite variable was computed using maternal years of education and approximate family income at both time points. To create the composite, the *z* scores from each variable were calculated and then the respective *z* scores were summed in order to create a composite variable. This composite variable will be referred to henceforth as "family SES". As discussed previously, the teen's type of disability as well as sibling demographic and constellation variables were examined to see if there were differences in the criterion variables across groups. If any differences were found, the appropriate variables were included in the analysis.

Question 1: How do future planning issues impact the sibling relationship quality when the teen is 18 years of age?

Question 1a: Are concurrent concerns for the teen, discussion of teen needs, and sibling future roles predictive of sibling cooperation above and beyond family SES and teen functional skills at T18?

Question 1b: Are concurrent concerns for the teen, discussion of teen needs, and sibling future roles predictive of sibling conflict above and beyond family SES and teen functional skills at T18?

Statistical Analysis. Sibling cooperation and sibling conflict at T18 were analyzed in separate parallel regression models. This resulted in two OLS hierarchical regression analyses to address question 1. To address questions 1a and 1b, the regression analysis included the cooperation and conflict subscales of the Sibling Relationship Questionnaire (SRQ; Furman & Buhrmester, 1985) at T18 regressed on predictor variables entered in the following order: 1) Family SES T18; 2) Teen functional skills T18; 3) Teen behavior problems T18; 4) Concerns for teen; 5) Discussion of future/needs; 6) Sibling future roles. The models appeared as follows:

Question 1a:

(Y1) T18 Sibling Cooperation = a + b1*SES$_1$ + b_2 teen functional skills T18 + b_3*teen behavior problems T18 + b_4*concerns for teen + b_5*discussion of future/needs + b_6*sibling future roles + e.

Question 1b:

(Y2) T18 Sibling Conflict = a + b_1*SES1 + b_2 teen functional skills T18 + b_3*teen behavior problems T18 + b_4*concerns for teen + b_5*discussion of future/needs + b_6*sibling future roles + e.

Question 2. Is there a change in sibling relationship closeness from when the teen is age 15 to when the teen is age 18? (Quantitative analysis)

Question 2a: Is the change predicted by sibling expectations or pessimism for the teen with a disability?

Question 2b: Is the change predicted by how often siblings talk to parents about teen's needs at T15?

Statistical Analysis. To test question 2, a repeated measures analysis of covariance (ANCOVA) was performed. This was used to determine if there was a mean change in sibling relationship closeness between T15 and T18 controlling for family SES at T15, teen functional skills at T15, and teen disability type. This analysis is appropriate for question 1 because it involves a continuous outcome (sibling relationship closeness) measured at two time points by the same subjects, as well as multiple predictors, two of which are continuous (family SES and teen functional skills) and one of which is categorical (teen disability type).

To address questions 2a, 2b, and 2c, sibling relationship closeness at T18 were analyzed in a series of OLS lagged regression analyses. To do this, sibling relationship closeness at T15 was mean centered prior to entering it into the analyses. For each of these questions, the basic regression analysis included sibling relationship closeness (Bengtson & Black, 1973) at T18 regressed on predictor variables entered in the following order: 1) Sibling relationship closeness at T15; 2) Family SES at T15; 3) Teen functional skills at T15. The analyses for question 2a built off this basic model, so that sibling relationship closeness at T18 was regressed on predictor variables entered in the following order: 1) Sibling relationship closeness at T15: 2) Family SES at T15: 3) Teen functional skills at T15: 4) Teen behavior problems at T15: 5) Frequency that siblings talk to parents about teen's needs at T15. Finally, question 2c will be examined similarly with sibling relationship closeness at T18 regressed onto predictor variables entered in the following order: 1) Sibling relationship closeness at T15; 2) Family SES at T15; 3) Teen functional skills at T15; 4) Teen behavior problems at T15; 5) Sibling expectations at T15; 6) Sibling pessimism at T15. The models appeared as follows:

Question 2a:

(Y4) T18 Sibling Relationship closeness a + b_1*T15 sibling relationship closeness + b_2*T15 SES1 + b_3*teen functional skills T15 + b_4*T15 teen behavior problems + b_5*frequency talk about teen's needs T15 + e

Question 2b:

(Y5) T18 Sibling Relationship closeness = a + b_1*T15 sibling relationship closeness + b_2*T15 SES1 + b_3*teen functional skills T15 + b_4*T15 teen behavior problems + b_5*sibling expectations T15 + b_6*sibling pessimism T15+ e

Section 2. Qualitative analyses. To address both research questions 3 (3a-3d) and 4, qualitative content analysis were used.

Research question 3: What are the siblings' feelings about their brother or sister with a disability in the present and about the future of their brother or sister with a disability? (Qualitative analysis)

Research Question 3a. What makes siblings proud of their brother or sister when the teen is 18?

Research Question 3b. What are the siblings' concerns about their brother or sister's future when the teen is 18?

Research Question 3c. What are the siblings' hopes for their brother or sister's future when the teen is 18?

Research Question 3d. What are the siblings' lessons learned from living with the teen with the teen is 18?

Research Question 4: Do the lessons learned from the teen at T15 look different than the lessons learned from the teen at T18?

Analysis – Qualitative Approach: In order to condense large amounts of information in a more efficient manner, qualitative content analysis aims to provide knowledge and understanding of the phenomenon being studied by classifying text into *in vivo* codes, categories, and clusters (Downe-Wambolt, 1992; Sandelowski, 2000). The key feature to all content analysis is to take large amounts of text and classify the many words into much smaller content categories (Burnard, 1996; Weber, 1990). In this method, data analysis is interactive and reflexive in that the process of analysis and the evolving findings are constantly being modified in order to accommodate researcher insights and any new data (Sandelowski, 2000). Additionally, data analysis is data-derived so that preconceived categories are not forced onto the data. The categories and codes that emerge do so from the data as coding progresses (Downe-Wamboldt, 1992; Sandelowski, 2000). Finally, qualitative content analysis is low inference, as will be further discussed below. Therefore, it does not permit the development of theories but, rather, stays true to the participants' experiences and perceptions to provide rich descriptions of the phenomenon of interest. This is appropriate, given the dearth of literature on this topic.

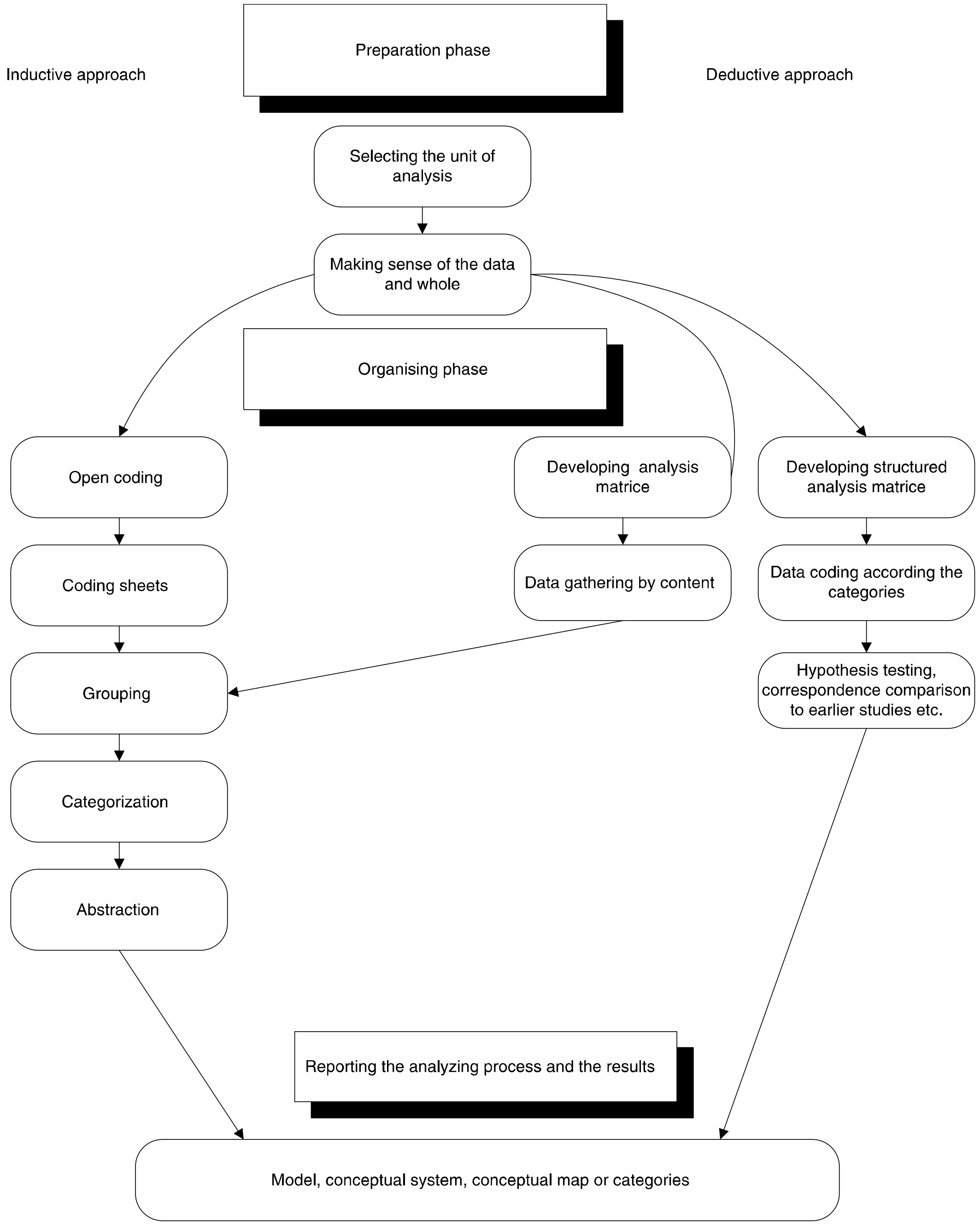
Three separate approaches to qualitative content analysis have been delineated: directed, summative, and conventional (Hsieh & Shannon, 2005). In the first approach, directed analysis, prior theory or research is used to guide the development of a priori coding categories that are subsequently applied to the data; this is a deductive approach. In the second approach, summative analysis, key words and content are identified and quantified. This approach also involves subsequent interpretation of possible latent meanings and usage of words or phrases. Finally, the third approach, conventional analysis, involves the inductive derivation of codes directly from the data as analysis progresses.

The current dissertation approached the qualitative data using conventional qualitative content analysis. This is the most appropriate approach, as the experiences of siblings of teens with DD is an under-researched area and, thus, there is a limited body of existing theory and literature on this topic. This approach aims to stick closely to the data so that the results reported reflect the meanings, experiences, and reality of the siblings participating in this study (Hsieh & Shannon, 2005; Patton, 1990). This epistemology allows for theorizing around experience and meaning in a more direct way because it implies that language reflects meaning and experience (Potter & Wetherell, 1987; Widdicombe & Wooffitt, 1995). Additionally, a rich thematic description of the entire data set is provided, rather than a more detailed description of any particular theme. Furthermore, inductive approaches to qualitative analysis are recommended when there is not enough prior knowledge or research about a phenomenon, or if the knowledge or research is fragmented in some way (Braun & Clarke, 2006; Elo & Kyngäs, 2007). Inductive approaches begin with the specific and move to the general, so that instances are first observed and then combined into a larger whole (Chinn & Kramer, 1999). As per this approach, I systematically ascertained and applied codes as they arose from the data without imposing pre-existing coding schemas (Milne & Oberle, 2005; Sandelowski, 2000).

Analysis: Procedure. Qualitative content analysis can be divided into three main phases of analyses: preparation, organizing, and reporting (Elo & Kyngäs, 2007). The preparation phase occurs prior to actual data analysis. The organizing phase involves the coding, categorizing, and abstraction of data. Qualitative content analysis ends with the reporting of the analyzing process and results. For the purposes of this dissertation, I followed the process for qualitative content analysis as outlined by Elo and Kyngäs

(2007). The full process for both inductive and deductive qualitative content analysis as proposed by Elo and Kyngäs can be found in Figure 3.1.

Figure 3.1. *Preparation, Organizing, and Resulting Phases in the Content Analysis Process (Elo and Kyngäs, 2007)*



Note: this dissertation will be using the inductive approach. Note well the left side of the model.

Prior to beginning data analysis, I began the preparation phase by selecting the unit of analysis (Cavanagh, 1997; Guthrie, Yongvanich, & Ricceri, 2004; McCain, 1988). The unit of analysis can be a word, phrase, sentence, portion of a page, letter, or theme (Polit & Beck, 2004; Robson, 1993). Additionally, a decision must be made as to whether to analyze "manifest content" only, or include latent content as well (Graneheim & Lundman, 2004). For the purposes of this dissertation, in order to accurately reflect the feelings and experiences of siblings of teens with DD, I only analyzed the "manifest content". Broader latent themes or trends were only explored when using the qualitative findings to elucidate the quantitative findings. Only "manifest content" was analyzed for the main qualitative analyses. Once these decisions were made, the next step was to make sense of the data and get a sense of the whole (Burnard, 1991; Morse & Field, 1995; Tesch, 1990). In order to do this, I will read through the entirety of the data several times with the aim of becoming immersed in the data. According to Dey (1993), while reading through the data, questions to be kept in mind and for which to search for answers are:

1) Who is telling?
2) Where is this happening?
3) When did it happen?
4) What is happening?
5) Why?

Due to the nature of the questions asked of the siblings in this study, not all of these questions were addressable. The question "where is this happening?" is not a question that is relevant to the research questions and is not in the data. Additionally, the questions “who is telling?” and “when did it happen?” can be answered before reading the data as, due to sampling for this study, we know all the reporters are siblings of teens with DD and that the data was collected in the years that the teens with DD were 15 and 18 years old. After reading through the data several times, I was completely familiar with the data and, thus, was able to arrive at insights and theories appropriately during the analysis process (Polit & Beck, 2004).

As I had already chosen an inductive approach to qualitative content analysis (the conventional approach) the first step in the organizing phase, was to organize the qualitative data. This includes coding the data in three steps: open coding, generating categories, and abstraction. In open coding, headings are written on the text while reading the data. The data were read through again in order to ensure that all facets of the data are captured by the headings (Burnard 1991, 1996; Hsieh & Shannon, 2005). This results in the first level of codes, or the initial codes. Initial codes are then transferred to coding sheets (Burnard, 1991; Dey, 1993; Cole, 1988; Downe-Wamboldt, 1992). Codes are defined as “the most basic segment, or element, of the raw data or information that can assessed in a meaningful way regarding the phenomenon” (Boyatzis, 1998, p. 63). Copies of the written answers given by the siblings were made so that notes on coding during this step could be written directly on the data items. Data extracts (individual chunks of coded data) were allowed to be coded more than once, if needed. In this step, I identified words of participants directly by making notes on the copies of the siblings’ answers. As I coded these interviews, I recorded the resulting *in vivo* codes so by the end of this step I had an exhaustive list of all the codes across all the sibling responses. From these *in vivo* codes, I generated a list of initial codes. Multiple *in vivo* codes, though expressed differently in the data, referred to the same fundamental idea.

Once open coding was completed, initial codes were condensed so that they were grouped together under higher order codes or themes. This condenses the initial codes (Hsieh & Shannon, 2005; Morse & Field 1995). When making decisions regarding themes, it is important to compare data belonging to a particular group and data that did not belong in the same category, rather than only grouping observations that seem to be related (Dey, 1993). To accomplish this step, I examined the initial codes for similarities. To condense the initial codes, codes were analyzed to see how different but related codes combined to illustrate a broader theme (Morse & Field, 1995). In addition, I checked to make sure that each theme was cohesive and could be easily distinguished from other subcategories. These themes were named. At this stage, some themes were identified that later needed to be combined to make main categories. Next, all of the themes were reviewed and refined. Any themes that did not have enough data to support them were dropped, and some themes needed to be combined. By the end of this step, I had a compilation of themes that originated from the initial codes. Therefore, themes reflected my choice to only code the “manifest content”, thus remaining very close to the original data (Graneheim & Lundman, 2004). At the conclusion of this step I had have a compilation of clusters, or broad categories, that intertwine all of the subcategories. The aim of this compilation was to reveal some of the more latent meanings of the original data (Graneheim & Lundman, 2004).

Once categories had been generated, the final step as abstraction. Themes from the previous step were grouped together as larger categories that can be used to describe the research topic (Kyngäs & Vanhanen, 1999; Robson, 1993). Patton's (1990) criteria will be used for these categories: internal homogeneity and external heterogeneity. According to these criteria, data within categories should adhere together significantly (internal homogeneity) while there should be clear, identifiable distinctions between categories (external heterogeneity). Within this step, the coded data were first reviewed to see if they formed coherent patterns or relationships, then the abstracted categories were examined to ensure they reflected the meanings illustrated in the whole data set. This confirmed that the categories worked in relation to the data set and that additional data that was missed got coded (Braun & Clarke, 2006). These abstracted categories were necessarily broad so as to include all the relevant subcategories.

The final step in qualitative content analysis is to report the analysis and results. In this step, the themes were defined and named. This included explaining each theme and how it fit into the overall findings. The final step was to write up the report of the data, including examples and extracts. In this step, the data were not only described, but also related to the larger dissertation. Additionally, for research questions 3a-3d, the report illustrated findings around what the hopes, concerns, and points of pride were for siblings when the teen was 18 years old. For research question 4, the report specifically looked at themes that arose in relation to lessons learned from living with a teen with DD at T15 and T18, as well as the similarities and differences between the time points.

During the course of the qualitative data analysis, I consulted with the faculty members comprising my committee to confirm that all the initial codes, themes, and categories, as well as the relationships between them, accurately represented the data and that they were reasonably arranged (Milne & Oberle, 2005). This will be further outlined below.

Trustworthiness. It is essential that all research take the necessary steps to confirm that the data being obtained and analyzed is of high quality. When performing quantitative research, reliability and validity are often used as the gold standards for assessing data quality (Popay, Rogers, & Williams, 1998). However, both reliability and validity have sprung from a positivistic paradigm, meaning that they are based on the assumptions that there is an objective reality (realist ontology) and that people can know this objective reality and accurately describe and explain it using symbols (representational epistemology; Crocker & Algina, 1986; Glesne & Peshkin, 1992; Winter, 2000). Reliability and validity follow naturally from a positivistic paradigm because this paradigm offers an objective reality against which researchers can compare their assertions and, thus, determine truth. The goal of research falling into this paradigm is to maximize the distance between any subjective biases of the researcher and the objective reality of the phenomenon he studies (Popper, 1972).

Consequently, validity and reliability, and the paradigm in which they are rooted, are discordant with the underlying assumptions of qualitative research, which is rooted in a constructivist perspective (Whittemore, Chase, & Mandle, 2001). This perspective, in contrast, is based on the assumption that reality is socially constructed and can change depending on the context or circumstance (Golafshani, 2003). Constructivism has been defined as "the view that all knowledge, and therefore all meaningful reality as such, is contingent upon human practices, being constructed in and out of interaction between human beings and their world, and developed and transmitted within an essentially social context" (Crotty, 1998, p. 42). Therefore, there is no "objective reality" upon which researchers can compare their assertions and determine truth. Necessarily, qualitative research requires different standards to assess data quality.

In qualitative research, the idea of trustworthiness replaces the ideas of reliability and validity (Golafshani, 2003). There are many criteria that may be used in qualitative research in order to ensure trustworthiness is maintained (Clont, 1992; Davies & Dodd, 2002; Lincoln & Guba, 1985; Sandelowski, 1986, 1993**;** Seale, 1999; Stenbacka, 2001). A synthesis of these criteria by Whittemore et al. (2001) was used as a framework to assess trustworthiness for this dissertation. This synthesis names and defines four main constructs: credibility, authenticity, criticality, and integrity. I will address each of these constructs in turn and will speak to how I addressed each one within this dissertation.

Credibility. Ensuring credibility refers to the conscious effort of the researcher to ascertain confidence that the meaning of the data was accurately interpreted (Carboni, 1995). This construct addresses the need for assurance that interpretations reveal some truth about the data outside of the investigator's experience (Thorne, 1997). Generally speaking, credibility is ensured through sampling and recruitment strategies, as well as data analysis procedures (Graneheim & Lundman, 2004). As the current dissertation is utilizing secondary data, I could only address credibility in the data analysis procedures. To obtain credibility during the data analysis procedure, I routinely met with my faculty advisor in order to guarantee that the codes and categories were appropriately derived from the data. Although this may not have eradicated my biases during the coding process, it mitigated their effects. This helped to ensure that the codes and categories arose from the participants' perceptions rather than my own interpretations so that their experiences were reflected to the fullest extent possible. This process of consultation also helped to confirm that the codes and categories were representative of the data. In other words, this process ensured that no data had been excluded from the analysis, that any discrepancies within the data had been recognized, and that multiple understandings of the data had been considered (Graneheim & Lundman, 2004; Whittemore et al., 2001). In addition, please see the explanation of interrater reliability below.

Authenticity. Authenticity is closely linked to credibility, and encompasses the portrayal of research that accurately mirrors the experiences and meanings that are lived and perceived by the participants in a study (Sandelowski, 1986). It is critical that the researcher pays close attention to the voices of the participants in order to remain true to the phenomenon under study (Hammersley, 1992). Generally, authenticity involves three fundamental components: the participants' voices are heard, the participants are free to speak, and the participants' perceptions are accurately represented (Neergaard, Olesen, Andersen, & Sondergaard, 2009).

For the current study, I used secondary data of siblings' written responses to open-ended questions in a response booklet. As I was not involved in the data collection, I could not assure authenticity during the data collection process. However, I can address some concerns. First, at every time point in the EICS project, participants have been contacted and asked if they would like to participate. For those families who could not make an appointment due to scheduling or personal constraints, materials could be mailed to them or a phone interview could be conducted. This addresses the component that participants have their voices heard to some extent. Researchers on the EICS project made every effort to make sure every participant that wanted to contribute was able to. In terms of the siblings, whether or not they received a response packet was, unfortunately, sometimes at the mercy of the parents. For example, if the parents decided that the family was no longer participating in the study, the sibling did not have the chance to complete the questions. Every effort was made to mail response booklets directly to the siblings when possible, except when parents requested that siblings not be contacted.

Second, for the siblings that did participate, the booklets were filled out at their convenience in the absence of the researcher and were mailed in. This allowed siblings to take their time to thoughtfully address each question. In this way, siblings were free to bring up what was most salient to them. Finally, as the siblings wrote their responses themselves, their perceptions are portrayed as accurately as possible. The responses to the questions being utilized for the qualitative analyses in this dissertation did not require the involvement of the researcher. In order to ensure that my presentation of the data through the coding process did not inaccurately portray the participants' perceptions, I calculated interrater reliability in addition to consulting my faculty advisor (see below).

Criticality. Criticality refers to the critical evaluation as well as explanation of any decisions and procedures executed during a study (Milne & Oberle, 2005). In this dissertation, criticality was upheld through consultation with my faculty advisor. I kept track of the steps, process, and rationale in regard to the data analysis process. My faculty advisor, as well as an undergraduate student that assisted me with interrater reliability, assessed the decisions made along the way. The goal of this process was to diminish some of the impact of researcher bias. The interrater reliability procedure put into place also helped to mitigate these biases (see below).

Integrity. In this study, integrity referred to assuring that any interpretations were valid and grounded in the data to the fullest extent possible. Additionally, it encompassed that I was aware of any biases that may have shaped my interpretations (Marshall, 1990; Whittemore et al., 2001). First, to maintain integrity throughout the data analysis process, I consulted regularly with my faculty advisor and research assistant to address my subjectivity as a researcher, as well as any impact that may have had on the data, as previously noted. Second, I participated in routine reflexivity in order to attend to my beliefs, values, and assumptions and how they influence the data analysis (Lietz, Langer, & Furman, 2005). The goal of these two processes is twofold: to assist me as a researcher and to elucidate the lens through which I view the data and the topic of study for any readers of my research (Morrow, 2005). In the following section, I explore my background and how it may inform and influence my current research.

Personal identity and philosophy. I do not assume to be “objective” in my view towards this research topic. The goal of this section is to elucidate how my previous experiences, beliefs, and values may be shaping the research process in this study, rather than to just identify them as conceivable sources of bias and then disclaim them.

I have been raised in a very large, very close family. I have one sister, and she and I have always been very close. My relationship with my sister has always been one of the most, if not the most, cherished relationships in my life. Accordingly, I have a very distinct idea of what sibling relationships “should” entail. Foremost, I have always believed that siblings should support and love each other unconditionally. I have also grown up being all too aware of the vast differences between my sister and me. I know that she has encouraged me to foster my creativity and emotionality, instead of defaulting to my analytic nature. Conversely, I know that I have encouraged her to stay grounded and rational when her emotions get the best of her. As a result, I view the sibling relationship to be a critical one in which individuals can grow and develop, and as a relationship that is largely influential for social and emotional outcomes.

However, I have always been keenly aware of the fact that many sibling relationships that I encounter are not as close as the one my sister and I share. I have observed many sibling relationships in which, despite the efforts of both parties involved, conflict prevails over harmony. I have often found myself wondering what allows some sibling pairs to easily overcome differences, while others struggle endlessly to get along. I have initiated this study, in part, due to my belief that if the sibling relationship can be improved, perhaps the well-being of all siblings can be improved greatly as well.

It is important to note that my standpoint likely differs greatly from those of the participants in the study. My sister is typically developing, and I cannot assume to understand what it may be like to grow up with a brother or sister with a disability. I do not assume to understand the struggles, obstacles, or joys that these siblings have experienced over the course of their development together. Therefore, I am mindful of the need to recurrently explore how my viewpoint and experiences might impact my research study, especially during the course of the qualitative content analysis.

Additionally, I have some experiences with individuals with developmental disabilities that have shaped my interest in this topic as well as my perspective on the phenomenon of study. I have worked with individuals with disabilities in various capacities, including as volunteer visitor at group homes, paraprofessional in a school, respite care provider (noted below), Best Buddy, and family member. I have found myself, over the years, becoming very dedicated to ensuring that individuals with disabilities, especially children, are given the opportunity to realize their full potential. Most of my work has been with children with severe developmental disabilities with varying etiologies. My love for each child that I have worked with over the years, and my desire for their happiness and fulfillment, has influenced my area of research greatly. As a result, I do have a personal investment in the current study, as I have an emotional tie to the topic. In my research process, I must be mindful of this and make every effort to separate the participants' voices from my own emotional connections.

Furthermore, I have an 8-year-old cousin with a developmental disability (Sam) who has two younger brothers. The youngest brother is only 3. However, I have noticed that the older of the two brothers takes on a great deal of responsibility for Sam. He tends to be very protective, and watches over him much like a caretaker. In contrast, he is much quicker to argue and become frustrated with his younger brother. Even from a very young age, he seemed to understand that Sam required a different type of sibling relationship than his younger brother. Consequently, I often find myself wondering if this largely self-assigned role will become overwhelming as they grow older. I have also worked as a respite care provider for a family for three and a half years. Their child with a disability is 10, and he has an older sister and a younger brother. Similarly, I have watched his older sister care for him and provide unconditional love, whereas she is much quicker to act in anger towards her youngest brother, who is only five. The youngest brother, however, is quick to blame his brother for many things, although he does show him quite a bit of affection. Again, I wonder what these roles will develop into as these children grow older. I must be mindful not to use these sibling relationships as a lens through which I view the data. The participants' voices are separate and valid viewpoints from those that I must keep separate from my own experiences.

In closing, every researcher has a unique perspective that impacts the way in which they interpret, approach, and report the research that they do. In order to elucidate my perspective for myself and for the readers of my work, I have explored the aspects of my own experiences, beliefs, and values above. However, reflexivity must continue to be a prominent process throughout the course of qualitative content analysis.

Interrater reliability. In order to ensure trustworthiness in the data analysis procedure, a step-by-step process will be used to establish interrater reliability. There are several types of reliability to consider (stability, reproducibility, accuracy), but reproducibility is disputably the greatest, and it the most feasible kind to test (Krippendorff, 2004; Hayes & Krippendorff, 2007). What this type of reliability evaluates is whether or not a set of codes yields the same set of results when implemented by different observers within a reasonable margin of error. Therefore, agreement among independent observers is imperative for this type of reliability. The more agreement demonstrated between observers, the more likely the data will be accepted as reproducible and trustworthy (Hayes & Krippendorff, 2007).

To safeguard trustworthiness in this study, interrater reliability or agreement will have to be established at each phase of qualitative content analysis. Here I present the steps that were taken at each phase of analysis.

1) I read through the data in its entirety several times and created a list of *in vivo* codes. I met with my faculty advisor to discuss ways that these *in vivo* codes could be combined into a more condensed list of initial codes.
2) I analyzed the initial codes and decided how they grouped together into themes. These were discussed with my faculty advisor, as well as the undergraduate research assistant.
3) The undergraduate research assistant and I each coded the same 20% of cases (random) in the data using the themes. Interrater reliability was calculated. Any discrepancies were discussed between us. If suitable interrater reliability was achieved, we continued to code the remainder of the data. Interrater reliability was calculated again.
4) I analyzed the themes and decided how they grouped together into categories. These were discussed with my faculty advisor, as well as the undergraduate research assistant.
5) The undergraduate research assistant and I each coded the same 20% of cases (random) in the data using the categories. Interrater reliability was calculated. Any discrepancies were discussed between us. If suitable interrater reliability

was achieved, we continued to code the remainder of the data with the categories. Interrater reliability was calculated again.

To interpret the Kappa for interrater reliability, I used the guidelines provided by Landis and Koch (1977). These guidelines suggest that a Kappa less than 0 is considered “poor agreement”, a Kappa between 0 and 0.20 is considered “slight agreement”, a Kappa between 0.21 and 0.40 is considered “fair agreement”, a Kappa between 0.41 and .60 is considered “moderate agreement”, a Kappa between 0.61 and 0.80 is considered “substantial agreement”, and a Kappa between 0.80 and 1.00 is considered “almost perfect agreement”.

Analysis – Mixed Methods: The overarching mixed method design employed by this dissertation was a mixed-method component design. In these types of designs, the methods are conducted as distinct aspects of an overall investigation and they remain discrete throughout the analysis (Caracelli & Greene, 1997). Any combination of methods in these types of designs occurs at the interpretation stage or conclusion of the inquiry, rather than during the data collection stage. This type of design is well-suited for the current study, as the data for this dissertation is secondary; it was not collected specifically for the purposes of this inquiry. Therefore, it is not possible to use an integrated design using this data and this sample. More specifically, this dissertation is a complementarity design. This type of design entails one dominant type of analysis (in this study, quantitative analyses) that is further developed and elucidated using the results from another method type (in this study, qualitative analyses; Caracelli & Greene, 1997). This design fits this dissertation, as it is a poorly researched area. Therefore, using qualitative analyses to further clarify the quantitative pieces of the study allows for a deeper understanding the sibling relationship during this time in adolescence.

Given that this dissertation took a mixed methods approach to an under-researched area, the qualitative research questions are mostly descriptive. However, the findings from the qualitative portion of this dissertation were used in two ways aside from description. First, the themes elucidated in the qualitative analyses were used to supplement the findings from the quantitative analysis. The qualitative analysis relating to concerns for the teen helped to especially clarify any findings regarding the quantitative concerns and sibling relationship quality (question 1). The qualitative concerns relating to hopes were helpful in clarifying the positive aspects of future planning that the siblings have in relation to the teen with DD and, in concert with the qualitative analysis of "what makes you proud of your brother/sister?", this illustrated the quality of the sibling relationship in more detail. The analysis of lessons learned from living with a teen with DD at T15 and T18 was helpful in clarifying how the dynamic of the sibling relationship may be changing over this period of three years. The second way that the qualitative findings were integrated into the overall dissertation was that the patterns that emerged from analyzing the five qualitative items revealed some hypotheses that will be important to address in future research. This was facilitated by the complementarity design of the study as it captured a broader understanding of sibling relationships in this population than a quantitative or qualitative analysis alone. This is an especially important contribution for this area of research, as very little is known about how siblings of teens with DD deal with and think about the future for their brothers and siblings.

Table 3.5. *Summary of Research Questions, Methods and Analysis Plan*

Research Question	**Method**	**Analysis Plan**	**Equation**
1) Is there a change in sibling relationship closeness from when the teen is age 15 to when the teen is age 18?	Quantitative Analysis	Repeated Measures ANCOVA *Covariates: Family SES @ T15, teen functional skills @ T15, teen disability type*	
1a) Is the change predictive by sibling expectations or pessimism for the teen with a disability?	Quantitative Analysis: OLS Regression	Lagged regression analysis *Predictor variables: T15 sibling relationship closeness, T15 family SES, T15 teen functional skills, T15 teen behavior problems, T15 sibling expectations, T 15 sibling pessimism*	(Y_1) T18 Sibling Relationship closeness = a + b_1*T15 sibling relationship closeness + b_2*T15 SES_1 + b_3*teen functional skills T15 + b_4*T15 teen behavior problems + b_5*sibling expectations T15 + b_6*sibling pessimism T15+ e
1b) Is the change predicted by how often siblings talk to parents about teen's needs at T15?	Quantitative Analysis: OLS Regression	Lagged regression analysis *Predictor variables: T15 sibling relationship closeness, T15 family SES, T15 teen functional skills, T15 teen behavior problems, T15 talk about teen's needs*	(Y_2) T18 Sibling Relationship closeness a + b_1*T15 sibling relationship closeness + b_2*T15 SES_1 + b_3*teen functional skills T15 + b_4*T15 teen behavior problems + b_5*frequency talk about teen's needs T15 + e

2) How do future planning issues impact the sibling relationship quality when the teen is 18 years of age?	Quantitative Analysis: OLS Regression		
2a) Are concurrent concerns for the teen, discussion of teen's needs and sibling future roles predictive of sibling cooperation above and beyond control variables?	Quantitative Analysis: OLS Regression	Hierarchical regression analysis *Predictor variables: T18 family SES, T18 teen functional skills, T18 teen behavior problems, T18 concerns for teen, T18 discussion of teen's future, T18 sibling future roles*	(Y_3) T18 Sibling Cooperation = a + b_1*SES$_1$ + b_2 teen functional skills T18 + b_3*teen behavior problems T18 + b_4*concerns for teen + b_5*discussion of future/needs + b_6*sibling future roles + e.
2b) Are concurrent concerns for the teen, discussion of teen's needs and sibling future roles predictive of sibling conflict above and beyond control variables?	Quantitative Analysis: OLS Regression	Hierarchical regression analysis *Predictor variables: T18 family SES, T18 teen functional skills, T18 teen behavior problems, T18 concerns for teen, T18 discussion of teen's future, T18 sibling future roles*)	(Y_4) T18 Sibling Conflict = a + b_1*SES$_1$ + b_2 teen functional skills T18 + b_3*teen behavior problems T18 + b_4*concerns for teen + b_5*discussion of future/needs + b_6*sibling future roles + e.

3) What are the siblings' feelings about their brother or sister with a disability in the present and about the future of their brother or sister with a disability?	Qualitative Description	Qualitative content analysis
3a) What makes siblings proud of their brother or sister when the teen is 18?	Qualitative Description	Qualitative content analysis *How has your brother or sister made you proud?*
3b) What are the siblings' concerns about their brother or sister's future when the teen is 18?	Qualitative Description	Qualitative content analysis *What worries you about your brother or sister's future?*
3c) What are the siblings' hopes for their brother or sister's future when the teen is 18?	Qualitative Description	Qualitative content analysis *What are your hopes for your brother or sister's future?*
3d) What are the siblings' lessons learned from living with the teen with the teen is 18?	Qualitative Description	Qualitative content analysis *What have you learned from living with your brother or sister?*
4) Do the lessons learned from teen at T15 look different than the lessons learned from teen at T18?	Qualitative Description	Qualitative content analysis *What have you learned from living with your brother or sister? (T15 & T18)*

Chapter 4: Results

This chapter details the steps in the data analysis, including preliminary analyses and missing data replacement, as well as the findings from the quantitative research questions outlined in chapter 3, the results of the qualitative methods outlined in chapter 3, and the additional analyses suggested by the initial findings. The level of significance reported for the quantitative portion of the results is at the .05 level. The quantitative data were analyzed using SPSS statistical software. Results for quantitative analyses will be presented first, followed by the results for qualitative analyses.

Missing Data

Several cases were missing values for some of the control, independent, and criterion variables. Missing data were addressed differently depending on the variable in question for reasons explained below.

When the adolescent with DD was approximately 15 and 18 years old (T15 and T18), mothers were asked to report their years of education completed and their approximate annual family income. Both years of education and annual family income were standardized to create a composite SES variable at each time point. At T15, no cases were missing maternal years of education (see below), and four cases were missing approximate family income. At T18, three cases were missing maternal years of education, and thirteen cases were missing approximate annual income. The T15 years of maternal education values were directly substituted for the missing T18 maternal education values, and vice versa (r=.88, p<.001; Table 4.1). The T15 approximate annual family income values were directly substituted for the missing T18 approximate annual family income values, and vice versa (r=.79, p<.001). Two cases did not have T15 or T18 approximate annual family income as reported by mothers, and in these cases the fathers' report of this value was substituted for the missing value. In both cases, the mothers were currently married to the fathers and living in the same household with the teen with DD.

Table 4.1. *Correlations for Missing Data Substitution: SES Variables.*

	T15 Mother's Years of Education	**T18 Mother's Years of Education**	**T15 Approximate Annual Family Income**	**T18 Approximate Annual Family Income**
T15 Mother's Years of Education	--	.88**	.48**	.60**
T18 Mother's Years of Education		--	.47**	.53**
T15 Approximate Annual Family Income			--	.79**
T18 Approximate Annual Family Income				--

** *r* is significant at the p<.001 level

Similarly, at both T15 and T18, adolescent IQ scores (Stanford-Binet Intelligence Scales) and adaptive scores (Vineland Adaptive Behavior Scales) were collected. Both adolescent IQ and adaptive scores were then standardized to create a composite functional skills variable at each time point. At T15, it was noted that there was one case missing an IQ score. This case was also missing the IQ score for T18. Consequently, the standardized IQ scores for this case and both time points were replaced with the respective standardized adaptive scores (r_{T15}=.80, p<.001; r_{T18}=.72, p<.001; Table 4.2). There were no cases missing adaptive scores at T15. At T18, it was noted that ten cases were missing IQ scores. The T15 IQ scores were directly substituted for the missing T18 IQ scores (r=.89, p<.001), with the exception of the single aforementioned case. There were no cases missing adaptive scores at T18.

Table 4.2. *Correlations for Missing Data Substitution: Teen Functional Skills.*

	T15 IQ Score	**T18 IQ Score**	**T15 Adaptive Score**	**T18 Adaptive Score**
T15 IQ Score	--	.89**	.80**	.78**
T18 IQ Score		--	.71**	.72**
T15 Adaptive Score			--	.88**
T18 Adaptive Score			.	--

** *r* is significant at the p<.001 level

Three measures required the use of regression–based multiple imputation: T15 Sibling Relationship closeness, T18 Relationship closeness, and T18 Sibling Relationship Quality. No cases were missing any of these measures in their entirety. Therefore, multiple imputation was employed for each measure on the item level. Within each measure, missing items were imputed using all the items in that particular measure. This was achieved by using the multiple imputation function in SPSS statistical software. A total of 5 imputed datasets were created. A total of 3 cases were missing items for the T15 Relationship closeness measure. The T18 Relationship closeness measure and the T18 Sibling Relationship Quality measure had 2 and 4 cases missing data, respectively. The final models for this dissertation were run on the aggregated imputed data. None of the imputed datasets differed on descriptive statistics from the aggregated data or the original data. Means, standard deviations, minimums, and maximums for the imputed data are presented in Table 4.3.

Table 4.3. *Descriptive Statistics for Imputed Variables.*

Variable	**N**	**Mean**	**SD**	**Min.**	**Max.**
T15 Sibling Relationship closeness					
Original Data	47	67.213	17.578	24	89
Set 1	49	66.939	17.915	24	89
Set 2	49	66.918	17.950	24	89
Set 3	49	67.061	17.994	24	89
Set 4	49	66.939	17.915	24	89
Set 5	49	66.979	17.901	24	89
Aggregate	49	66.967	17.932	24	89
T18 Sibling Relationship closeness					
Original Data	46	66.400	14.588	27	87
Set 1	49	66.415	13.902	27	87
Set 2	49	66.317	13.998	27	87
Set 3	49	66.354	13.912	27	87
Set 4	49	66.390	13.869	27	87
Set 5	49	66.415	13.899	27	87
Aggregate	49	66.688	14.278	27	87
T18 Sibling Relationship Quality: Cooperation					
Original Data	77	88.961	22.245	36	126
Set 1	84	88.191	22.591	36	126
Set 2	84	88.167	22.614	36	126
Set 3	84	88.119	22.672	36	126
Set 4	84	88.143	22.592	36	126
Set 5	84	88.167	22.607	36	126
Aggregate	84	88.157	22.614	36	126
T18 Sibling Relationship Quality: Conflict					
Original Data	80	29.513	8.562	0	53
Set 1	84	29.643	8.459	0	53
Set 2	84	29.560	8.463	0	53
Set 3	84	29.548	8.501	0	53
Set 4	84	29.619	8.444	0	53
Set 5	84	29.593	8.437	0	53
Aggregate	84	29.593	8.457	0	53

Steps in Data Analysis

The data were double-checked for any coding errors. As coding errors were found, they were rectified using the hard copies of the data on file. The distributions of the data were assessed for outliers. Histograms and Shapiro-Wilk tests were used to determine normality on the cooperation, conflict, and sibling relationship closeness variables. These results will be discussed later in this section.

Created variables. The family SES composite at T15 and T18 was created using the respective *z* scores for the mother's years of education and the available data for the approximate annual family income at each age. Maternal years of education and approximate annual family income were positively and significantly correlated at each time point (r_{T15}=.48, p<.001; r_{T18}=.60, p<.001). The *z* scores for maternal years of education and approximate annual family income were added together to create the family SES composite variable at T15 and then at T18.

The teen functional skills composite variables at T15 and T18 were created using the respective *z* scores for the teen's cognitive performance (IQ) and adaptive skills (Vineland score) at each time point. Cognitive performance and adaptive skills were positively and significantly correlated at both T15 and T18 (r_{T15}=.84, p<.001; r_{T18}=.74, p<.001). The *z* scores for adaptive skills and cognitive performance were then summed to create the teen functional skills composite variable at T15 and then at T18.

To create the outcome variables of T18 sibling cooperation and T18 sibling conflict, a factor analysis was performed on the Sibling Relationship Questionnaire (Furman & Burhmester, 1985). Based on previous analyses using this questionnaire in this sample, a principal components analysis (PCA) with varimax rotation was performed forcing 3 factors in accordance with the original SRQ subscales collected for this sample (relative power/status, warmth, conflict). It was established that items from the relative power/status subscale of the original SRQ were loading on the same factor as the items from the warmth/closeness subscale (e.g. “How much do you teach your brother or sister things he/she doesn’t know?”). Therefore, a second PCA with varimax rotation was performed forcing two factors. The result was two discrete factors accounting for 57% of the variance. Factor 1 (eigenvalue=18.83, variance explained=44.84%) consisted of 29 items, and Factor 2 (eigenvalue=5.28, variance explained=12.57%) consisted of 13 items. Based on item content, it was determined that two types of items existed for this scale in this sample: those that described “cooperation” (Factor 1) between siblings, and those that described “conflict” (Factor 2) between siblings. Both subscales demonstrated high reliability ($\alpha_{\text{cooperation}}$ =.96, α_{conflict} =.94). Cooperation and conflict were treated as two separate outcomes for the remainder of the analyses. Results from the factor analysis can be found in Table 4.4a and Table 4.4b.

Table 4.4a. *Final Principal Components Analysis for the Sibling Relationship Questionnaire: Cooperation.*

	Loadings			
Item	*Factor1: Cooperation*	*Factor2: Conflict*	*Communality*	*Original subscale*
How much do both you and this brother or sister do nice things for each other?	**.828**	.238	.743	W/C
How much do you show this brother or sister how to do things he or she doesn't know how to do?	**.512**	.207	.305	RS/P
How much does this brother or sister show you how to do things you don't know how to do?	**.621**	.073	.391	RS/P
How much do you tell this brother or sister what to do?	**.388**	.120	.165	RS/P
How much does this brother or sister tell you what to do?	**.433**	-.101	.198	RS/P
How much do you and this brother or sister care about each other?	**.730**	.480	.763	W/C
How much do you and this brother or sister go places and do things together?	**.713**	.064	.513	W/C
How much do you and this brother or sister like the same thing?	**.850**	.173	.752	W/C
How much do you and this brother or sister tell each other everything?	**.706**	.125	.514	W/C
How much do you admire and respect this brother or sister?	**.752**	.287	.648	W/C
How much does this brother or sister admire and respect you?	**.750**	.416	.735	W/C
How much do you and this brother or sister cooperate with each other?	**.727**	.313	.627	W/C
How much do you help this brother or sister with things he or she can't do by him or herself?	**.604**	.098	.375	RS/P
How much does this brother or sister help you with things you can't do by yourself?	**.676**	-.066	.462	RS/P
How much do you and this brother or sister love each other?	**.672**	.318	.554	RS/P
How much do you and this brother or sister play around and have with each other?	**.821**	.230	.727	W/C
How much do you and this brother or sister have in common?	**.829**	.176	.718	W/C
How much do you and this brother or sister share secrets and private feelings?	**.684**	.149	.491	W/C
How much do you look up to and feel proud of this brother or sister?	**.797**	.194	.673	W/C
How much does this brother or sister look up to and feel proud of you?	**.807**	.233	.705	W/C
How much do you and this brother or sister share with each other?	**.793**	.241	.686	W/C
How much do you teach this brother or sister things that he or she doesn't know?	**.734**	.157	.564	RS/P
How much does this brother or sister teach you things that you don't know?	**.764**	.011	.584	RS/P
How much is there a strong feeling of affection (love) between you and this brother or sister?	**.690**	.353	.600	W/C
How much free time do you and this brother or sister spend together?	**.783**	.213	.659	W/C
How much are you and this brother or sister alike?	**.801**	.192	.678	W/C
How much do you and this brother or sister tell each other things you don't want other people to know?	**.699**	.041	.490	W/C
How much do you think highly of this brother or sister?	**.730**	.209	.577	W/C
How much does this brother or sister think highly of you?	**.753**	.293	.653	W/C

Note: C=Conflict, W/C=Warmth/Closeness, RS/P=Relative Power/Status

Table 4.4b. *Final Principal Components Analysis for the Sibling Relationship Questionnaire: Conflict and Total Variance.*

Item	*Factor 1: Cooperation*	*Factor 2: Conflict*	*Communality*	*Original Subscale*
How much do you and this brother or sister insult and call each other names?	.222	**.740**	.596	C
How much do you and this brother or sister try to out-do each other at things?	.255	**.801**	.707	RS/P
How much do you and this brother or sister disagree and quarrel with each other?	.342	**.770**	.710	C
How much do you make this brother or sister do things?	-.139	**.605**	.385	RS/P
How much does this brother or sister make you do things?	-.064	**.705**	.501	RS/P
How much are you and this brother or sister mean to each other?	.281	**.474**	.303	C
How much do you and this brother or sister compete with each other?	.213	**.694**	.527	C
How much do you and this brother or sister get made at and get in arguments with each other?	.235	**.824**	.735	C
How much do you order this brother or sister around?	.093	**.705**	.506	RS/P
How much does this brother or sister order you around?	.020	**.767**	.588	RS/P
How much do you and this brother or sister bug and pick on each other in mean ways?	.313	**.732**	.634	C
Eigenvalue	18.83	5.28		
% of Total Variance	44.81	12.57		
Total Variance	57%			

Note: C=Conflict, W/C=Warmth/Closeness, RS/P=Relative Power/Status

Distributions. Histograms and Shapiro-Wilk tests were used to assess normality of the distribution of sibling relationship closeness (T15 and T18), sibling cooperation (T18), and sibling conflict (T18). If the *p* value of the Shapiro-Wilk test is non-significant, normality can be assumed. The results indicated that the distributions for sibling cooperation, sibling conflict, T15 sibling relationship closeness, and T18 sibling relationship closeness were non-normal.

The distribution of sibling cooperation at T18 was not normal (W=.969, p=.042). The stem-leaf and box plots of this variable did not reveal any outliers. A histogram revealed that sibling cooperation was negatively skewed; it was first reflected before a square root transformation was performed. The transformed variable was then reflected back (Howell, 2007; Tabachnick & Fidell, 2007). A subsequent normality test indicated that the new variable was normally distributed (W=.978, p=.173). Therefore, the transformed variable was used in all subsequent analyses.

The distribution of sibling conflict was also not normal (W=.967, p=.033). The stem-leaf and box plots of this variable revealed one outlier with an extreme value of 0 (Case ID 2806). This value was changed to the nearest number in the distribution, 14, rather than deleting the case in order to preserve power. A subsequent normality test indicated a normal distribution of this variable (W=.971, p=.055).

The distribution of T15 sibling relationship closeness was not normal (W=.891, p<.001). The stem-leaf and box plots of this variable did not reveal any outliers. A histogram of this variable suggested that this variable was negatively skewed. Therefore, T15 sibling relationship closeness was first reflected before a square root transformation was performed. The transformed variable was then reflected back (Howell, 2007; Tabachnick & Fidell, 2007). A subsequent normality test indicated a normal distribution of this variable (W=.966, p=.164). Therefore, the transformed variable was used in all subsequent regression analyses.

The distribution of T18 sibling relationship closeness was not normal (W=.951, p=.003). It was noted that T18 sibling relationship closeness had one outlier (Case ID 406) with an extreme value of 27. This value was changed to the nearest number in the distribution, 34, rather than deleting the case in order to preserve power. A subsequent normality test indicated that this variable was still not normally distributed (W=.950, p=.003). Therefore, the variable was reflected and then a square root transformation was performed. The transformed variable was then reflected back (Howell, 2007; Tabachnick & Fidell, 2007). A subsequent normality test indicated that this variable was normally distributed (W=.989, p=.717). As a result, the transformed variable was used in all subsequent analyses.

Descriptive statistics. All child and family characteristics can be found in Table 4.5. For the teen with DD, percentages were calculated for gender (T15 and T18), diagnosis (T15 and T18), and ethnicity (T15 and T18). For the sibling of the teen with DD, percentages were calculated for gender (T15 and T18), sibling order (T15 and T18), and sibling gender match (T15 and T18). At T15, 61.2% of the teens with DD were male and 38.8% were female; 30.6% of the teens with DD were diagnosed with Down syndrome, 42.9% were diagnosed with a motor impairment, and 26.5% were diagnosed with DD of unknown etiology. In the sibling sample at T15, 46.9% of siblings were male and 53.1% were female. At T15, 55.1% of the siblings were younger than the teen with DD, while 44.9% of the siblings were older than the teen with DD; 36.7% of the siblings were the opposite gender as the teen with DD, and 63.7% of the siblings were the same gender as the teen with DD. The majority of families identified as Euro-American (89.8%) at T15.

At T18, 53% of the teens with DD were male and 47% were female; 34.5% of the teens with DD were diagnosed with Down syndrome, 36.6% were diagnosed with a motor impairment, and 28% were diagnosed with DD of unknown etiology. In the sibling sample at T18, 43.4% of the siblings were male and 56.6% were female. At T18, 52.4% of the siblings were younger than the teen with DD, while 46.4% of the siblings were older than the teen with DD; 40.5% of the siblings were the opposite gender as the teen with DD, and 59.5% of siblings were the same gender as the teen with DD. The majority of families identified as Euro-American (90.2%).

Table 4.5. *Child and Family Characteristics.*

Variable	**Percentage**
T15 Teen Gender	
Male	61.2
Female	38.8
T18 Teen Gender	
Male	53.0
Female	47.0
T15 Teen Diagnostic Category	
Down syndrome	30.6
Motor impairment	42.9
Unknown etiology	26.5
T18 Teen Diagnostic Category	
Down syndrome	34.5
Motor impairment	36.6
Unknown etiology	28.0
T15 Sibling Gender	
Male	46.9
Female	53.1
T18 Sibling Gender	
Male	43.4
Female	56.6
T15 Sibling Pair Gender Match	
Same gender	63.7
Opposite gender	36.7
T18 Sibling Pair Gender Match	
Same gender	59.5
Opposite gender	40.5
T15 Sibling Pair Order	
Sibling younger	55.1
Sibling older	44.9
T18 Sibling Pair Order	
Sibling younger	52.4
Sibling older	46.4
T15 Ethnicity	
Euro-American	89.8
Other	10.2
T18 Ethnicity	
Euro-American	90.2
Other	9.8

The means and standard deviations were calculated for the sibling's age at each time point, mother's years of education at each time point, and approximate annual family income at each time point. The mean age of the siblings at T15 was 14.90 years (SD=3.64). The range of sibling ages at T15 was age 7 to age 21. The mean years of education for mothers at T15 were 14.58 (SD=2.43). At T18, the mean age of the siblings was 18.19 years (SD=4.75). The range of sibling ages at T18 was age 10 to age 25. The mean years of education for mothers at T18 were 14.68 (SD=2.57). These means and standard deviations are presented in Table 4.6.

The means and standard deviations for family income, teen's cognitive performance, the teen's adaptive skills, and teen behavior problems for each time point can also be found in Table 4.6. As the mean and standard deviations for the composite variables "teen functional skills" and "family SES" are not meaningful, the variables from which they were created are presented in Table 4.6. The percentage of participants scoring above the clinical cutoff (*t* score ≥ 60.0) on the Child Behavior Checklist (CBCL) at each time point is reported in the above-mentioned table.

Table 4.6. *Descriptive Statistics of Control Variables at Both Time Points.*

Variable	**Mean**	**SD**	**Range**
Sibling Age			
T15	14.90	3.64	7-21
T18	18.19	4.75	10-25
Mother's Years of Education			
T15	14.58	2.43	
T18	14.68	2.57	
Approximate Annual Family Income			
T15	11.23 ($45,000-$49,999)	3.35 ($7,500-$9,999)	
T18	12.06 ($50,000-$54,999)	3.66 ($7,500-$9,999)	
Teen Cognitive Performance (Stanford-Binet)			
T15	61.74	28.67	
T18	69.00	25.05	
Teen Adaptive Skills (Vineland)			
T15	47.69	24.28	
T18	50.24	24.58	
Teen Behavior Problems (CBCL)			
T15	54.55 (25.5% above cutoff)	10.82	
T18	53.68 (24.4% above cutoff)	10.51	

Means and standard deviations for the T18 predictor variables used to address question 1 (concerns for the teen, discussion of the teen's future with parents, and sibling future roles) can be found in Table 4.7. The frequencies of responses to discussion of teen's needs with parents at T18 can also be found in Table 4.7. Means and standard deviations for the T15 predictor variables used to address research question 2 can be found in Table 4.8. The frequencies of responses to discussions of teen's needs with parents at T15 can also be found in Table 4.8. Finally, the means and standard deviations for each of the outcome variables used in the models for questions 1 and 2 can be found in Table 4.9.

Table 4.7. *Descriptive Statistics for Research Question 1 Predictor Variables.*

Variable	Frequency	Mean	SD
T18 Concerns for Teen		14.25	5.72
T18 Sibling Future Roles		13.13	5.75
T18 Discussion of Teen's Needs with Parents		3.02	1.12
Hardly at all	10 (12.2%)		
Not too much	11 (13.4%)		
Somewhat	37 (44.6%)		
Very much	15 (18.1%)		
Extremely much	9 (10.8%)		

Table 4.8. *Descriptive Statistics for Research Question 2 Predictor Variables.*

Variable	Frequency	Mean	SD
T15 Sibling Expectations		5.43	2.78
T15 Sibling Pessimism		2.91	2.24
T18 Discussion of Teen's Needs with Parents		1.06	0.60
Not at all	7 (14.6%)		
Sometimes	31 (64.6%)		
Very often	10 (20.4%)		

Table 4.9. *Descriptive Statistics for Outcome Variables for Research Questions 1 & 2.*

Variable	Mean	SD
Sibling Relationship closeness		
T15	66.97	17.93
T18	66.31	13.83
T18 Sibling Cooperation Score	88.15	22.75
T18 Sibling Conflict Score	29.42	8.36

Preliminary Analyses

Preliminary analyses included two-way analysis of variance (ANOVA) and bivariate correlations. These analyses were performed in order to determine which variables must be included in the final analyses, and which variables could be excluded to preserve power.

First, two-way analysis of variance (ANOVA) was used to test for main effects and interaction effects between diagnostic group (Down syndrome, motor impairment, and unknown etiology) and teen gender among the criterion variables. Analyses revealed that there were no differences in T18 sibling relationship closeness by diagnostic group (*F*(2, 48)=.87, *p*=.43) or teen gender (*F*(1, 48)=.96, *p*=.33). There was no interaction between diagnostic group and gender (*F*(2, 48)=.05, *p*=.95).

Analyses indicated that there were no differences in T18 sibling cooperation by diagnostic group (*F*(2, 82)=.34, *p*=.71) or teen gender (*F*(1, 82)=.28, *p*=.60). There was no interaction between diagnostic group and gender (*F*(2, 82)=.32, *p*=.72). Additionally, analyses revealed that there were no differences in T18 sibling conflict by diagnostic group (*F*(2, 82)=.98, *p*=.38) or teen gender (*F*(1, 82)=1.45, *p*=.23). There was no interaction between diagnostic group and gender (*F*(2, 82)=2.90, *p*=.07).

Next, two-way analysis of variance was also used to test for main effects and interaction effects between sibling gender match (same gender and opposite gender) and sibling order (sibling older than teen with DD and sibling younger than teen with DD) among the T15 criterion variables. Analyses indicated that there were no differences in

T18 sibling relationship closeness by sibling gender match (*F*(1, 82)=1.41, *p*=.24) or by sibling order (*F*(1, 82)=1.30, *p*=.26). There was no interaction between sibling gender match and sibling order (*F*(2, 82)=1.63, *p*=.21).

Analyses indicated that there was a difference in T18 sibling cooperation by sibling gender match (*F*(1, 82)=5.58, *p*=.02) so that sibling pairs that were the same gender had higher scores on cooperation (mean of 93.36) than sibling pairs that were opposite gender (mean of 81.74). There was no main effect of sibling order on T18 sibling cooperation (*F*(1, 82)=2.59, *p*=.11). There was no interaction between sibling gender match and sibling order (*F*(2, 82)=1.07, *p*=.31).

Analyses revealed that there was no difference in T18 sibling conflict by sibling gender match (*F*(1, 82)=.51, *p*=.48). There was a main effect of sibling order on T18 sibling conflict (*F*(1, 82)=7.86, *p*=.01) such that sibling pairs in which the sibling was younger than the teen with DD had higher conflict scores (mean of 31.66) than those in which the sibling was older than the teen with DD (mean of 26.54). There was no significant interaction between sibling order and sibling gender match (*F*(2, 82)=.42, *p*=.52).

Next, two-way ANOVA was used to test for interaction effects of diagnostic group with sibling gender match and diagnostic group with sibling order among the criterion variables. Analyses revealed that there were no interaction effects of diagnostic group with sibling gender match for T18 sibling relationship closeness (*F*(2, 82)=.32, *p*=.73), for T18 sibling cooperation (*F*(2, 82)=.66, *p*=.52), or for T18 sibling conflict (*F*(2, 82)=.21, *p*=.81). In addition, analyses also indicated that there were no interaction effects of diagnostic group with sibling order for T18 sibling relationship closeness (*F*(2, 82)=.07, *p*=.94), for T18 sibling cooperation (*F*(2, 82)=1.36, *p*=.26), or for T18 sibling conflict (*F*(2, 82)=3.08, *p*=.06).

Finally, two-way ANOVA was used to test for interaction effects of teen gender and sibling order among the criterion variables. Analyses revealed that there were not interaction effects for T18 sibling relationship closeness (*F*(2, 82)=1.71, *p*=.20), for T18 sibling cooperation (*F*(2, 82)=1.89, *p*=.17), or for T18 sibling conflict (*F*(2, 82)=.04, *p*=.84).

Bivariate correlations were run between sibling age, research question 1 and 2 predictor variables, and the outcome variables. The correlations for the predictor variables for research question 1 can be found in Table 4.10. The correlations for the predictor variables for research question 2 can be found in Table 4.11.

Table 4.10. *Correlations Between Predictor Variables and T18 Cooperation and Conflict – Research Question 1.*

	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
1. T18 SES	--	.16	-.02	-.01	-.04	-.11	-.10	-.03	.02	-.01
2. T18 Functional Skills		--	.01	.03	-.12	-.26*	-.52**	-.65**	.06	.17
3. T18 Sibling Order			--	.10	.12	-.01	.24*	.08	.15	-.28**
4. T18 Sibling Gender Match				--	.04	-.01	-.07	.05	.25*	.02
5. T18 Behavior Problems					--	.13	.07	.05	.09	.16
6. T18 Concerns						--	.37**	.30**	-.04	.10
7. T18 Discussion of Needs							--	.46**	.34**	-.10
8. T18 Future Roles								--	.40**	-.14
9. T18 Sibling Cooperation									--	-.09
10. T18 Sibling Conflict										--

Note: *=*p*<.05, **=*p*<.01

Table 4.11. *Correlations Between Predictor Variables and T18 Sibling Relationship closeness – Research Question 2.*

	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
1. T15 SES	--	.04	-.11	-.03	-.11	-.04	-.12	.11	-.13	-.10
2. T15 Functional Skills		--	.10	-.07	-.02	-.38*	.71**	-.32*	.18	-.08
3. T15 Sibling Order			--	-.08	-.03	.33*	.07	.06	.88**	.12
4. T15 Sibling Gender Match				--	-.15	.01	.01	.06	-.09	.08
5. T15 Behavior Problems					--	.24	-.02	.31*	-.12	-.37*
6. T15 Talk About Teen's Needs						--	-.35*	.23	.17	.01
7. T15 Expectations							--	-.36*	.15	.17
8. T15 Pessimism								--	-.07	-.51**
9. T15 Sibling Age									--	.06
10. T18 Sibling Relationship closeness										--

Note: *=*p*<.05, **=*p*<.01

The bivariate correlations for the variables involved in research question 1 indicate that T18 sibling order was significantly related to the outcome of T18 sibling conflict (r=-.28, p<.05). This supports what was discovered in the aforementioned ANOVA analyses. Sibling gender match at T18 was significantly related to the outcome of T18 sibling cooperation (r=-.25, p<.05). Child behavior problems were not significantly related to the outcome of T18 sibling cooperation (r=.09, p=.44) or the outcome of T18 sibling conflict (r=.16, p=.15). Additionally, T18 family SES and T18 teen functional skills were also not significantly related to either outcome of T18 sibling cooperation or T18 sibling conflict.

Regarding the predictor variables for research question 1, the frequency at which siblings discussed the needs of the teen with DD with their parents and the sibling's future roles in the teen with DD's life were both significantly related to the outcome of T18 sibling cooperation (r=.34, p<.01 and r=.40, p<.01, respectively). In other words, siblings who expected a greater number of future roles and who discussed the teen's needs more frequently with their parents, reported higher levels of sibling cooperation. None of the predictor variables for research question 1 were significantly correlated with the outcome of T18 sibling conflict.

The bivariate correlations for the variables involved in research question 2 indicate that T15 teen behavior problems were significantly related to the outcome of T18 sibling relationship closeness (r=-.37, p<.01). Siblings of teens with higher behavior problems reported lower relationship closeness than siblings of teens with lower behavior problems. The outcome variable of T18 sibling relationship closeness was not significantly related to T15 family SES (*r*=-.10, *p*=.48), T15 teen functional skills (*r*=-.08, *p*=.56), T15 sibling order (*r*=.12, *p*=.43), or T15 sibling gender match (*r*=.08, *p*=.57).

The bivariate correlations between the outcomes used to address research question 1 and those used to address research question 2 are presented in Table 4.12 for the paired sample of siblings who participated in the study at both T15 and T18.

Table 4.12. *Bivariate Correlations Between Outcome Variables for Research Question 1 and Research Question 2.*

	1	**2**	**3**
1. T18 Sibling Relationship Closeness	--	.71**	-.03
2. T18 Sibling Cooperation		--	.09
3. T18 Sibling Conflict			--

Note: *=*p*<.05, **=*p*<.01

Bivariate correlations between outcome variables for research question 1 and research question 2 reveal that sibling relationship closeness at T18 was significantly correlated to T18 sibling cooperation (*r*=.71, *p*<.01). Sibling conflict at T18 was not significantly correlated to either T18 sibling cooperation (*r*=.09, *p*=.44) or T18 sibling relationship closeness (*r*=-.03, *p*=.83).

Research Question Results

In this section the results for each research question will be reported. A summary of the results of each question is available in Table 4.17 and Table 4.18 on pages 118 and 119, respectively.

As indicated in the correlation analyses reported above, T18 teen behavior problems were not significantly related to either outcome of T18 sibling cooperation or T18 sibling conflict. This variable was initially included in the proposed regression analyses. Upon review, it became clear that T18 teen behavior problems did not add any additional variance to the models. Consequently, this variable was excluded from the final models in order to preserve power. Additionally, according to the bivariate correlation analyses, sibling gender match was related to T18 sibling cooperation, while T18 sibling order was related to T18 sibling cooperation. These variables were not initially included in the proposed regression analyses. However, upon review, it was noted that these variables did contribute additional variance to the models. Therefore, both variables were added to both regression models used to address research question 1. All other variables were included as written.

Research Question 1. How do future planning issues impact the sibling relationship quality when the teen with DD is 18 years of age?

Research Question 1a. Are concurrent concerns for the teen, discussion of the teen's needs and sibling future roles associated with sibling cooperation, above and beyond control variables?

Research Question 1b. Are concurrent concerns for the teen, discussion of the teen's needs and sibling future roles associated with sibling conflict, above and beyond control variables?

Sibling cooperation and sibling conflict at T18 were analyzed in separate regression models, resulting in two OLS hierarchical regression analyses, one for each outcome (Pedhazur, 1997). The regression analysis for research question 1a included sibling cooperation regressed on the predictor variables entered in the following steps: 1) Family SES at T18; 2) Teen functional skills at T18; 3) Sibling gender match at T18; 4) Sibling order at T18; 5) Sibling concerns for the teen at T18; 6) Frequency of discussion of teen's needs at T18; 7) T18 Future roles of the sibling, resulting in the following model:

(Y1) T18 Sibling Cooperation = a + b_1*SES_1 + b_2*T18 teen functional skills + b_3*T18 sibling gender match + b_4*T18 sibling order + b_5*T18 sibling concerns + b_6*T18 discussion of needs + b_7*T18 sibling future roles +e

Results indicated that higher levels of teen functional skills at T18 were associated with higher levels of sibling cooperation while controlling for concurrent family SES. Additionally, sibling gender match was significantly related to sibling cooperation at T18, so that same-gender sibling pairs reported higher levels of cooperation than opposite-gender sibling pairs (β=.465, p<.05). The level of frequency at which siblings discussed the teen with DD's needs with their parents was also significantly associated with sibling cooperation at T18, so that siblings who discussed the teen's needs more frequently also reported more sibling cooperation (β=.446, p<.01). Finally, the total number of roles that siblings expected to fill in the teen's future was also significantly related to sibling cooperation at T18, so that siblings who expected to fill more roles in the teen with DD's future also reported higher levels of cooperation when the teen with DD was 18 years old (β=.511, p<.001). The results for research question 1a can be found in Table 4.13.

Table 4.13. *Hierarchical Regression Analyses for Research Question 1a, Model Y1: Variables Associated with T18 Sibling Cooperation.*

	B	***SE***	***β***	**ΔR^2**	**Model R^2**
Model 1					.001
T18 SES	-.035	.233	-.030	.001	
Model 2					.003
T18 SES	-.026	.137	-.022	.001	
T18 Teen Functional Skills	-.055	.128	-.051	.003	
Model 3					.097
T18 SES	-.026	.131	-.022	.001	
T18 Teen Functional Skills	-.078	.123	-.071	.003	
T18 Sibling Gender Match	1.265	.461	.306**	.093**	
Model 4					.102
T18 SES	-.023	.132	-.019	.001	
T18 Teen Functional Skills	-.081	.124	-.074	.003	
T18 Sibling Gender Match	1.233	.465	.298*	.093**	
T18 Sibling Order	.289	.454	.072	.005	
Model 5					.103
T18 SES	-.020	.133	-.017	.001	
T18 Teen Functional Skills	-.071	.127	-.065	.003	
T18 Sibling Gender Match	1.237	.468	.299*	.093**	
T18 Sibling Order	.287	.457	.071	.005	
T18 Sibling Concerns	.015	.041	.041	.002	
Model 6					.236
T18 SES	-.139	.128	-.110	.001	
T18 Teen Functional Skills	.198	.141	.182	.003	
T18 Sibling Gender Match	1.284	.435	.311**	.093**	
T18 Sibling Order	-.209	.448	-.052	.005	
T18 Sibling Concerns	-.038	.041	-.107	.002	
T18 Talk About Needs	.879	.252	.494**	.132**	
Model 7 (Final Model)					.380
T18 SES	-.168	.117	-.144	.001	
T18 Teen Functional Skills	.507	.150	.265**	.003	
T18 Sibling Gender Match	1.056	.399	.256*	.093**	
T18 Sibling Order	-.209	.407	-.052	.005	
T18 Sibling Concerns	-.069	.038	-.194	.002	
T18 Talk About Needs	.793	.230	.446**	.132**	
T18 Sibling Roles	.185	.046	.511***	.144***	

Note: *=*p*<.05, **=*p*<.01, ***=*p*<.001

The regression analysis for research question 1b included sibling conflict regressed on the predictor variables entered in the following steps: 1) Family SES at T18; 2) Teen functional skills at T18; 3) Sibling gender match at T18; 4) Sibling order at T18; 5) Sibling concerns for the teen at T18; 6) Frequency of discussion of teen's needs at T18; 7) T18 Future roles of the sibling, resulting in the following model:

(Y2) T18 Sibling Conflict = a + b_1*SES1 + b_2*T18 teen functional skills + b_3*T18 sibling gender match + b_4*T18 sibling order + b_5*T18 sibling concerns + b_6*T18 discussion of needs + b_7*T18 sibling future roles +e

Results indicated that sibling order at T18 was associated with levels of sibling conflict such that siblings who were older than the teen with DD reported lower sibling conflict than those who were younger than the teen with DD (β=-.302, p<.05). The remaining predictor variables did not relate significantly to sibling conflict at T18. The results for research question 1b can be found in Table 4.14.

Table 4.14. *Hierarchical Regression Analyses for Research Question 1b, Model Y2: Variables Associated with T18 Sibling Conflict.*

	B	*SE*	*β*	ΔR²	Model R²
Model 1					.000
T18 SES	.003	.537	.001	.000	
Model 2					.026
T18 SES	-.113	.540	-.024	.000	
T18 Teen Functional Skills	.711	.504	.164	.026	
Model 3					.026
T18 SES	-.113	.543	-.024	.000	
T18 Teen Functional Skills	.707	.508	.163	.026	
T18 Sibling Gender Match	.213	1.904	.013	.000	
Model 4					.108
T18 SES	-.157	.524	-.034	.000	
T18 Teen Functional Skills	.760	.490	.175	.026	
T18 Sibling Gender Match	.713	1.846	.043	.000	
T18 Sibling Order	-4.624	1.803	-.288*	.082	
Model 5					.128
T18 SES	-.115	.523	-.025	.000	
T18 Teen Functional Skills	.895	.500	.206	.026	
T18 Sibling Gender Match	.763	1.839	.046	.000	
T18 Sibling Order	-4.648	1.785	-.289*	.082	
T18 Sibling Concerns	.203	.160	.145	.020	
Model 6					.129
T18 SES	-.164	.546	-.035	.000	
T18 Teen Functional Skills	1.006	.601	.232	.026	
T18 Sibling Gender Match	.782	1.851	.048	.000	
T18 Sibling Order	-4.853	1.906	-.302*	.082	
T18 Sibling Concerns	.181	.174	.129	.020	
T18 Talk About Needs	.462	1.072	.051	.001	
Model 7 (Final Model)					.132
T18 SES	-.147	.550	-.032	.000	
T18 Teen Functional Skills	.827	.705	.191	.026	
T18 Sibling Gender Match	.914	1.880	.056	.000	
T18 Sibling Order	-4.853	1.916	-.302*	.082	
T18 Sibling Concerns	.199	.178	.142	.020	
T18 Talk About Needs	.412	1.083	.058	.001	
T18 Sibling Roles	-.107	.218	-.075	.003	

Note: *=$p<.05$, **=$p<.01$, ***=$p<.001$

Research Question 2. Is there a change in sibling relationship closeness from when the teen is age 15 to when the teen is age 18?

Research Question 2a. Is the change associated with sibling expectations or pessimism for the teen with a disability?

Research Question 2b. Is the change associated with how often siblings talk to parents about the teen's needs at T15?

To address research questions 2, 2a, and 2b, only siblings who participated at both T15 and T18 were included in the analyses, for a sample of 49 sibling pairs. For research question 2, a repeated measures ANCOVA was used to assess if there was a change in sibling relationship closeness from T15 to T18 while controlling for T15 family SES, teen functional skills, and teen diagnostic category. Results indicated that there was a difference in sibling relationship closeness between T15 and T18, even after controlling for family SES, teen functional skills, and teen diagnostic category (F=4.640, p<.05). Generally, sibling relationship closeness decreased slightly from T15 to T18 (Mean at T15=66.97, Mean at T18=66.57).

As mentioned, T15 behavior problems were significantly related to the outcome variable of T18 sibling relationship closeness in the bivariate correlations. Consequently, T15 behavior problems will be kept in the final regression analyses, as had been originally proposed. All other variables are included as originally proposed. The lagged hierarchical regression analysis for research question 2a included sibling relationship closeness at T18 regressed on the predictor variables entered in the following steps: 1) T15 Sibling relationship closeness (mean centered); 2) T15 Family SES; 3) T15 Teen functional skills; 4) T15 Teen behavior problems; 5) T15 Sibling expectations for teen's future; 6) T15 Sibling pessimism for teen's future, resulting in the following model:

(Y3) T18 Sibling Relationship closeness = a + b_1*T15 sibling relationship closeness 1 + b_2*T15 family SES + b_3*T15 teen functional skills + b_4*T15 teen behavior problems + b_5*T18 sibling expectation + b_6*T18 sibling pessimism + e

Results indicated that neither sibling expectations nor sibling pessimism for the teen's future at T15 were significantly associated with a change in sibling relationship closeness from T15 to T18. However, sibling pessimism was related to the change in sibling relationship closeness at trend level (β=-.272, p=.056). As sibling expectations were not significant in this model, they were dropped and the lagged regression was re-run. However, pessimism was still related to change in sibling relationship closeness at trend level (β=-.187, p=.056). This will be discussed in Chapter 5. Results for research question 2a can be found in Table 4.15.

Table 4.15. *Lagged Hierarchical Regression Analyses for Research Question 2a, Model Y3: Variables Associated with T18 Sibling Relationship Closeness.*

	B	***SE***	***β***	**ΔR^2**	**Model R^2**
Model 1					.426
T15 Sibling Relationship closeness	.539	.091	.652***	.426***	
Model 2					.429
T15 Sibling Relationship closeness	.550	.095	.666***	.426***	
T15 SES	.051	.105	.056	.003	
Model 3					.432
T15 Sibling Relationship closeness	.548	.096	.664***	.426***	
T15 SES	.052	.105	.058	.003	
T15 Teen Functional Skills	-.048	.091	-.060	.004	
Model 4					.467
T15 Sibling Relationship closeness	.494	.099	.598***	.426***	
T15 SES	.019	.105	.020	.003	
T15 Teen Functional Skills	-.053	.089	-.065	.004	
T15 Teen Behavior Problems	-.028	.017	-.198	.035	
Model 5					.478
T15 Sibling Relationship closeness	.457	.106	.554***	.426***	
T15 SES	.029	.106	.032	.003	
T15 Teen Functional Skills	-.148	.135	-.184	.004	
T15 Teen Behavior Problems	-.030	.017	-.209	.035	
T15 Sibling Expectations	.090	.095	.163	.011	
Model 6 (Final Model)					.521
T15 Sibling Relationship closeness	.350	.117	.424**	.426***	
T15 SES	.035	.103	.038	.003	
T15 Teen Functional Skills	-.219	.135	-.271	.004	
T15 Teen Behavior Problems	-.023	.017	-.163	.035	
T15 Sibling Expectations	.088	.092	.159	.011	
T15 Sibling Pessimism	-.186	.095	-.272†	.044†	

Note: *=p<.05, **=p<.01, ***=p<.001, †= trend level, p>.05

The lagged hierarchical regression analysis for research question 2a included sibling relationship closeness at T18 regressed on the predictor variables entered in the following steps: 1) T15 Sibling relationship closeness (mean centered); 2) T15 Family SES; 3) T15 Teen functional skills; 4) T15 Teen behavior problems; 5) Frequency of discussion of teen's needs at T15, resulting in the following model:

(Y4) T18 Sibling Relationship closeness = a + b_1*T15 sibling relationship closeness (centered) + b_2*T15 family SES + b_3*T15 teen functional skills + b_4*T15 teen behavior problems + b_5*T18 discussion of needs + e

Results indicated that the frequency at which siblings discussed the teen's needs with their parents did not significantly relate to the change in sibling relationship closeness from T15 to T18 (β=.060, p=.633). Results for research question 2b can be found in Table 4.16.

Table 4.16. *Lagged Hierarchical Regression Analyses for Research Question 2b, Model Y4: Variables Associated with T18 Sibling Relationship Closeness.*

	B	***SE***	***β***	**ΔR^2**	**Model R^2**
Model 1					.431
T15 Sibling Relationship Closeness	.547	.093	.547***	.431***	
Model 2					.436
T15 Sibling Relationship Closeness	.563	.097	.676***	.431***	
T15 SES	.066	.107	.072	.005	
Model 3					.439
T15 Sibling Relationship Closeness	.560	.098	.673***	.431***	
T15 SES	.066	.108	.072	.005	
T15 Teen Functional Skills	-.040	.092	-.049	.002	
Model 4					.470
T15 Sibling Relationship Closeness	.505	.102	.606***	.431***	
T15 SES	.030	.108	.032	.005	
T15 Teen Functional Skills	-.047	.091	-.058	.002	
T15 Teen Behavior Problems	-.027	.017	-.190	.031	
Model 5 (Final Model)					.473
T15 Sibling Relationship Closeness	.503	.103	.604***	.431***	
T15 SES	.029	.109	.032	.005	
T15 Teen Functional Skills	-.029	.099	-.035	.002	
T15 Teen Behavior Problems	-.029	.018	-.205	.031	
T15 Discussion of Needs	.156	.325	.060	.003	

Note: *=p<.05, **=p<.01, ***=p<.001

Table 4.17. *Summary of the Results from Quantitative Analyses: Research Question 1.*

Research Question	Results
Research Question 1:*How do future planning issues impact the sibling relationship quality when the teen is 18 years of age?*	
Research Question 1a: *Are concurrent concerns for the teen, discussion of the teen's needs and sibling future roles associated with sibling cooperation above and beyond control variables?*	Results indicated that higher levels of teen functional skills were associated with higher levels of sibling cooperation while controlling for concurrent family SES. Sibling gender match was significantly related to sibling cooperation at T18, so that same-gender sibling pairs reported higher levels of cooperation than opposite-gender sibling pairs. The level of frequency at which siblings discussed the teen with DD's needs with their parents was also significantly associated with sibling cooperation, so that siblings who discussed the teen's needs more frequently also reported more sibling cooperation. The total number of roles that siblings expect to fill in the teen's future was also significantly related to sibling cooperation, so that siblings who expected to fill more roles in the teen's future also reported higher levels of cooperation.
Research Question 1b: *Are concurrent concerns for the teen, discussion of the teen's needs and sibling future roles associated with sibling conflict above and beyond control variables?*	Results indicated that sibling order was associated with levels of sibling conflict so that siblings who were older than the teen reported lower sibling conflict than those who were younger than the teen.

Table 4.18. *Summary of Results from Quantitative Analyses: Research Question 2*

Research Questions	Results
Research Question 2: *Is there a change in sibling relationship closeness from when the teen is age 15 to when the teen is age 18*	Results indicated that there was a difference in sibling relationship closeness between T15 and T18, even after controlling for family SES, teen functional skills, and teen diagnostic category. Sibling relationship closeness generally decreases from T15 to T18.
Research Question 2a: *Is the change associated with sibling expectation or pessimism for the teen's future?*	Results indicated that sibling expectations for the teen's future at T15 was not significantly associated with a change in sibling relationship closeness from T15 to T18. Sibling pessimism was related to the change in sibling relationship closeness at trend level.
Research Question 2b: *Is the change predicted by how often siblings talk to parent's about teen's needs at T15?*	Results indicated that the frequency at which siblings discussed the teen's needs with their parents did not significantly relate to the change in sibling relationship closeness from T15 to T18.

Qualitative Results

To address research questions 3 and 4, siblings' written responses to open-ended questions were analyzed using qualitative content analysis. Prior to presenting the results, I will first summarize the preparation phase of data analysis. As the research questions indicate, a separate set of codes was developed for each question the siblings responded to. Consequently, the results for each question will be presented in response to the research questions, followed by an integration of findings across questions. The results for each question will include results regarding interrater reliability. Results for the interrater reliability for research questions 3a, 3b, 3c, 3d, and 4 can be found in Table 4.24 on page 177.

As discussed in chapter 3 of this dissertation, several decisions needed to be made prior to beginning data analysis. First, as mentioned earlier, this dissertation took an inductive approach to data analysis. This is an approach in which the codes and categories identified are strongly connected to the data themselves (Patton, 1990). The categories identified were not driven by a particular theoretical interest but, rather, the data were coded without trying to make it fit to any preconceptions. Next, it was decided that the unit of analysis would depend, to some extent on, the case. For most cases, this meant that the unit of analysis was a sentence. However, as some siblings chose to present bulleted lists for their answers as opposed to putting their responses in a sentence structure, the unit of analysis was sometimes a word. Finally, and similarly, only semantic (explicit) themes were coded, as opposed to latent (interpretive) themes (Boyatzis, 1998). In this way, only the "manifest content" was analyzed (Graneheim &

Lundman, 2004). By only identifying explicit codes, the significance of themes can be theorized in relation to an existing literature base, rather than theorizing prior to identifying the codes (as is the case when identifying latent codes).

Results for all the qualitative research questions are presented in the following format:

Categories.

Themes.

Initial codes.

Research Question 3. What are the siblings' feelings about their brother or sister with a disability in the present and about the future of their brother or sister with a disability?

Research Question 3a. What makes siblings proud of their brother or sister when the teen is 18?

Siblings reported two capacities in which the teen made them feel proud: the teen's positive personal characteristics and the teen's accomplishments. Results from the qualitative content analysis for research question 3a can be found in Table 4.19. Interrater reliability was calculated on a random 20% of the data before proceeding to further analysis. This was done for level 1 codes (the themes) and then again for level 2 codes (the categories). The initial interrater reliability for the level 1 codes for research question 3a was within the almost perfect reliability range (Kappa=.825, p<.001). The decision was made to continue coding the remainder of the cases. Interrater reliability was recalculated with all 49 cases. Interrater reliability continued to be near perfect (Kappa=.885, p<.001). The initial interrater reliability for the level 2 codes for research question 3a was near perfect (Kappa=.833, p<.001). The decision was made to continue coding the remainder of the cases. Interrater reliability was recalculated with all 49 cases. Interrater reliability remained almost perfect (Kappa=.886; p<.001).

Positive personal characteristics. Siblings spoke of the teen's positive personal characteristics more often than then noted their concrete accomplishments. Within this category of being proud of the teen's personal characteristics, four sub-categories were identified.

Teen has a strong work ethic. First, some siblings accentuated their pride in the teen's strong work ethic. These siblings noted that the teen worked hard to accomplish their goals consistently and that the siblings admired them for that quality. The initial codes included in this sub-category were the teen works hard, the teen perseveres, and the teen tries his or her best. One sibling stated,

> My brother has made me so proud in accomplishing things I never though possible. He puts in a great deal of effort and it pays off in all he has become able to do.

Similarly, another sibling had this to say about the teen:

> She NEVER gives up. If everyone had her determination, there would be a cure for cancer and world peace! She never complains about what she doesn't have. She just works harder.

Teen has good interpersonal skills. Many siblings emphasized that the teen got along with people very well. Often this included comments that the teen was well-loved by everyone and that they were always kind or a good person. The initial codes in this sub-category were teen inspires people, teen is always smiling, teen is friendly, teen has positive energy/attitude, teen does not judge others, and teen does good/nice things. One sibling remarked,

> My sister faces life each and every day with a smile on her face and a loving and caring attitude towards everyone, especially the ones she loves the most. Her positive attitude and energy make me SO proud of her.

Likewise, another sibling reported,

> [TEEN] makes me proud in so many ways, it's impossible to write them all down. She has paved a pathway for other people in her situation. She is not shy. She would never hurt anyone.

Teen has strong intrapersonal skills. Some siblings observed that the teen had a very strong set of intrapersonal skills. This sub-category highlighted that the siblings were proud of the teen for their unique ability to be self-aware and be a distinctive, independent person. These siblings were proud of the teen for his or her inspiring ability to know themselves. The initial codes included in this sub-category included: teen does not let people get to him/her and teen does not care that he/she is different. One sibling put it,

> The way he fights the stress of being a different person. He doesn't care that he's different.

And another observed,

> She just likes to be herself and doesn't let people bother her.

Teen demonstrates resilience. Finally, siblings mentioned that the teen overcame obstacles and demonstrated resilience. Often these siblings explained that the teen was able to overcome obstacles despite their disability. Initial codes subsumed by this sub-category were teen accomplishes undertakings in spite of their disability, teen does things people never thought he/she could do, and teen overcomes obstacles. For example, one sibling noted,

> The way that even with her disability she still tries her hardest to be the best that she can be.

While another sibling noted,

> My sister has made me proud because even though she has Down syndrome, she's able to do many things that normal kids can do.

Teen's concrete accomplishments. The second sub-category involved concrete accomplishments that made the sibling proud of the teen. Most of these siblings remarked on the school accomplishments of the teen, while some siblings focused more on accomplishments in sports or activities and daily living skills. For siblings that mentioned the teen's concrete accomplishments, most simply listed them. It was not often that these siblings explained why they were proud of the teen in more depth.

School accomplishments. Many of the siblings who remarked on the teen's concrete accomplishments mentioned how well the teen did in school. All of these points of pride fell into four initial codes: academic awards, graduation, going to/getting into college, and getting good grades. Nearly all of the siblings who noted school accomplishments merely listed them, rather than explaining as they had done for the teen's personal characteristics.

Sports/activities. Some siblings commented on the teen's accomplishments in sports or activities. Again, nearly all of these siblings merely listed the activities rather than explaining them in a text. Initial codes in this sub-category were sports, dance, Special Olympics, and art. Examples of sports or activities that siblings mentioned were basketball, drawing, and manager of the varsity football team.

Daily living skills. Some siblings remarked on their pride in the teen's accomplishment of or improvement upon daily living skills. These ranged from social skills, to motor skills, to communication skills. Of the siblings who commented on daily living skills when asked about how the teen made them proud, most of them mentioned motor skills (walking, feeding themselves). Some siblings mentioned communication (speaking, communication with family improved) and some noted social skills (appropriate social reactions). One sibling mentioned being proud of the teen when he received his driver's license.

Table 4.19. *Results from Qualitative Content Analysis: Research Question 3a.*

In what way has your brother or sister made you proud?

Category	Sub-category	Initial Codes
Teen's personal characteristics	Work ethic	Works hard Perseveres Tries his/her best
	Interpersonal skills	Is always smiling Is friendly Does nice/good things Inspires people Has positive energy/attitude Does not judge others
	Intrapersonal skills	Does not let people get to him/her Does not care that he/she is different
	Resilience	Does things in spite of disability Overcomes obstacles Does things people did not think he/she could do
Teen's concrete accomplishments	School	Receives awards Graduated from high school Went to college Gets good grades/does well in school
	Activities/sports	Sports Dance Art Special Olympics

Research Question 3b. What are the siblings' concerns about their brother or sister's future when the teen is 18?

Qualitative content analysis of the T18 sibling responses revealed that siblings reported six categories of concerns for the teen's future: concerns regarding the teen's level of independence, concerns regarding social skills, concerns regarding society, concerns regarding health, concerns regarding uncertainty after parents die, and no concerns. Results from the qualitative content analysis for research question 3b can be found in Table 4.20. The initial interrater reliability for the level 1 codes for research question 3b was within the almost perfect agreement range (Kappa=.899, *p*<.001). The decision was made to continue coding the remainder of the cases. Interrater reliability was recalculated with all 49 cases. Interrater reliability remained near perfect (Kappa=.885, *p*<.001). The initial interrater reliability for the level 2 codes for research question 3b was within the almost perfect agreement range (Kappa=.833, *p*<.001). The decision was made to continue coding the remainder of the cases. Interrater reliability remained near perfect when all the cases were included (Kappa=.886, *p*<.001). The initial interrater reliability for the level 2 codes for research question 3b was near perfect (Kappa=1.00, *p*<.001). The decision was made to continue coding the remainder of the cases. Interrater reliability was recalculated with all 49 cases. Interrater reliability remained almost perfect(Kappa=.911; *p*<.001).

Level of independence. Many siblings expressed a concern regarding the teen's level of future independence. The main concern for these siblings appeared to be that the teen wouldn't be able to live independently, but that was not the only concern raised. The themes included in the level of independence concerns were: independent living, finances and jobs, and that the teen depends too much on the family. This category was, by far, the most frequent concern of siblings regarding the teen's future.

Independent living. Some siblings expressed concern regarding whether or not the teen would be able to live on his or her own in the future. Most of the siblings noting this concern remarked that teen cannot live alone in the future and would need care or supervision. Some siblings articulated uncertainty around the teen's future living arrangement, and simply asked "where will he or she live in the future?". Examples of initial codes for the former are:

> I am worried if she is going to live by herself and be okay.
>
> I worry that my sister will not be able to function on her own and always will need to monitored or assisted in some way.

Finances/jobs. Many siblings articulated concern that the teen wouldn't be able to get or hold down a job. Some of these siblings noted that the teen would not be able to financially support themselves. Initial codes for worries regarding future jobs or finances included: the teen will need someone to support them financially, the teen will not get a job, and the teen will not be able to make his or her own money. For example, one sibling noted,

> I worry she will never be able to live on her own financially.

While a few siblings stated,

> That [TEEN] won't get a job.

Many of the siblings who noted a concern in finances or jobs for the future also were concerned with independent living. These sub-categories co-occurred for nearly all the siblings who mentioned them. For example, one sibling expressed,

> I worry about how independent she'll be able to be and the kind of job that she'll be able to get.

This type of statement was not uncommon among the siblings. Perhaps the reason for this is that a large piece of being able to live independently is being able to financially support oneself.

Teen depends too much on the family. Some siblings expressed concern that the teen is too depended on the family and, thus, the level of their future independence is unclear. Siblings tended to be general in their communication of this concern. In other words, siblings were not clear as to in what capacity teens relied on the family. Initial codes for this sub-category were: teen requires prompting, teen must live with family, and teen is overly dependent on mom/family. One sibling remarked,

> I worry about the fact that she may never become independent. I tend to feel that my sister depends a lot on my parents and me and my little sister.

Another sibling noted,

> Sometimes, we have to tell [TEEN] to do ordinary things like "take your medicine" or "go get some lunch". He knows he has to do these things but sometimes he needs prompting or reassurance to get going.

Social concerns. Some siblings stressed some concern regarding the social life of the teen. The siblings highlighted a number of ways in which the teen's social skills were concerning for their future well-being including the teen’s ability to have a social life and that the teen interacts with people poorly.

Teen’s ability to have a social life. Some siblings who had social concerns for the teen’s future mentioned that the teen was unable to have a “normal” social life. These concerns seemed to be more about the teen’s social maturity or social skills, rather than the teen’s personality. Initial codes subsumed under concerns regarding the teen’s ability to have a social life were: teen cannot have a social life and teen does not understand social relationships.

One sibling expressed concern regarding the teen’s understanding of relationships:

> I am worried that the people whom she calls ‘best friends’ are not very nice to her. Of course, she calls everyone her friend because she thinks that that’s what everyone thinks of her.

Another sibling was concerned that the teen would not be able to have a social life,

> I feel bad that he doesn’t have too much of a future – he can’t get a job or have a social life. I will be sure to take care of him completely.

Teen interacts with others poorly. Most of the siblings who raised social concerns for the teen’s future noted that the teen did not interact with people well. Interestingly, these siblings did not mention that the teen lacked social skills due to their disability or was socially immature but, rather, that they simply interacted with people poorly. Initial codes subsumed under concerns regarding the teen interacting with people poorly were: teen is confrontational, teen is antisocial, and teen will not be nice to others.

Regarding concerns that the teen interacts with people poorly, one sibling noted,

> He interacts with other people poorly. He is confrontational so teachers don't like him. He is oblivious to personal presentation so other college students won't like him.

Concerns about society. Many siblings raised concerns regarding the nature of society. In other words, the concerns raised by these siblings had little to do with the teen's abilities or characteristics, but more to do with how society might perceive or treat the teen. The themes that arose within siblings' concerns about society were: discrimination against the teen, availability of services for the teen, teen will have barriers to achieving what he/she wants, and teen will be taken advantage of. This category was the second most frequent category of concerns raised by siblings regarding the teen's future.

Discrimination against the teen. Some siblings mentioned that they were concerned that the teen would face discrimination in the future. The underlying idea in this theme was that people might treat the teen poorly in some way because he or she is different. The initial codes in this theme were: people can be mean/biased and people will not understand teen.

One sibling reported,

> I do worry about my brother's ability to live independently and hold a job. This is not to say I doubt him, but simply worry about discrimination as well as the difficulties that come along with the working world.

While another stated,

> People will be scared of her and misunderstand her.

Availability of services for teen. Some siblings who reported concerns about society for the teen's future mentioned that they were worried about the availability of services for the teen. This was not the most frequent theme in concerns, but for the siblings who reported this concern, it was extremely salient. None of the siblings who mentioned they were concerned about services mentioned any other concerns; this seemed to be the most pressing concern on their mind. Initial codes in this category included: teen will not be able to get into the right program and teen will need adult services.

An exemplary instance of this theme is this sibling, who described,

> He wants to go to college and I believe there are day programs such as [program] where he would be able to expand social and living skills – but the public school told my mother she was not even aloud [sic] to look around at other programs. This is something we are currently fighting. [TEEN] walked in the grad and it is not healthy to then say he has to go back to the same school/ program.

Teen will encounter barriers to what he/she wants. Among siblings who brought up societal concerns for the teen's future, worries that the teen will encounter barriers to what he/she wants was the most frequent concern. These concerns reflected the difficulties that teen might encounter when living in the world. The initial codes for this theme were: teen will be discouraged and teen will not be able to do what he/she is passionate about.

For example, one sibling explained,

> I am worried that she will be discouraged and intimidated by the busy world. I am worried that she won't be proud of herself.

Similarly, another sibling said,

> I feel she will be overwhelmed by experiencing the real world.

Teen will be taken advantage of. Among siblings who had concerns regarding society, some siblings noted that there was some concern that the teen would be taken advantage of due to their disability. These siblings did not say specifically how this may happen, or what about the teen made them feel that way, but simply that this general concern was salient in their minds.

For example,

> I worry someone will try to take advantage of her disability.

Health. Some siblings raised health concerns for the teen with a disability. This was the least prevalent concern mentioned but for the siblings that mentioned it, it was the only concern they listed. These siblings simply stated that they only were concerned with the teen's future health. These siblings were not specific, but just mentioned health as a concern. The siblings who mentioned health as a concern often listed hopes that the teen have a long healthy life in response to the following question (see below). The cooccurrence of these concerns and hopes indicated that health was an extremely salient area for the siblings when thinking about the teen's future.

Uncertainty when parents die. One of the most frequent concerns raised by siblings at this time point, and one of the most relevant to this dissertation, had to do with a feeling of uncertainty regarding what happens to the teen when their parents die. Themes included in this category were: impact on family and "who will care for the teen?". These siblings noted the uncertainty they felt regarding what would happen in the future if the family were not around to care for the teen. Again, this concern was incredibly salient for siblings. If this concern was mentioned, it was always the only concern the sibling brought up, suggesting that this uncertainty was at the forefront of their minds. The results of the qualitative analyses will be discussed here; further analyses will be addressed in Chapter 5 of this dissertation.

Impact on family. Some of the siblings who raised this feeling of uncertainty regarding what would happen to the teen when their parents die spoke about the impact this would have on the family. Furthermore, these siblings stated that they wanted to take on the responsibility when the time came, but were unsure how that would impact their family dynamic. The initial codes in this theme were: sibling wants the responsibility but is unsure how it will impact their family and sibling wants the responsibility but is unsure how to integrate the teen into their new family. Some siblings were more specific about this concern than others.

For example, one sibling reported,

> I worry what will happen once my parents are gone. I will probably be the one to take care of him and that’s fine but I want him to be happy. My current boyfriend and I are talking about getting married. I need him to be ok with [TEEN] eventually living with us and I worry about money. Will I be able to take care of him as well as my stepchildren.

While another stated,

> When my parents are gone I have always wanted to take care of [TEEN] but wonder how this will impact my family.

“Who will care for teen?”. Most of the siblings who raised this feeling of uncertainty regarding what would happen to the teen when their parents die questioned who would care for the teen in the future. Initial codes for this theme were: “who will care for the teen when parents die?” and “who will care for the teen when the sibling and parents die?”. The majority of these siblings simply stated this as “who will care for teen when my parents are gone?” or “who will live with teen when my parents are gone?”. However, some siblings used different phrasing when addressing this concern.

One sibling asked,

> What will happen to my sister if something unexpected happens to my parents?

While another, similarly, wondered,

> When my parents and I die and it’s just him. What will happen?

One sibling mentioned guardianship specifically,

> Guardianship issues since she has the cognitive development level of a 1 to 3 month old.

No worries. A handful of siblings reported that they had no worries for the teen's future. However, these siblings qualified this statement, resulting in two themes: there is nothing to worry about and that the future is taken care of. The decision was made to code these rather than omit them, as the answers seemed to indicate that the siblings had thought about the future but were not concerned for the teen for various reasons.

There is nothing to worry about. Some siblings who stated they had no concerns for the teen's future said that there was nothing to worry about. These siblings expressed a great deal of faith in the teen's abilities, which squashed their concerns for the future. The initial codes in this theme were: teen is capable and teen is strong.

One sibling stated,

> I don't worry much about my brother's future. He is quite capable.

While another explained,

> I realize [TEEN] is not intimated by anyone/anything!

And another,

> None; he is very self-sufficint [sic].

The future is taken care of. Most of the siblings fell in the "no worries" category cited that the future was already taken care of as the reason for lack of concern. These siblings stated that the future had already been thought about and addressed to some extent. The initial code in this theme was "the teen will always be loved and cared for".

In spite of any obstacles they may face, these siblings felt that the most important aspects of the teen's future were taken care of.

One sibling responded,

> I don't have any. He will always be loved and taken care of.

Similarly, another sibling said,

> None at all, he will be taken care of.

Table 4.20. *Results from Qualitative Content Analysis: Research Question 3b.*

What worries do you have about your brother or sister's future?		
Category	**Sub-category**	**Initial Codes**
Level of independence	Independent living	Where will teen live?
		Cannot live alone
	Finances/job	Will need someone to support them financially
		Will not get a job
		Will not make own money
	Teen depends too much on family	Needs prompting
		Has to live with family
		Overly dependent on mom, dad, siblings
Social skills	Ability to have a social life	Teen cannot have a social life
		Teen lies about friends
	Interacts with people poorly	Teen will not be nice to others
		Teen is antisocial
		Teen is confrontational
Society	Discrimination	People can be mean/biased
		People will not understand teen
	Availability of services	Teen will not be able to get into right program
		Teen will need adult services
	Teen will encounter barriers to what he/she wants	Teen will be discouraged
		Teen will not be able to do what he/she is passionate about
	Will be taken advantage of	Teen will be taken advantage of
		Someone will take advantage of teen's disability
Health	Worries about health	Generally health is a concern
Uncertainty when parents die	Impact on family	Sibling wants responsibility, impact on rest of family
		Sibling does not know how to integrate teen into their new family
	Who will care for teen?	If parents die
		If sibling and parents die
No worries	Nothing to worry about	Teen is capable
		Teen is strong
	It's taken care of	Will always be loved and cared for

Research Question 3c. What are the siblings' hopes for their brother or sister's future when the teen is 18?

Qualitative content analysis of the T18 sibling responses revealed that siblings reported five categories of hopes they held for the teen's future. These categories were: daily living skills, social life, health, independence, and success and fulfillment. Results from the qualitative content analysis for research question 3c can be found in Table 4.21. The initial interrater reliability for the level 1 codes for research question 3c was perfect (Kappa=1.000, p<.001). The decision was made to continue coding the remainder of the cases. Interrater reliability was recalculated with all 49 cases. Interrater reliability continued to be almost perfect (Kappa=.908, p<.001). The initial interrater reliability for the level 2 codes for research question 3c was near perfect (Kappa=1.00, p<.001). The decision was made to continue coding the remainder of the cases. Interrater reliability was recalculated with all 49 cases. Interrater reliability remained substantial (Kappa=.792; p<.001).

Daily living skills. Some siblings reported that their hopes for the teen's future included the accomplishment of daily living skills. These siblings focused primarily on the hope that the teen would accomplish basic daily living skills including two themes: motor skills and cognitive or social skills. Given that the teens were 18 years of age at this time, these hopes were salient to the siblings who mentioned them, as they refer to skills that would have been acquired many years ago if the teen were typically developing. This will be further discussed in Chapter 5 of this dissertation.

Motor skills. Most of the siblings who had hopes for the teen involving daily living skills listed motor skills that they wished the teen would accomplish in the future. Initial codes in this theme were: teen learns to talk and teen learns to walk. These siblings did not explain their hopes for the future, but merely listed the skill the hoped the teen would accomplish.

For example, one sibling stated,

> That he'll be able to talk.

While another hoped,

> That he walks with only his own suports [sic].

Cognitive or social skills. Some siblings hoped that the teen would accomplish cognitive or social skills in the future. These were less frequent than hoping for the teen to acquire motor skills in the future. Initial codes in this theme included: learns to read and improves social skills. Again, these siblings merely stated the skill they hoped the teen would accomplish rather than explaining their hopes more fully.

An illustrative example of this theme was:

> That he can read and know when to keep comments to himself.

Social life. Many siblings hoped for things related to the teen's future social life. This was the second most frequent category of hopes raised by the siblings. These hopes varied, but the underlying matter was that the teen had a happy and full social life in some way. This category included three themes: finds a significant other, family relationships, and friends.

Finds a significant other. Some siblings noted that they hoped that the teen would find a significant other in the future. There were two initial codes subsumed in this theme: finds a girl/boy and gets married. These hopes were often listed of a variety of other hopes, and most often listed with hoping the teen gets a job. This may suggest that siblings view getting married or finding a significant other as part of an overall successful life.

For example, one sibling stated,

> That he will become a successful politician or mathematician and find a girl that will straighten him out the ways I was not able to.

And another replied,

> That he has a good relationship and gets a very decent job.

Family relationships. Some siblings hoped that the teen continues to have a good relationship with the family in some way. Initial codes for this theme were: teen can stay with the family and a continued sibling relationship. The siblings whose responses fell into this theme did not mention any other hopes, but focused only on the family relationship, suggesting that this was a prominent wish for these siblings.

In terms of hoping the teen can stay with the family in the future, one sibling stated,

> That she can live with our family for the rest of her life.

While a sibling who hoped for a continued sibling relationship specified,

> I hope that I can always be there for her.

Friends. Most of the siblings who had hopes regarding the teen's future social life cited friends as an important aspect of that. These siblings hoped that the teen had a support system outside of the family in the future. Initial codes included in this theme were: develops relationships outside the family, finds a 'real friend' to stick by teen, and teen will have close friends. For those siblings who listed hoping the teen will develop relationships outside the family, there was little elaboration.

For example, one sibling simply stated,

> That she can be independent and have a social life aside from the family.

For the siblings that revealed that they hoped the teen finds a 'real friend' to stick by them, they also often reported wanting the teen to be happy and wanting the teen to find a job they enjoy (see below). These co-occurrences suggests that having a close friend is an integral piece to being happy.

A representative example of this is this sibling's response,

> I ultimately want [TEEN] to be happy. I want him to have a home he is comfortable in and a job he really loves. I also am praying that he finds a great friend who will stick by him forever.

Finally, for the few siblings that mentioned that they hope the teen will have close friends, a similar pattern emerged. These siblings also stated that they had this hope as well has hopes for the teen's job success, happiness, and having a good place to live.

An illustrative example of this initial code is this sibling's reply,

> I hope that my brother is able to live in an apartment or home with roommates and hold down a job. I simply want him to be happy and have friends to socialize with on a regular basis.

Health. Some siblings had hopes for the teen's future health. Most of the siblings who had hopes for the teen's health had also mentioned that they were concerned for the teen's health in the future. This was not the most frequently mentioned hope, but coupled with the concerns for the teen, it was a robust one. This manifested in two themes: teen stays healthy and teen has a long life.

Teen stays healthy. Most of the siblings who had hopes regarding the teen's continued good health simply stated just that. These siblings were not specific as to the area of health that they hoped continued to be steady nor the reason why they hoped this to be the case. In other words, it seems that the siblings who wished for the teen to continue being healthy were hoping for overall good health. Initial codes in this theme were: teen has a healthy life and teen continues to be in good health.

Siblings that wished for the teen to have a healthy life stated that exactly. For example, one sibling listed the hope,

> She lives a healthy life.

One sibling that hoped the teen continued to be in good health stated,

> I hope he always has good health.

Teen has a long life. Siblings that wished for the teen to have a long life differed slightly from those wishing for the teen to have a healthy life (as those discussed above). These siblings highlighted that they hoped the teen would enjoy a long life, rather than just focusing in on the teen's health. The initial codes included in this theme were: teen has a long life and more research is done to extend teen's life. Siblings that hoped the teen had a long life, again, merely stated that exactly.

For example, this sibling replied,

> He will live a long and happy life.

Only one sibling mentioned more research being needed on the teen's disability. I chose to highlight this case because of the unique nature of the teen's disability. This sibling had a sister with Rett syndrome, a degenerative syndrome that is relatively rare and often results in premature death.

The sibling stated,

> I hope more studies can be done about Rett syndrome to enable my sister to live a little longer than what is expected because of her disease.

Independence. The most frequently mentioned category of hope for the teen's future included hopes around the teen's independence. These hopes manifested in two themes: living independently and jobs/finances. Sibling responses in this category expressed a desire for the teen to be able to live independently or more independently, and to be able to get a job or support themselves financially. Unlike some of the other hopes mentioned above, this category of hopes was often combined with categories of hopes in sibling responses including success and fulfillment, and social life.

Living independently. Some of the siblings who had hopes for the teen's independence reported that they wished the teen would be able to live by themselves in the future. These siblings discussed such topics as: living away from the family, living with roommates, having a house, and being in an apartment. Contrary to siblings who had hopes that the sibling would stay with the family for the rest of their lives, these siblings really wanted the teen to get out of the house and be able to live on their own. Siblings who had hopes the teen would live independently often also had hopes that the teen would have a job in the future (see below). Initial codes within this theme were: teen gets their own place to live (alone), and teen can live with roommate. Siblings that talked about the teen getting their own place to live highlighted their desire for the teen to live on their own.

For example, one teen stated,

> I hope that she someday will be able to live on her own.

Other siblings hoped the teen would have a home to live in, even if it were not on their own. This was often mentioned along with success and fulfillment, getting a job, and social life hopes. For example, a sibling explained,

> I hope that my brother is able to live in an apartment or home with roommates and hold down a job. I simply want him to be happy and have friends to socialize with on a regular basis.

Financial independence and employment. Many siblings mentioned that they had hopes regarding the teen's financial independence and future employment. This was the second most frequent hope reported by siblings. Within this theme were the following initial codes: teen will get a job, teen will make his/her own money/can support him/herself, and teen will have a good career. Siblings who mentioned that they hoped the teen would get a job in the future simply stated just that and often also mentioned hopes that the teen find a significant other and finds a place to live.

For example, one sibling stated,

> That he gets a good job and a decent house.

While another sibling said,

> That she gets a good job and gets married one day.

Siblings that hoped the teen would make his or her own money in the future and be able to support him/herself always combined it with an element of hopes for the teen's happiness or fulfillment (see below). In other words, siblings hoped for the teen's financial success, but they also hoped that the teen would like the job they were doing.

A model example of this is,

> I hope that he gets a good paying job that he likes.

Most of the siblings whose responses related to financial independence and future employment indicated that they hoped the teen would have a good career. This code was combined especially frequently with hopes for the teen's happiness (see below).

One sibling hoped,

> That she will have a good life and career.

While another sibling was more specific, stating,

> Beyond graduating college, I expect he will get a job that makes him happy and do well for himself.

Success and fulfillment. The most frequent hope for the teen's future expressed by the siblings were hopes related to the teen's success and fulfillment in life. Some of these hopes were general, reflecting the sibling's desire to see the teen successful and happy in life, while others were more specific. Themes within this category were: happiness, teen will feel supported, teen will feel fulfilled, and teen will continue his/her success.

Happiness. Many siblings expressed a hope that the teen will be happy in the future. This was sometimes combined with hopes that the teen would find a job or that they would find friends or a significant other. It was sometimes also combined with hopes that teen will feel fulfilled. Initial codes identified within this theme were: general happiness and teen will have a happy life. In terms of general happiness, siblings often just stated that they wanted the teen to be happy, but sometimes specified this wish more.

For example, one sibling simply responded,

> That she'll be happy and productive.

While another sibling specified further what was meant by wishing for the teen's happiness,

> I just hope he is happy and doesn't get too frustrated or disapointed [sic] with what life has to offer him.

Other siblings talked more about hoping the teen would life a happy life. This hope was sometimes combined with success or fulfillment to paint a fuller picture of what the sibling wished for the teen.

One sibling replied,

> I hope that he can be satisfied and live a happy life.

A different sibling expressed this hope slightly differently,

> I just want him to continue his progress and be happy always no matter what he decides to do.

Teen will feel supported. Many siblings expressed their hopes that the teen would always feel supported by those around them. This theme was combined with other themes less frequently, but if it was not mentioned alone, it often co-occurred with hopes regarding the teen's social life. The initial codes identified in this theme were: teen will always be taken care of, and teen will always be supported by those around him/her.

Siblings who identified that they hoped the teen will always be taken care of combined it with hopes for the teen's happiness. This hope was the least frequent of the two codes included in the theme that teen will feel supported.

For example, this sibling replied,

> That she will continue to be well taken care of, and that she will be comfortable and happy.

Siblings that spoke of hopes that the teen will feel supported by those around him or her often mentioned only this one hope. This occurred more frequently than siblings hoping that the teen will be taken care of. These siblings had a very clear idea regarding the level of support they wished the teen to have in the future.

One sibling, quite poignantly, put it,

> I hope all the people around her believe in her and help her achieve her dreams.

Another sibling combined this hope with the hope for happiness and a long life. Additionally, this sibling honed in on the sibling relationship more specifically,

> He will live a long and happy life and we'll always be there for him and he'll be there for me.

Teen will feel fulfilled. The most frequent of sibling hopes for the teen's success and fulfillment came in the form of hopes that the teen will feel fulfilled. The hopes expressed by the siblings whose responses fell into this theme were varied and specific. The initial codes identified within this theme were: teen likes what he/she does, teen will be proud of him/herself, teen will have the opportunity to do what he/she wants, and teen will have a fulfilled life.

The most frequent code identified within this theme was the hope that the teen will like what he or she does in the future. This was almost exclusively identified in conjunction with the teen getting a job in the future, but these sibling responses took the extra step beyond just hoping the teen find any job.

For example, one sibling remarked,

> I hope she finds a career that makes her happy.

Some siblings also mentioned that they hope that the teen is proud of him or herself in the future. This usually involved a component regarding the teen being happy with their decisions as well.

An exemplary instance of this is this sibling, who said,

> I mainly hope that she is proud of herself and happy with her decisions during the present and in the future.

Some siblings remarked that they hoped the teen would have the opportunity to do what they would like in the future. These siblings underscored the hope that the teen would not be restricted, but would have the opportunity to do what makes them happy.

This sibling put it best,

> I hope that she has the opportunity to do whatever she wants in the future. I hope that she can be anything from operator to computer genius.

And another wrote,

> I hope the school system is able to work with us to find a good program for my brother where he can continue to grow.

Finally, many siblings specified hopes that the teen have a fulfilled life in the future. These siblings highlighted the hope that the teen have a lot of experiences in the future, and that the teen's dreams came true.

One sibling simply, but delightfully, said,

> That his dreams are fulfilled.

Another, very similarly, encompassed happiness as well as fulfillment,

> A happy fulfiled [sic] life full of growth and development.

While another sibling was more precise in expressing her hopes,

> I hope she lives a very enriched and full life by trying everything and getting involved in a variety of activities.

Success. Finally, within the category of hopes for the teen's success and fulfillment, were siblings who expressed their hopes that the teen be successful in life. Some siblings were specific as to in what aspect they hoped the teen would be successful, while others just hoped for general success. Two initial codes were identified within this theme: teen will continue to do well, and teen will succeed in life. Siblings who stated that they hoped the teen would continue to do well did not elaborate on this hope. However, the siblings who identified this hope suggested that the teen had been doing well, and they hoped that this would continue.

For example, one sibling put it,

> That he will continue to be as successful as then [sic] he has been so far.

While another simply stated,

> That he will continue to do well.

Within this theme, however, siblings more frequently hoped for the teen’s success in life. This was often, but not always, tied to a specific career that the teen would like to have. To illustrate, one sibling said,

> That he will become a successful politician or mathematician.

And another,

> He will be happy and get a marketing job like he wants to.

While other siblings just hoped for the teen’s overall success in life, without tying it to a specific job or achievement. Purely, as this sibling put it,

> I hope she succeeds in life.

Table 4.21. *Results from Qualitative Content Analysis: Research Question 3c.*

What hopes do you have about your brother or sister's future?		
Category	**Sub-category**	**Initial Codes**
Daily living skills	Motor skills	Will learn to walk
		Will learn to talk
	Cognitive or social skills	Will learn to read
		Will improve social skills
Social life	Finds a significant other	Will find a girl/boy
		Will get married
	Family relationship	Can stay near family
		A continued sibling relationship
	Friends	Develops relationships outside the family
		Finds a real friend to stick by teen
		Teen will have close friends
Health	Stays healthy	Continues to be in good health
		Will have a healthy life
	Will have a long life	Teen will have a long life
		More research is done to extend teen's life
Independence	Living independently	Teen will get their own place to live
		Teen will live with roommates
	Financial independence and employment	Teen will get a job
		Teen will make own money/can support him/herself
		Teen will have a good career
Success and fulfillment	Happiness	Happiness
		Teen will have a happy life
	Will feel supported	Will always be taken care of
		Supported by friends
	Will feel fulfilled	Teen will like what he/she does
		Teen will be proud of him/herself
		Opportunity to do what teen wants
		Teen will have fulfilled life
	Success	Teen will continue to do well
		Teen will succeed in life

Research Question 3d. What are the siblings' lessons learned from living with the teen with the teen is 18?

Qualitative content analysis of the T18 sibling responses revealed three categories of lessons learned by living with the teen reported by siblings. These categories were: lessons learned for/about the sibling themselves, lessons learned about the teen, and lessons learned about life. Results from the qualitative content analysis for research question 3d can be found in Table 4.22. The initial interrater reliability for the level 1 codes for research question 3d was substantial (Kappa=.741, p<.001). The decision was made to continue coding the remainder of the cases. Interrater reliability was recalculated with all 49 cases. Interrater reliability was then almost perfect (Kappa=.820, p<.001). The initial interrater reliability for the level 2 codes for research question 3d was substantial (Kappa=.724, p<.001). The decision was made to continue coding the remainder of the cases. Interrater reliability was recalculated with all 49 cases. Interrater reliability remained substantial (Kappa=.729; p<.001).

Lessons learned for/about the sibling themselves. Many siblings stated that they learned something for or about themselves from living with the teen. This means that when asked what lessons they learned from living with the teen, these siblings responded with something that they learned that was specific to how they behave and interact with the world, rather than something specific to the teen or something about life more generally. Seven themes arose within lessons learned for or about the sibling themselves: virtues, how to interact with and treat people with a disability, how to interact with and treat people generally, the meaning of having a brother or sister with a disability, the sibling is lucky, the sibling learned a specific skill, and the sibling learned something specific about a disability. Lessons learned very infrequently occurred in isolation; they were often combined.

Virtues. Most of the siblings responded that they had learned some sort of virtue from living with the teen. These teens highlighted that the lessons they learned were actually personality traits they acquired which they viewed to be beneficial. Initial codes identified within this theme were: patience, understanding/acceptance, perseverance, and love. Many siblings identified learned patience through living with the teen. This was often just listed, but also it was quite frequently paired with understanding and acceptance.

For example, one sibling expressed,

> I have learned to be patient and to understand somewhat what it is like to live with a disability.

Many siblings also mentioned that they learned to persevere by living with the teen. These siblings underscored the importance of learning that they could achieve what they wanted if they never give up.

One sibling wrote,

> I learned that nothing can stop me (or [TEEN] for that matter), if I put my mind to it. [TEEN] has an indominable [sic] spirit and he has shown that hard work and perserverence [sic] can take you anywhere!

Another said,

> If you put your mind to something you can do it.

Some siblings stated that they learned love by living with the teen. These siblings always placed this in the context of learning as a family. Specifically, these siblings highlighted the fact that they learned the same lessons that you would learn from living with any family.

This sibling explained,

> I guess what most family members learn: how to share things as a family, love and support one another, etc.

How to interact with and treat people with a disability. Many siblings emphasized that they had learned how to interact with and treat people with a disability by living with the teen. These siblings noted a variety of lessons that were specifically related to interacting with people with disabilities, rather than the general population. Initial codes identified within this theme were: how to teach and interact with someone with a disability and not to make fun of people with disabilities.

Some siblings noticed that they had learned how to teach and interact with someone with a disability. These siblings generally mentioned things like how to communicate with people with a disability and that they need respect and extra time.

One sibling put it,

> I have learned how to work with children who have the same condition as my sister and be able to handle them and better communicate with them.

While another combined this idea with learning not to make fun of people with disabilities,

> To not look at people in a wheelchair, as most people do. Also to always help people that can't always do things for themselves.

Finally, most siblings whose responses fell into this theme mentioned learning not to make fun of people with disabilities. The underlying idea with these responses was that the siblings' experiences with the teen helped them to understand that they should not treat people with disabilities differently.

One sibling simply stated,

> I have learned not to make fun of people like her.

While another sibling was more specific,

> I have learned to accept people for who they are and never to stare at people because of a physical or mental disability.

How to interact with and treat people generally. Most siblings who learned something for or about themselves stressed that they learned how to treat people in general. These siblings took the experiences they had with the teen and generalized them to apply to their interactions with people on a daily basis. Initial codes found within this theme were: sharing, not to judge by appearance, cooperation, kindness, and "the golden rule". A few siblings mentioned learning to share, but this was always mentioned within the context of learning to live as a family (see extract above). A similar pattern was found for learning cooperation.

For example, this sibling put it,

> I have learned how to do typical work and how to cooperate from living with my big brother.

By far the most frequently mentioned lesson learned overall was not to judge people by their appearance. Many siblings emphasized that they had learned to get to know someone thoroughly before passing judgment.

One sibling explained,

> That you don't need to judge anyone by outward appearance. You can't judge a book by the cover.

While, similarly, another wrote,

> That you should never judge someone before you get to know them.

Some siblings wrote about learning kindness and to treat people the way they wished to be treated ("the golden rule"). This was very often combined with lessons learned about the teen's positive personal characteristics (see below).

This sibling provides a perfect example of this,

> I have learned how to be kind to others and how to treat other people. She is an extremely wonderful role model. She plays such a big part in my life. I honestly couldn't live without her!

The meaning of having a brother or sister with a disability. Some siblings noted having learned what it means to have a brother or sister with a disability. The initial codes included in this theme were: it is not easy to have a brother or sister with a disability, and it is rewarding to have a brother or sister with a disability. Most of these siblings emphasized the difficulty of living with the teen.

A sibling wrote,

> That is it hard to go out with family.

While another stated, quite simply,

> It is hard.

The sibling is lucky. For some siblings, the most salient lesson learned was that they were lucky on a variety of levels. There were two initial codes identified here: lucky to have a great brother or sister, and lucky for their own abilities. The message extracted from these siblings' experiences with the teen was that they were fortunate to have what they have. Most of the siblings emphasized that they felt lucky or happy to have such a great brother or sister.

A sibling wrote,

> [TEEN] can't talk, so we don't argue or fight at all, but we always are happy with each other and he always smiles. He's a great brother and I couldn't be happier with him.

Some siblings stated that they were lucky to have their health or abilities. These siblings emphasized that by living with the teen with a disability, it made them realize that they were fortunate.

For example, this sibling noted,

> Being greatful [sic] for my abilities.

One sibling combined both sentiments to express feeling lucky overall,

> I've learned that I don't have it bad at all. I'm incredibly lucky to be a normal person and even luckier to have such a great brother.

Sibling learned a specific skill. A couple siblings highlighted having learned a specific skill from living with the teen. Although this was a very small number of cases, this was included in the results because of the dynamic is accentuates in the sibling pair. For these siblings, the most salient lesson learned from living with the teen was a concrete skill. I chose to highlight these siblings as a result of the contrast they provide to the siblings that took their experiences living with the teen and generalized them to broader lessons. The skills listed by these siblings were how to do typical work and how to take care of themselves. This will be discussed further in Chapter 5 of this dissertation.

Sibling learned something specific about a disability. One sibling talked about having learned about the teen's disability more specifically. This was, again, a sibling of a teen with Rett syndrome. I chose to highlight this case because of the unique nature of the teen's disability. Although the sibling did not elaborate, due to the nature of Rett syndrome, education around the disability may be especially important.

This sibling simply stated,

> I have learned about what she has, Rett syndrome.

Lessons learned about the teen. Many siblings focused, more specifically, on things they learned about the teen. These sibling responses were in direct contrast to responses reflecting lessons about life or lessons that siblings took to heart for themselves. It was extremely infrequent that siblings combined learning a lesson about the teen with other categories of lessons. The themes identified in this category were: the teen's positive personal characteristics, the teen's negative personal characteristics, and how to teach or treat the teen.

Teen's positive personal characteristics. Most of the siblings who highlighted learning lessons about the teen, emphasized learning something positive about the teen's personality. These sibling responses honed in on the teen's good qualities. Initial codes identified within this theme were: teen is fun, teen is a good person, and teen inspires people. Some of these siblings underscored that the teen was a fun person to be around. The teen's fun nature was revealed in the siblings experiences in living with the teen.

This sibling put it,

> Even though my sister has a disability it's fun to have her around because she makes everyone laugh.

Most siblings emphasized that they had learned that the teen was a good person. This manifested in a variety of ways. Some siblings focused on the fact that the teen did good or kind things, while others highlighted that the teen inspired people, and still others emphasized the teen's position as a role model.

One sibling wrote,

> My sister has been an incredible inspiration in my life. She has the kindess [sic] heart that I've ever seen or experienced in any human being. She is a very special person with a big heart and I can't even explain in words or a survey how much she means to me. With every day, she struggles that brings her that much closer to her life goals and happiness.

Another reported,

> My brother is verry [sic] smart. He has a great attitued [sic] and a lot of potential. He has his days where he's not happy, but we all do. He is very well taken care of and all around great kid. I love him with all my heart and wouldn't change him for the world!

Some siblings noted that the teen inspired people around him or her,

> People like my brother inspire others – myself included.

Teen's negative personal characteristics. A few siblings stated that they had learned about the teen's negative personal characteristics. This was very infrequent, but often reflected the nature of the other responses that the sibling provided. In other words, siblings who focused on the negative qualities of the teen tended to have overall more negative answers in response to the questions asked of them at T18. Initial codes within this theme were: teen is immature and teen is different.

When asked what was learned by living with the teen, one sibling simply responded,

> He likes being the baby.

Another sibling wrote that the teen needed to mature and do things on his own,

> [TEEN] relies too much on Mom. He needs to get a pair of balls and do something for himself because I am sick of being stuck in the middle of them when they each complain about each other. I know it is selfish, but I don't want to put myself through the stress anymore of mediating.

One sibling emphasized that going to school with the teen highlighted how different the teen was, and this was difficult to process,

> It has been a negative experience because my sister looks and acts differently. She goes to the same school as I do, so I hear people say many cruel things about her. At first it bothered me, but now I know that Rett

> syndrome is a very rare disease and not many people know anything about it.

How to teach or treat the teen. Some siblings highlighted the skills they had gained in regards to understanding how to interact with or teach the teen. Instead of focusing only on the teen's characteristics, these particular siblings wrote about how those characteristics impacted the interactions with the teen. The initial codes in this theme were identified as: how to effectively communicate with teen, and how to teach the teen.

Simply, as one sibling noted,

> How to communicate and understand him.

While another sibling was very specific in how she acknowledged the teen's learning style and how to address it,

> He needs more repetition and practice to learn things, and has trouble sometimes with higher level/analytical thinking.

Lessons learned about life. The most frequent category of lessons learned by siblings from living with the teen, were lessons learned about life. These siblings really spoke about having a changed view of life and the nature of human beings, both with and without disabilities. These siblings noted profound changes in thinking that occurred as a result of their experiences having a brother or sister with a disability. The themes that arose in this category were: gaining a new life perspective, learning that people with disabilities are the same as everyone else, and learning that everyone is unique.

Gaining a new life perspective. The most frequent response to the question asking about lessons learned by living with the teen were responses related to gaining a new life perspective. These siblings focused on insightful changes they had in their views on life. The initial codes identified in this theme were: general changes in life perspective, do not take things for granted, and life is to be enjoyed. Change in life perspective were varied, but often addressed the idea of finding a silver lining and that "time heals all wounds".

This sibling's response is illustrative of the responses across siblings,

> Nothing is impossible – hard work and self-confidence are the most important. Nothing worthwhile comes easy. Bad days and disappointment disappear when you forget about them.

Many siblings also addressed the idea that they no longer took things for granted. Often these responses referred to life and people. These responses underscored the idea that the precious things in life must be appreciated.

One sibling wrote,

> True appreciation of people. Being so emotionally giving and compassionate is the best (and only way to have true, solid relationships).

While another wrote,

> I have learned that life should be treasured and it is not always as bad as you may think.

Finally, one sibling emphasized the realization that life is to be enjoyed. Instead of just learning the value of life, this sibling learned to enjoy it,

> Life is to have a good time!

People with disabilities are the same as everyone else. Some siblings spoke to lessons regarding people with disabilities. These siblings specifically and consistently remarked on the lesson that people with disabilities are the same as everyone else. Initial codes identified in this theme were: can be happier/smarter than other people and they are no different than you or me. Some siblings commented that they learned that people with disabilities can be just as happy or smart, and maybe more so, than the average person.

One sibling stated,

> I learned that a simple minded person like my brother is a lot smarter and happier than most other people that I know.

Other siblings noted that, despite what one might think, people with disabilities are the same as anyone else. These siblings focused heavily on the commonalities between people with disabilities and everyone else.

This sibling wrote,

> They may look different but they are still normal people.

Everyone is unique. Finally, many siblings remarked on learning that each person is distinct. In living with the teen with a disability, these siblings learned, not only that their brother or sister was different, but that no one is exactly the same. Initial codes identified in this theme were: everyone has a reason to be who they are, and it doesn’t matter if you’re different. Some siblings emphasized the idea that everyone is different for a reason. These siblings acknowledged that no two people are the same, and that everyone has different qualities.

For example, this sibling expressed,

> More than I could ever write down – all people have a reason to be who they are.

While another addressed the strengths in all people,

> All kids are special in some ways.

Other siblings instead underlined the idea that it does not matter if a person is different from everyone else. These siblings suggested that your differences and how people treat you are of little consequence.

A sibling explained,

> That it's alright if people make fun of you, you're still cool.

While another simply stated,

> It doesn't matter if you're different.

Table 4.22. *Results from Qualitative Content Analysis: Research Question 3d.*

What have you learned by living with your brother or sister?		
Category	**Sub-category**	**Initial Codes**
Lessons learned about or for the sibling themselves	Virtues	Patience
		Understanding/acceptance
		Perseverance
		Love
	How to interact with and treat people with a disability	How to teach and interact with people with disability
		Not to make fun of people with disabilities
	How to interact and treat people generally	Sharing
		Don't judge people by appearance
		Cooperation
		Kindness and treat others as you want to be treated
	Meaning of having a brother or sister with DD	Having a sibling with DD is hard
		Having a sibling with a disability is rewarding
	Sibling is lucky	To have a great brother or sister
		For all his/her abilities
	Specific skill	How to do typical work
		How to talk care of self
	Learned about a specific disability	Rett syndrome

Note: table continued on following page.

Lessons learned about the teen	Teen's positive personal characteristics	Teen is a good person
		Teen is fun
		Teen inspires people
	Teen's negative personal characteristics	Teen is different
		Teen is immature
	How to treat/teach teen	How to communicate with teen
		How to teach teen
Lessons learned about life	New life perspective	General new life perspective
		Do not take things for granted
		Life is to be enjoyed
	People with disabilities are the same as everyone else	People with disabilities can be happier and smarter than typically developing people
		People with disabilities are no different from you or me
	Everyone is unique	Everyone has a reason to be who they are
		It does not matter if you are different

Research Question 4. Do the lessons learned from living with the teen at T15 look different than the lessons learned form the teen at T18?

To address research question 4, siblings' written responses to open-ended questions were analyzed using qualitative content analysis In order to address research question 4, I will first present the T15 results, followed by a discussion of how these responses differ from the responses at T18 (discussed above). The results for each question will include results regarding interrater reliability.

Qualitative content analysis of the T15 sibling responses revealed three categories of lessons learned by living with the teen reported by siblings. These categories were: lessons learned for/about the sibling themselves, lessons learned about the teen, and lessons learned about life. A summary of results from the qualitative content analysis for research question 4 can be found in Table 4.23. The initial interrater reliability for the level 1 codes for research question 4 was substantial (Kappa=.744, $p<.001$). The decision was made to continue coding the remainder of the cases. Interrater reliability was recalculated with all 49 cases. Interrater reliability continued to be substantial (Kappa=.729, $p<.001$). The initial interrater reliability for the level 2 codes for research question 4 was substantial (Kappa=.636, $p<.001$). The decision was made to continue coding the remainder of the cases. Interrater reliability was recalculated with all 49 cases. Interrater reliability was then almost perfect (Kappa=.875; $p<.001$).

Lessons learned for/about the sibling themselves. Many siblings stated that they learned something for or about themselves from living with the teen. This means that when asked what lessons they learned from living with the teen, these siblings responded with something that they learned that was specific to how they now behave and interact with the world, rather than something specific to the teen or something about life more generally. Six themes arose within lessons learned for or about the sibling themselves: virtues, how to interact with and treat people with a disability, how to interact with and treat people generally, the meaning of having a brother or sister with a disability, the sibling is lucky, and the sibling learned a specific skill. These lessons were often mentioned in isolation, rather than in combination with other categories of lessons learned.

Virtues. Most of the siblings responded that they had learned some sort of virtue from living with the teen. These teens highlighted that the lessons they learned were actually personality traits they acquired which they viewed to be beneficial. Initial codes identified within this theme were: patience, understanding/acceptance, perseverance, and love/kindness. Many siblings identified learned patience through living with the teen. This was often just listed in isolation. However, learning patience was sometimes mentioned in the context of family relationships.

For example, one sibling expressed,

> From living with my brother, I have learned patience is key to a good family relationship. I have learned to have an open mind.

Many siblings noted that they had learned understanding or acceptance from living with the teen. These siblings did not identify the cause of this lesson to be the teen's disability but, rather, merely noted the lesson in general.

This sibling said,

> How to be a better person. Understanding and compassionate.

Many siblings also mentioned that they learned to persevere by living with the teen. These siblings remarked at how the teen had taught them to continue working for their goals.

One sibling wrote,

> I believe being the sister of a special needs child has been one of the most important factors in the shaping of me. My brother is one of my main motivations. When I get despaired with something, my brother is always there to cheer me up, and remind me that no matter how tough life may seem at times, there is always a reason to work harder.

Some siblings stated that they learned love or kindness by living with the teen. These siblings sometimes placed this in the context of learning as a family. Specifically, some siblings highlighted the fact that they learned the same lessons that you would learn from living with any family.

This sibling explained,

> I suppose the same types of things as most brother and sisters – how to share, compromise, forgive and love each other, learn from each other, etc.

While another wrote, more simply,

> To be less selfish and more giving.

How to interact with and treat people with a disability. Some siblings emphasized that they had learned how to interact with and treat people with a disability by living with the teen. These siblings noted a variety of lessons that were specifically related to interacting with people with disabilities, rather than the general population. Initial codes identified within this theme were: how to understand someone with a disability and how to interact with someone with a disability.

Some siblings noticed that they had learned how to understand someone with a disability. These siblings noted that, specifically, their ability to understand people with a variety of disabilities was strengthened through their experiences living with the teen.

One sibling put it,

> I have learned to understand people with certain handicaps.

While another said,

> How to understand how it works to understand handycaped [sic] kids.

Some siblings mentioned that they learned how to interact with someone with a disability. These siblings remarked that, specifically, their opportunity and ability to interact with people with a variety of disabilities were expanded through their experiences living with the teen.

This sibling wrote,

> I have learned how to deal with people who have mental problems.

Another sibling focused on their opportunity to interact with people with disabilities,

> I have learned about disabilities, and have got to meet several disabled kids because of [TEEN].

How to interact with and treat people generally. Most siblings who learned something for or about themselves stressed that they learned how to treat people in general. These siblings took the experiences they had with the teen and generalized them to apply to their interactions with people on a daily basis. Initial codes found within this theme were: sharing, not to judge someone prematurely, and “the golden rule”. A few siblings mentioned learning to share, but this was always mentioned within the context of learning to live as a family (see extract above). A similar pattern was found for learning cooperation.

Some siblings mentioned they had learned not judge people prematurely. These siblings emphasized that they had learned to get to know someone thoroughly before passing judgment.

One sibling explained,

> Not to judge people without getting to know them first.

Some siblings wrote about learning kindness and to treat people they way they wished to be treated (“the golden rule”).

For example, this sibling put it,

> That everyone should be treated the way they might treat you.

The meaning of having a brother or sister with a disability. Some siblings noted having learned what it means to have a brother or sister with a disability. The initial codes included in this theme were: it is not easy to have a brother or sister with a disability, and it is rewarding to have a brother or sister with a disability.

One sibling remarked,

> How much I need the time to be around him so I can act like a little kid and play Monopoly and stuff like that. I don’t know how only children do

> it, but he is the only kid who I can be that side of myself around. I know, sappy, sappy, sappy.

Most of these siblings, however, emphasized both aspects of living with the teen. A sibling wrote,

> That even though it's a lot of work she's still my sister and no matter how big a pain she is, I love her with all my heart.

While another stated,

> That putting up with my brother isn't easy! I really like my brother a lot. Sometimes he can be a pain, but I really love him. I love having him around the house because I have someone to talk [to].

The sibling is lucky. For most of the siblings, the most salient lesson learned was that they were lucky on a variety of levels. There were two initial codes identified here: lucky to have a great brother or sister, and lucky for their own abilities. The message extracted from these siblings' experiences with the teen was that they were fortunate to have what they have. Most of the siblings emphasized that they felt lucky or happy to have such a great brother or sister.

A sibling wrote,

> It's fun having a sister because you always have someone to talk to.

Another sibling commented on the exceptionality of her sibling relationship,

> I think everyone should experience the special relationship I have with my brother.

A few siblings thanked God for their brother or sister. These siblings considered the teen to be a blessing in their lives.

One sibling remarked,

> That I am lucky to have someone like her and I thank God for such a sister I could not have ask [sic] for a better sister ever! She's the best!

While another stated,

> My brother is one of the nicest blessings in my life and I thank God everyday for him.

Some siblings stated that they were lucky to have their health or abilities. These siblings emphasized that by living with the teen with a disability, it made them realize that they were fortunate.

An excellent example of this is the response given by this sibling,

> I fully understand how lucky I am to do the things I am able to do, and to have the ability to achieve my goals.

Sibling learned a specific skill. A couple siblings highlighted having learned a specific skill from living with the teen. Again, although this was a very small number of cases, this was included in the results because of the dynamic is accentuates in the sibling pair. For these siblings, the most salient lesson learned from living with the teen was a concrete skill. I chose to highlight these siblings as a result of the contrast they provide to the siblings that took their experiences living with the teen and generalized them to broader lessons. The skills listed by these siblings were wheelchair basketball and math skills. This will be discussed further in Chapter 5 of this dissertation.

Lessons learned about the teen. Some siblings focused, more specifically, on things they learned about the teen. These sibling responses were in direct contrast to responses reflecting lessons about life or lessons that siblings took to heart for themselves. It was extremely infrequent that siblings combined learning a lesson about the teen with other categories of lessons. The themes identified in this category were: the teen's positive personal characteristics, the teen's negative personal characterisitcs, and how to teach or treat the teen.

Teen's positive personal characteristics. Most of the siblings who highlighted learning lessons about the teen, emphasized learning something positive about the teen's personality. These sibling responses honed in on the teen's good qualities. Initial codes identified within this theme were: teen is fun, teen is a good person, and teen is capable. Some of these siblings underscored that the teen was a fun person to be around. The teen's fun nature was revealed in the siblings' experiences in living with the teen.

This sibling put it,

> I learned that he is really fun and when we get along he likes having fun.

While this sibling remarked,

> He's taught me a lot despiste [sic] the fact he is non-verbal, nonambulatory and cognitively delayed. He's terrific – I would do anything for him.

Most of these siblings emphasized that they had learned that the teen was a good person. This manifested in a variety of ways. Some siblings focused on the fact that the teen did good or kind things, and others emphasized the teen's position as a role model.

One sibling wrote,

> Usually he sets a good example of honesty, respect, and good behavior.

Another stated, simply,

> That she is a special person.

Still other siblings discussed that the teen was capable. Most of these siblings commented that the teen was able to do the same things that they themselves were able to accomplish.

As this sibling said,

> That he can do anything that I do and do reading, sports, math, spelling and he has a good life and everyone should treat that person fairly.

Teen's negative personal characteristics. Some siblings stated that they had learned about the teen's negative personal characteristics. This was more frequent among younger siblings. Upon closer inspection, it was revealed that the siblings that mentioned the teen's negative personal characteristics at T15 did not have negative responses overall. This reflects an aspect of sibling conflict within a great context of sibling cooperation or warmth. Initial codes within this theme were: teen is hard to get along with and teen is lazy. Most of these siblings indicated that the teen was hard to get along with.

When asked what was learned by living with the teen, one sibling simply responded,

> Sometimes you have to stay out of her way. She can be very bossy now and again.

A younger sibling wrote about keeping track of belongings,

> That they will breake [sic] your toy sometime so hide them.

Yet another sibling commented on the emotional nature of the teen,

> That she is very sensitive and emotional.

A few siblings observed that the teen was lazy. These siblings remarked that the teen preferred to stay home all day.

For example, this sibling noted,

> My sister is a couch pototato [sic]. She sits on her bed 24/7.

How to teach or treat the teen. Many siblings who concentrated on lessons learned about the teen highlighted the skills they had gained in regards to understanding how to interact with or teach the teen. Instead of focusing only on the teen's characteristics, these particular siblings wrote about how those characteristics impacted the interactions with the teen. The initial codes in this theme were identified as: how to treat with teen, and how to teach the teen. Most of the siblings whose responses fell into this theme highlighted that they learned how to treat their brother or sister with a disability.

As one sibling noted,

> That they are just the same as other people. Need respect and people to be kind to them.

Another said,

> To treat your brothers and sister with respect and your friends siblings.

And, yet another sibling stated, similarly,

> That you need to respect him.

Some of the siblings who concentrated on treating or teaching the teen highlighted lessons learned around how to teach or work with the teen effectively.

This sibling expressed it quite plainly,

> I have learned patience, which is very important with him. I've learned to understand that some things come difficult with him, so encourage him and give him time to understand.

This sibling remarked on the patience and understanding it took to work with the teen,

> I have learned that being patient is the key. You must be understanding and have the extra time to work with her.

In contrast, one sibling highlighted learning to avoid the teen, rather than how to interact with the teen successfully. This case was included in the results section because, although seemingly negative, it may be a successful tactic for avoiding conflict and tension with the teen.

The sibling stated,

> To stay away from him most of the time.

Lessons learned about life. The least frequent category of lessons learned by siblings from living with the teen, were lessons learned about life. These siblings really spoke about having a changed view of life and the nature of human beings, both with and without disabilities. These siblings noted profound changes in thinking that occurred as a result of their experiences having a brother or sister with a disability. The themes that arose in this category were: gaining a new life perspective, learning that people with disabilities are the same as everyone else, and learning that everyone is unique.

Gaining a new life perspective. The most frequent response to the question asking about lessons learned by living with the teen were responses related to gaining a new life perspective. These siblings focused on insightful changes they had in their views on life. The initial codes identified in this theme were: general changes in life perspective, and do not take things for granted. Change in life outlook were varied, but often addressed the idea of finding a silver lining and to keep your hardships in perspective.

This sibling's response is illustrative of the responses across siblings,

> No matter how hard something is for you, it's even harder for someone else. That there is good in <u>EVERY</u> situation.

Some siblings also addressed the idea that they no longer took things for granted. Often these responses referred to life and people. These responses underscored the idea that the precious things in life must be appreciated.

One sibling poignantly wrote,

> I have learned to value each day I encounter. [TEEN] has shown me that family is vital part of my life. [TEEN] taught me to be more aware of the world and its surroundings, unlike the typical teenager who takes things for granted. I have learned through these difficult lessons that love and support teach us what really is important in life. The fragility of [TEEN] and her classmates show me how valuable life really is.

People with disabilities are the same as everyone else. Some siblings spoke to lessons regarding people with disabilities. These siblings specifically and consistently remarked on the lesson that people with disabilities are the same as everyone else. The initial code in this theme was that people with disabilities can accomplish a lot.

One sibling stated,

> That disabled people can almost always do anything normal people can do.

Everyone is unique. Finally, many siblings remarked on learning that everyone is different. This was the most frequent theme within life lessons learned from living with the teen. In living with the teen with a disability, these siblings learned, not only that their brother or sister was different, but that no one is exactly the same. Initial codes identified in this theme were: everyone has different strengths and weaknesses, and it doesn’t matter if you’re different. Some siblings emphasized the idea that everyone is different for a reason. These siblings acknowledged that no two people are the same, and that everyone has different qualities.

For example, this sibling expressed,

> Everyone has different gifts and talents.

While another addressed the differences in needs between people,

> That people are different. They all need their own needs.

Another sibling highlighted that everyone is different, and everyone has their own talents,

> I have learned a lot about patience, but mostly I have learned that God's gifts come in all different shapes and sizes and that all people can be great and we should give everybody a chance.

Other siblings instead underlined the idea that it does not matter if a person is different from everyone else. These siblings suggested that your differences and how people treat you are of little consequence.

A sibling explained,

> I have learned that even if unnormal people are unnormal they can still learn and do things like normal people can do.

While another simply stated,

> I've learned that if you truely [sic] get to know a person, he can be really amazing, even if he is different in some ways.

Table 4.23. *Results from Qualitative Content Analysis: Research Question 4.*

What have you learned by living with your brother or sister? (T15)		
Category	**Sub-category**	**Initial Codes**
Lessons learned about or for the sibling themselves	Virtues	Patience
		Understanding/acceptance
		Perseverance
		Love/kindness
	How to interact with and treat people with a disability	How to understand people with disabilities
		How to interact with people with disabilities
	How to interact and treat people generally	Sharing
		Do not judge people prematurely
		Treat others as you want to be treated
	Meaning of having a brother or sister with DD	Having a sibling is not easy
		Having a sibling with a disability is rewarding
	Sibling is lucky	To have a great brother or sister
		For all his/her abilities
	Specific skill	Math skills
		How to play wheelchair basketball

Note: table continued on next page.

Lessons learned about the teen	Teen’s positive personal characteristics	Teen is a good person
		Teen is fun
		Teen is capable
	Teen’s negative personal characteristics	Teen is hard to get along with
		Teen is lazy
	How to treat/teach teen	How to treat teen
		How to teach teen
Lessons learned about life	New life perspective	General new life perspective
		Do not take things for granted
	People with disabilities are the same as everyone else	People with disabilities can accomplish a lot
	Everyone is unique	Everyone has different strengths and weaknesses
		It does not matter if you are different

Table 4.24. *Interrater Reliability – Cohen's Kappa for Research Questions 3a-4.*

	Initial Kappa (20% of cases)	**Total Kappa (all cases)**
Research Question 3a		
Themes (Level 1)	.825***	.885***
Categories (Level 2)	.833***	.886***
Research Question 3b		
Themes (Level 1)	.899***	.885***
Categories (Level 2)	1.00***	.911v
Research Question 3c		
Themes (Level 1)	1.00***	.908***
Categories (Level 2)	1.00***	.792***
Research Question 3d		
Themes (Level 1)	.741***	.820***
Categories (Level 2)	.833***	.886***
Research Question 4		
Themes (Level 1)	.744***	.729***
Categories (Level 2)	.724***	.729***

Note: ***=p<.001

Differences in lessons learned from T15 to T18. Several notable differences arose when comparing sibling responses to the question “What have you learned by living with your brother or sister?” at T15 and T18. I will first address the responses in terms of the categories, themes, and initial codes generally, followed by a more specific analysis of the observed changes.

There were no surface differences in the categories observed at T15 and T18. At each time point, the categories identified were: lessons learned for or about the sibling themselves, lessons learned about the teen, and lessons learned about life. Changes in the distributions of these categories are discussed below. However, the themes that arose from the initial codes did vary across the two time points. Within the category of “lessons learned for or about the sibling themselves”, siblings did not identify having learned something about a specific disability at T15, but this was addressed at T18. Changes in the distributions of these themes are discussed below. Surprisingly, there were negligible differences between the initial codes identified at T15 and those identified at T18. The types of responses observed at both time points were virtually identical. The only discernable differences were in how the siblings worded their responses and in the fact that lessons learned about a specific disability were not identified at T15. This was reflected in the codes. Changes in the distributions of these themes are discussed below.

Generally speaking, the lessons learned by the siblings were much more positive at T15 than at T18. There was a larger focus on the feeling lucky to have the teen, positive teen characteristics, and positive changes in life perspective at T15 as compared to T18. This emphasis on positive lessons learned will become clearer in the following section.

Lessons learned about or for the sibling themselves. This category was well represented at both time points. Slightly more siblings included lessons learned for themselves at T18 than they did at T15. Within the category, however, the themes varied considerably from the first time point to the second time point, even aside from the omitted theme at T15 mentioned above. First, siblings cited having learned a virtue less at T15 than they did at T18. Although the types of virtues learned (patience, understanding, etc.) remained the same over time, more siblings reported having learned a virtue from living with their brother or sister at T18 than they had when the teen was 15. Furthermore, the types of virtues varied more greatly at T18 than they did at T15, although patience and understanding were the most frequent initial code in each (see Table 4.22 and Table 4.23).

Second, far fewer siblings commented on having learned how to interact with or treat people generally at T15 than at T18. Again, the initial codes were very similar, but siblings remarked more on learning how to treat other people less frequently when the teen was 15 than they did when the teen was 18. However, within this theme, a greater proportion of siblings identified having learned to treat others as they wished to be treated and to never judge a person prematurely at T15 than at T18. At T18, more siblings concentrated on learning how to share and cooperate than the “golden rule” and passing judgment on people.

Third, siblings commented more frequently on the meaning of having a sibling with a disability when the teen was 18 than they did when the teen was 15. In other words, when the teen was 18, the impact of having a brother or sister with a disability appeared to be more salient for the siblings in this study. However, within time points, more siblings emphasized that having a brother or sister with a disability was rewarding in spite of the difficulties at T15 than they did at T18. In other words, siblings at T18 were more likely to highlight that having a brother or sister with a disability was only difficult than they were at T15.

Fourth, the distribution of siblings having learned how to treat or interact with people with disabilities was similar at both time points. However, at T15 no siblings discussed having learned not to make fun of people with disabilities. At T18, this was the most frequent initial code within this theme. Instead, at T15, siblings emphasized understanding people with disabilities. Similarly, at T18, some siblings mentioned having learned how to teach or work with people with disabilities, and this was not identified at T15.

Next, more siblings emphasized learning that they were lucky in some way at T15 then they did at T18. There were an overwhelming number of responses at T15 that discussed the siblings feeling lucky for having the teen or for their own abilities whereas this was much more infrequent at T18. In addition, a nearly equal number of siblings talked about feeling lucky for having the teen in their lives and feeling lucky for their own abilities at T15. In contrast, the siblings at T18 were more likely to talk about feeling lucky for the teen than about feeling lucky for their own abilities.

Lessons learned about the teen. In general, many more siblings addressed having learned lessons specifically about the teen at T15 than at T18. Again, the initial codes that arose at each time point were very similar, but the distributions looked quite different. First, aside from the fact that more siblings mentioned learned specifically about the teen at T15 than at T18, there was a much heavier emphasis at T15 on how to treat the teen. Although, at T18 the siblings focused very heavily on how to teach and understand the teen, at T15 there was an emphasis on treating the teen with acceptance, respect, and love. It appeared that everyday interactions with the teen were more salient than teaching interactions at T15, whereas the opposite appeared to be true at T18.

Second, siblings highlighted having learned about more positive characteristics of the teen at T15 than at T18. Yet again, the types of positive characteristics that arose (in the initial codes) were similar at each time point, but they arose more frequently at T15. Interestingly, siblings also highlighted having learned about more negative characteristics of the teen at T15 than at T18. Within each time point, however, there were many more instances of having learned positive characteristics than having learned negative characteristics. This increased level of both positive and negative characteristics identified at T15 may indicate a relationship including conflict within a context of warmth. This will be further discussed in Chapter 5 of this dissertation.

Lessons learned about life. Perhaps the most profound difference observed between T15 and T18 in terms of the identified lessons learned from living with the teen was in relation to the lessons learned about life. On the surface, there was a similar number of siblings who emphasized having learned a life lesson at each time point.

Additionally, with the exception of wording arising from the siblings' responses, the initial codes were virtually identical at T15 and T18. However, across time points, the distributions of themes were remarkably different. At T18, there was a heavy emphasis on having gained a new life perspective. This theme was less marked at T15. The siblings who commented on life perspectives at T18 overwhelmingly concentrated on lessons pertaining to finding the silver lining and the unpredictable nature of life. This contrasted to the siblings who mentioned learning a life perspective at T15, who emphasized the value of people and life almost exclusively.

Additionally, at T15, the siblings who identified having learned a lesson about life strongly emphasized learning that everyone is unique, whereas this was much less frequently addressed at T18. At both time points, very few siblings mentioned having learned that it does not matter if you are different. However, at T15, many siblings wrote that they had learned that everyone is unique. These siblings really picked up on the idea that everyone has different needs, talents, and appearances. At T18, this was less frequent, and the siblings who did remark on learning this lesson stated it as everyone being different, without highlighting the idea that everyone has different assets. In this way, the T15 responses that identified learning that everyone is unique appeared to be much more strength-based, rather than difference-based.

How these findings tie in to the quantitative findings reported earlier in Chapter 4 will be discussed in depth in Chapter 5.

Chapter 5: Discussion

This chapter includes a review of the goals of this dissertation, a summary and discussion of the findings of this study in relation to previous literature, and an integration of the quantitative and qualitative findings of this study. Next, I will address the limitations of this study. Finally, I will suggest directions for future research based on these findings and the remaining gaps in the literature.

Review of the Aims of the Current Investigation

The bioecological model (Bronfenbrenner, 1979; 1986), the developmental contextual model (Lerner, 1984; 1986; 1991), and Family Systems Theory (Minuchin, 1988) indicate that the developing child is situated within a context. The bioecological model of child development asserts that development occurs in the context of the child's environment, which encompasses multiple mutually dependent levels. The most proximal context for a child's development is the family. Therefore, family is considered to exert the most immediate and direct influence and represents a critical developmental factor (Bronfenbrenner, 1986). Similarly, the developmental contextual model posits that there are multiple levels of the organism as well as multiple levels of the context that are both qualitatively distinct and dynamically intertwined (Lerner, 1991). Finally, Family Systems Theory (Minuchin, 1988) emphasizes the importance of the dyadic relationships within the family system separately from each other as well as the significance of studying transition points for families (Minuchin, 1988; Wachs, 2000). All three theories of child development underscore the criticality of examining the any aspect of child development longitudinally.

The literature on families of children with DD to date has focused primarily on the relationship with and between the parents. Although the sibling relationship has been of increasing interest as of late, critical gaps in the literature remain (Seltzer et al., 2005). An important aspect of sibling relationships in which one individual has DD is the role asymmetry that characterizes the relationship (Knott et al., 1995). Additionally, the individuals with DD are living longer now than ever before, resulting in the need for families to look forward and plan for the future (Seltzer & Krauss, 1989). An important aim of this dissertation is to address the impact of future planning on the sibling relationship, as siblings have been shown to exhibit concern and stress regarding their role in the teen's future during the teen's adolescence, (Harris & Glasberg, 2003).

The current investigation highlights the significance and uniqueness of the sibling relationship during adolescence for sibling pairs where one individual has DD. Although an overwhelming emphasis in sibling literature has been placed on early to middle childhood sibling pairs, siblings remain a considerable influence on development continuing through adolescence. Furthermore, the influence of siblings may be even greater for individuals with a developmental disability, as they have limited opportunity for friendships and regular interactions with peers (Coleby, 1995; Gresham & MacMillan, 1997; Stoneman et al., 1988). As a result of these limited peer networks, siblings are the most dependable and principal interactions for adolescents with DD (Guralnick, 1997), and these adolescents often rely on their siblings for support rather than their peers (Wenz-Gross & Siperstein, 1996). In support of these findings, Krauss, Seltzer, & Goodman (1992) conducted a study of informal social networks of individuals with DD and found that siblings constituted one-quarter of their total social networks. Moreover, for siblings of individuals with DD, the sibling relationship is apt to change over time regarding levels of importance throughout different stages of life (Evans, Jones, & Mansell, 2001).

It has been found that individuals with DD live with a parent well into their adulthood (Emerson & Hatton, 2008). In fact, the most dominant residential arrangement for individuals with intellectual disabilities is family-based care (Grosser & Conley, 1995). This is complicated by the fact that more than one-quarter of the individuals living with family are residing in households headed by aging parents (Braddock et al., 2005; Fujiura, 1998). Despite this growing need to think about future planning, many parents show reluctance in involving their children in future planning (Heller & Caldwell, 2006). Griffiths and Unger (1994) conducted a study of families of individuals with DD and found that 78% of parents reported having discussed the issues of placement with their typically developing children, but 64% of those children were unsure as to what their parents' future plans for their siblings were after their parents could no longer fulfill the caregiving role. Similarly, a study by Davys, Mitchell, and Haigh (2010) reported that 57% of siblings had had a full discussion of future support with their parents, 33% of siblings had not had this discussion with their parents. In addition, 57% of siblings reported that no clear future plan was in place for the teen's future.

Furthermore, many siblings feel a particular sense of responsibility for when the time comes that their parents will no longer be able to maintain the previous level of support for the individual with a disability (Orsmond & Seltzer, 2007). Indeed, many siblings have expectations that their level of caregiving and commitment to their brother or sister will increase in the future (Greenberg et al., 1999). Some studies have found that siblings who were found to have more negative relationships with their brother or sister with DD were less likely to be expected to take on a future caregiving role (Bigby, 1997; Griffiths & Unger, 1994). All of the aforementioned studies examining future planning investigate siblings of adults with DD. Nothing is known about the very beginnings of this process.

The second critical aim of this investigation is to identify the experiences of siblings of individuals with DD over the teen's adolescence. The sibling relationship is often considered to be the longest lasting and most intricate relationship an individual will experience in his or her lifetime (Seligman & Darling, 1989; Seltzer et al., 2005). By the time a child is one year of age, they spend as much time with their siblings as they do with their mothers, and more time than they do with their fathers (Lobato et al., 1988). Additionally, sibling lifespans overlap more with each other than with parents, resulting in relationship longevity that cannot be matched in any other relationship (Lobato et al., 1988). Given the estimate that 80 to 90% of individuals grow up with one or more siblings (Cicirelli, 1995), this relationship can exert substantial influence throughout an individual's lifetime. The sibling relationship provides a unique context in which children develop emotional, social, and behavioral competencies (Dunn, 1999). As children move into adolescence, sibling interaction generally becomes less intensive (Dunn et al., 1994) but, nevertheless, adolescents still spend approximately 13% of their time with their sibling (Csikszentmihalyi & Larson, 1984). Therefore, although an overwhelming emphasis in sibling literature has been placed on early to middle childhood sibling pairs, siblings remain a considerable potential influence on development continuing through adolescence.

Very little is known regarding the sibling's experience of the relationship within sibling dyads in which one individual has DD. As is found in the literature on sibling relationship quality, studies on sibling experiences focus primarily on negative aspects of the sibling relationship (Cox, Marshall, Mandleco, & Olsen, 2003). This is just as true of the qualitative literature, where aspects of the sibling relationship such as coping strategies, stressors, and poor quality of life are explored (e.g. Cox et al., 2003; Moyson & Roeyers, 2011). Of the studies that have addressed both positive and negative experiences of siblings of individuals with DD, most have focused on one specific disability (e.g. ASD, Mascha & Boucher, 2006; Spina Bifida, Bellin, Kovacs, & Sawin, 2008). Other studies have chosen to only focus on positive experiences of siblings of individuals with DD (i.e. Behr, 1989; Behr, 1990; Behr, Murphy, & Summers, 1992; Stainton & Besser, 1998). Still other studies have addressed the issue from the parent's perspective (i.e. Mulroy, Robertson, Aiberti, Leonard, & Bower, 2008). No studies to date have addressed the sibling's experiences with the individual with DD from a more holistic perspective. Additionally, previous studies examining sibling perspectives and experiences have primarily focused on sibling relationships in childhood, rather than adolescence.

Mixed Methods Discussion

The current mixed methods investigation offers evidence to help understand the sibling relationship quality in sibling pairs in which one individual has DD within a context of future planning. In this section, I will demonstrate how the content of the qualitative data offered contextual meaning that served two functions: to augment the understanding of the quantitative findings, and to provide detailed and novel information about sibling relationships in this population. I will speculate how trends in the qualitative data may point to latent relationships to be addressed in future research.

Relationship Between Aspects of Future Planning and Sibling Relationship Quality. Among the sample of siblings examined at T18, results indicated that the teen's functional skills were associated with higher levels of sibling cooperation while controlling for concurrent family SES. In other words, higher levels of teen functional skills were associated with higher levels of reported sibling cooperation. There has been some conjecture in the field that the functional skills of the individual with a disability may be related to a seeming lack of affective intensity in the sibling relationship (Begun, 1989). Despite lack of empirical evidence for this hypothesis, per se, there is evidence that indicates the instrumental involvement of the sibling is associated with the level of the individual with DD's functional skills (Hannah & Midlarsky, 2005). However, this is to be expected, as individuals with lower adaptive and cognitive skills require increased levels of instrumental support. Additionally, research suggests that a more pronounced role asymmetry in sibling relationships may be related to the sibling with DD's lower level of functional skills (Dallas et al., 1993; McHale & Gamble, 1989; Stoneman et al., 1988). This research intimates that lower levels of functional skills create a more extreme role asymmetry, which results in decreased levels of sibling warmth or cooperation. However, this hypothesis has not been explicitly tested and further research is needed to determine if this may be the case.

Kersh and Hauser-Cram (in prep) found that, in the EICS sample at T15, teens who had lower functional skills provoked more pessimism in their siblings and also had siblings who worried more about the future. Similarly, it was found that the needs of children with disabilities were related to their sibling's involvement in helping and with families' pragmatic worry (McHale & Gamble, 1989); children with more needs had siblings who helped out more and families with increased worry. Taken in conjunction with the results of Kersh and Hauser-Cram (in prep), it would seem that, although the sibling relationships in these families are not typical, they are better described as adaptive, not as problematic (Stoneman, 2001). The observed increased concern in these siblings may just be a realistic response to the vulnerability related with the teen's disability (Kersh & Hauser-Cram, in prep).

The current study identified patterns within the qualitative content analysis to support this notion. Among siblings of teens with lower functional abilities (functional skills that were at or below the sample mean; $\text{mean}_{\text{Binet}} = 69.00$; $\text{mean}_{\text{Vineland}} = 50.24$), the concerns and hopes were substantially different than the concerns and hopes of siblings of teens with higher functional abilities (above the sample mean). While there is some overlap, there were significant differences in the sibling responses. The concerns for the future of the siblings of teens with lower functional capacities reflected themes such as "teen cannot have a social life", "who will care for the teen when parents die?", "teen will be taken advantage of", "health" and "teen is too dependent on the family". The responses from these siblings concentrated on the mentioned concerns much more heavily than on the other themes of concerns present in the sample as a whole. Conversely, the concerns of siblings of the teen with higher functional capacities strongly reflected the themes "job/finances", "independent living", and "nothing to worry about".

Arguably, the concerns identified as most salient to siblings of the teens with lower functional abilities are decidedly more serious, and have more far-reaching implications, than those identified as salient for the siblings of teens with higher functional abilities. For example, having the concern that there is no guardianship plan in place for the teen when your parents die is a weightier concern that being worried the teen may not get into college. Similarly, the siblings of teens with lower functional skills never responded that they did not have any worries regarding the teen's future, whereas the siblings of teens with higher functional skills did so quite frequently. However, in both cases, the concerns expressed by the siblings are realistic reflections of obstacles that may lie in the teen's future.

Concerns expressed by the siblings of higher functioning teens seem to reflect concerns that one might have for a typically developing sibling. These responses really emphasized that the sibling was concerned with how well the teen could care for him or herself in the future. These siblings seemed to be intuitively granting credit to the teen's abilities while recognizing their limitations and, consequently, were concerned with how well the teen would be able to "keep up" in a typically developing world. Conversely, concerns expressed by the siblings of lower functioning teens reflect concerns regarding meeting basic needs, such as safety, housing, and care. These responses really emphasized that the sibling was concerned with whether or not other people would be able to properly care for and protect the teen in the future. These siblings seemed to be intuitively recognizing the teen's inability to independently care for themselves and, consequently, were concerned with whether sufficient care would be available to the teen.

Therefore, it is possible that the increased worry carried by the siblings of teens with lower functional skills may be adaptive, but it may also negatively impact the warmth in the sibling relationship. It may be that for these particular siblings, the preoccupation with future uncertainty and worry causes them to interact differently with the teen. That being said, it is necessary to clarify the relationship between level of concern, functional skills of the teen, and sibling cooperation and warmth. However, it seems that the types of concerns exhibited by the siblings in these analyses may impact sibling relationship quality.

As mentioned above, the hopes expressed by siblings of teens with higher functional capacities were different from the hopes expressed by siblings of teens with lower functional capacities. However, the overlap in hopes between the two groups of siblings is relevant and thought-provoking as well. First, there were some notable differences between the types of hopes seen in sibling responses by teen functional skills. Siblings of teens with lower functional skills remarked that they hoped the teen would do things like learn to talk and learn to walk. These, for obvious reasons, were never addressed by siblings of teens with higher functional skills. Given that the teens were 18 years of age when the sibling responses were collected, these hopes may not be realistic.

If an individual is 18 years of age and he or she has yet to meet these developmental milestones, it is unlikely that he or she will ever do so. It seemed that siblings of teens with lower functional skills had hopes that focused on the disability, almost as if they were hoping the disability would go away to some degree.

This is in contrast to the hopes of siblings of teens with higher functional skills, which concentrated overwhelmingly on things such as "I hope he finds something he's passionate about", " I hope he finds a job he likes", "I hopes she is financially successful", and "I hope she gets married". These hopes were, seemingly, more life-focused than disability-focused. In other words, these siblings had hopes that the teen could lead a relatively "normal" life, while recognizing that there may be some limitations or obstacles. Again, there was this underlying idea that the siblings wanted the teen to be able to "keep up" in a typically developing world.

This could be seen, to some extent, in some of the answers that overlapped as well. For example, siblings from both groups replied that they hoped the teen would get a job or make their own money. However, for siblings of teens with lower functional abilities, this may not be a realistic hope. Similarly, many siblings of lower functioning teens and a few siblings of higher functioning teens hoped that the teen would be independent. Again, as the teen is already 18 years of age, these types of statements may represent a more realistic hope for siblings of higher functioning teens than for siblings of teens with higher functional capabilities than for siblings of teens with lower functional capabilities. Given this pattern, perhaps the unrealistic nature of the hopes of these siblings are indications that they have not fully accepted the teen's disability or the extent of the implications of the teen's disability. To some extent, it appears that these siblings have not completely dealt with the nature of the teen's disability. It is easy to see how this might negatively impact the sibling relationship, especially as the teen ages and continues his or her level of dependency. Further research is needed to determine the relationship between sibling hopes for the future, teen functional skills, and sibling relationship quality.

Additionally, sibling gender match was significantly related to sibling cooperation, so that same-gender sibling pairs reported higher levels of cooperation than opposite gender sibling pairs. Gender has consistently been associated with relationship quality and sibling interactions in families of children with and without disabilities (e.g., Buhrmester, 1992; Dunn, 2002; McHale & Gamble, 1989; Stoneman, Brody, Davis, & Crapps, 1987b). However, these studies focus principally on whether the sibling is male or female, rather than on the match of the siblings' genders. More specifically, sisters report higher levels of prosocial behavior, nurturance, and affection in their sibling relationships, regardless of their sibling's disability status (Kaminsky & Dewey, 2001).

Studies have also found that sisters are more positive in their interactions with their siblings with and without DD (e.g., Dunn et al., 1994; Eisenberg et al., 1998; Kaminsky & Dewey, 2001; Orsmond & Seltzer, 2000). Likewise, Hannah and Midlarsky (2005) found that sisters are more emotionally supportive of their siblings with disabilities. Gender has also been associated with differences in negative sibling relationship qualities. For example, one study showed that boys are more competitive with their siblings, irrespective of the gender or disability status of their brothers and sisters (Kaminsky & Dewey, 2001). Finally, sisters of individuals with DD have been found to be more involved in caregiving, and have reported higher levels of warmth and companionship in their sibling relationships than did brothers (Orsmond & Seltzer, 2000).

Interestingly, the current study found no effect of sibling gender on sibling relationship quality. This may be due to the fact that many of the aforementioned studies examined childhood, while this investigation focused on adolescence. Few studies to date have examined gender match on sibling relationship quality outcomes, although it has been called for (Stoneman, 2005). In a study of children with Down syndrome and their siblings, it was found that same-gender siblings had more positive interactions and higher empathy than opposite-sex siblings (Cuskelly & Gunn, 2003). In contrast, in a sample of siblings of children with intellectual disabilities, no difference was found between same-sex and opposite-sex sibling pairs in warmth/closeness (Floyd et al., 2009). Interestingly, the current study utilizes a sample more closely matched to that of Floyd et al. (2009) than that of Cuskelly and Gunn (2003), yet finds different results using the same outcome measure. This may be related to the fact that, in the current investigation, a principal components analysis was performed on the Sibling Relationship Questionnaire (Furman & Buhrmester, 1985) prior to including it in final analyses. Thus, the outcome measure was slightly different, and perhaps more sample-appropriate, in the current study compared to the Floyd and colleagues (2009) study.

One aspect of the qualitative content analysis in the current investigation did stand out as noteworthy in terms of differences between same-sex sibling pairs and opposite-sex sibling pairs. In response to the question “In what way has your brother or sister made you proud?”, siblings who were the opposite gender as the teen emphasized concrete accomplishments (school, awards) and only sometimes mentioned the teen’s work ethic or positive personal characteristics. Conversely, the siblings who were the same gender as the teen almost exclusively highlight two main ideas: that the teen was capable of so much despite their disability and that the teen was their own person without caring what others thought. These two ideas were not addressed by opposite-sex siblings. It would seem, then, that the same-sex siblings were reflecting a feeling of admiration for the teen. There was more of an affective quality to the same-sex sibling responses that was not necessarily there for the opposite-sex siblings. The nature of the sibling responses to this question may reflect a dynamic occurring in the relationship as a whole. Perhaps same sex siblings are sharing a more affect-rich relationship than opposite-sex sibling pairs, and this is reflected in both their responses to open-ended questions as well as in their sibling relationship quality scores.

The role of gender match in sibling pairs where one individual has a disability is still unclear. The results of the current study in conjunction with previous research, however, do suggest that same-sex sibling pairs may have increased amounts of positive interactions or, at the very least, gender match is worthy of additional investigation. Much more research is needed to elucidate the function of sibling gender match in these relationships.

The level of frequency at which siblings discussed the teen’s needs with their parents was also significantly associated with sibling cooperation, so that siblings who discussed the teen's needs more frequently also reported more sibling cooperation. Previous research has shown that parents tend to direct more attention to children with disabilities than they do to their typically developing siblings (Corter, Pepler, Stanhope, & Abramavitch, 1992; Lobato, Miller, Barbour, Hall, & Pezzullo, 1991; McHale & Pawletko, 1992; Stoneman, Brody, Davis, & Crapps, 1987a). Additionally, this differential parenting within families can lead to anxiety and depression in the typically developing sibling, especially when the sibling feels dissatisfied (Conger & Conger, 1994; McGuire, Dunn, & Plomin, 1995; McHale & Gamble, 1989; Stocker 1993, 1995). However, the relationship is more nuanced than it first appeared. In well-adjusted families, this favoritism is seen by the typically developing sibling as an appropriate response to the child with a disability's needs (McHale & Pawletko, 1992; Stoneman, 1998).

In considering the possible explanations for the current analyses, I speculate that the amount of discussion a family has around the teen's needs is a proxy for the family's adjustment. Indeed, it is easy to imagine that, with augmented discussion of the teen's needs, siblings may be better able to adjust to, or accept, the increased level of attention received by the teen. Furthermore, sibling adjustment and well-being has been repeatedly associated with sibling relationship quality, although the direction of this relationship is unclear (Dunn, 2002). While most studies hypothesize that the quality of sibling relationships impact sibling adjustment, it is likely that it is a bidirectional relationship. Therefore, it is plausible that the frequency of discussion of the families in this sample is serving as a proxy for family functioning, which acts as a mediator between sibling adjustment and sibling relationship quality. Further research and analyses would be needed to elucidate this relationship.

Additionally, the total number of roles the siblings expected to fill in the teen’s future was significantly related to sibling cooperation, so that siblings who expected to fill more roles in the teen’s future also reported higher levels of cooperation. Little is known regarding the effect that future planning has on the sibling relationship. Some studies have found that siblings who were found to have more negative relationships with their brother or sister with DD were less likely to be expected to take on a future caregiving role (Bigby, 1997; Griffiths & Unger, 1994). Therefore, the results of the current study suggest that siblings with more positive relationships with their brother or sister with DD may be more likely to take on future roles. However, I believe there is an alternative explanation for this observed relationship. It well may be that siblings who anticipate the need to play a variety of roles in the teen’s future conceptualize their sibling relationship differently than those who do not expect to take on a large part of the teen’s future. Perhaps these siblings are aware of the responsibility that awaits them in the future as previous literature has suggested (Greenberg et al., 1999; Orsmond & Seltzer, 2007), and this impacts how they view and act in the current sibling relationship. The direction of the relationship is unclear, and much more research is needed to determine how the sibling’s expectations of their future responsibilities impact their current relationship with the teen.

Results indicated that sibling order was associated with levels of sibling conflict so that siblings who were older than the teen reported lower sibling conflict than those who were younger than the teen. This was supported by the qualitative findings. All of the cases in which the siblings reported having learned a negative characteristic of the teen were younger siblings, as were most of the concerns regarding the teen's negative characteristics. Although few cases highlighted the negative characteristics of the teen, the birth order of the siblings who did so was consistent. This tendency toward negativity may be for several reasons.

First, as discussed earlier in this dissertation, younger siblings may experience a role crossover. The sibling of a child with a disability often takes a more dominant role as they teach and assist their sibling. Indeed, role relationships between children with intellectual disabilities and older siblings have been found to be especially asymmetrical, with older siblings assuming frequent teacher, manager, and helper roles, whereas siblings of typically developing children are more likely to engage their brothers and sisters as playmates (Stoneman et al., 1989). Both older and younger siblings of children with disabilities have been found to take on more extensive caregiving roles when compared to their peers who have a typically developing sibling (Cuskelly & Gunn, 2003). This role dominance is especially salient for younger siblings who begin as the less dominant sibling and, as time progresses, eventually surpass their older sibling developmentally (Farber & Jenné, 1963). This experience, known as role cross-over, contrasts to that found in typically developing sibling pairs which follows a pattern of older sibling dominance (Dallas et al., 1993).

Consequently, younger siblings may experience more negativity around the sibling relationship as they struggle to come to terms with this new role. Children's satisfaction with ther sibling relationship has been found to be, in part, a function of their ability to negotiate mutually acceptable role relationships (Stoneman & Brody, 1982). Given that the teen with DD was 18 years of age at the time of the current study, this role cross-over may be exceptionally salient as this is a time that most 18 year olds legally become independent adults, while this may not be the case for the teens in this study. Additionally, these younger siblings may be frustrated that their older sibling is not behaving as an older sibling should. This is supported by the responses written by the younger siblings, including those indicating the teen needs to “grow-up” and those related to feeling embarrassment about the teen. Consequently, these siblings may not have successfully negotiated acceptable role relationships, as their roles are largely determined by the needs of the teen, rather than a negotiation of mutually acceptable relationship roles.

Second, this effect may be compounded due to the increased amount of care given to the child with a disability. Previous research indicates that younger siblings are apt to show attention-seeking and regressive behaviors (Tew & Lawrence, 1973). Additionally, these siblings may feel displaced by the brother or sister with DD as they assume the more dependent role in the family (Jordan, 1962; Lavigne & Ryan, 1979). These studies imply that dependency is divided among siblings according to birth order. Assumedly, the younger child in the family receives more attention and care in a typical family. However, having a child with a disability in the family may disrupt that implicit order, thus resulting in poorer adjustment for the younger sibling (Breslau, 1982). Again, this can be supported with the responses received from the younger siblings mentioned above.

Next, the majority of the siblings in this study were also in adolescence. Therefore, perhaps the overall functional level of a brother or sister with a disability has particular importance during this stage of development. Adolescents often are renegotiating and redefining their roles and relationships within the family (e.g., Steinberg, 1990). Therefore, the functional skills and level of need of a brother or sister with a disability could be especially influential in this process. Indeed, the work of Wilson and colleagues (1992) indicates that the predictive power of functional skills on sibling involvement may decrease in the adult years. Further research is needed to determine the nuances of this relationship. Not enough is known about role cross-over and sibling relationship quality to determine the exact path or direction of the relationship.

Finally, it is important to note that behavior problems were not significantly related to any of the sibling relationship quality outcomes after functional skills had been accounted for. This is a surprising finding, as the relation between child behavior problems and parent well-being in families of children with disabilities is supported by an abundance of empirical evidence (e.g., Baker, Blacher, & Olsson, 2005; Floyd & Zmich, 1991; Hastings & Brown, 2002; Ricci & Hodapp, 2003). Consequently, it stands to reason that the teen’s behavior problems in this sample would impact the sibling relationship as well. Indeed, Kersh and Hauser-Cram (in prep), found that maternal warmth mediated a relationship between behavior problems and sibling warmth. As this relationship has not been extensively empirically tested, it is possible that behavior problems relate more to sibling and parent well-being, while functional skills are more important for the sibling relationship. Further research is needed to elucidate this relationship more fully.

Change in Sibling Relationship Closeness. Results indicated that there was a difference in sibling relationship closeness from when the teen was 15 years of age and when the teen was 18 years of age after controlling for family SES, teen functional skills, and teen diagnostic category. Sibling relationship closeness generally decreased over this span of three years. This is the first study to examine this pattern in sibling pairs in which one individual has DD. It is known that, in typically developing sibling pairs, the sibling relationship is likely to change in adolescence in tandem with cognitive, social and biological changes that are occurring at this time (Buhrmester, 1992; Dunn, 1992; Dunn et al., 1994; Steinberg & Morris, 2001). Previous research on typically developing sibling pairs has indicated that when compared to younger siblings, siblings entering adolescence report diminishing levels of companionship, intimacy, affect and interaction with their siblings (Buhrmester, 1992; Buhrmester & Furman, 1990). However, in studies of typically developing sibling pairs, this occurs in the context of the sibling relationship becoming increasingly egalitarian as siblings grow more similar in competence and developmental level (Buhrmester, 1992; Buhrmester & Furman, 1990).

In sibling pairs where one individual has DD, the sibling relationship is not becoming more egalitarian in adolescence. Indeed, these relationships are often marked by extreme role asymmetry and role cross-over (Abramovitch et al., 1987; Stoneman et al., 1989). Furthermore, as these children age, the relationship becomes more asymmetrical over time, in direct contrast to the findings in typically developing pairs

(Orsmond & Seltzer, 2000; Stoneman et al., 1989). Yet, the siblings in this sample still report an overall decrease in sibling relationship closeness over adolescence.

Without a doubt, sibling pairs in which both siblings are typically developing differ from sibling pairs in which one sibling has a developmental disability in countless ways. Therefore, it does not make sense to assume that changes in power differentials over time act similarly for both sets of siblings. Indeed, the type of role asymmetry and power differential experienced by siblings of individuals with a disability not only follow a different developmental course, but also arise for very different reasons than power differentials in typically developing pairs. It is possible that siblings of teens with DD are experiencing an increased power differential over time and, consequently, the nature of their relationship is changing. In considering the possible explanations for this relationship, I speculate that the increased level of caregiving associated with the increased power differential that occurs over time negatively impacts the sibling closeness. In addition, these findings, in conjunction with the trends noted in the following section, suggest that the sibling's role is, indeed, changing.

Trends reflecting a change in sibling roles. There was a much heavier emphasis at T15 on how to treat the teen, and this shifted to an emphasis on teaching the teen at T18. At T18 the siblings focused very heavily on how to teach and understand the teen, at T15 there was an emphasis on treating the teen with acceptance, respect, and love. It appeared that everyday interactions with the teen were more salient than teaching interactions at T15, whereas the opposite appeared to be true at T18. This particular change in theme, though subtle, reflects the changes occurring in the sibling roles. At

T15, it appears that the siblings are recognizing the teen's abilities as assets to appreciate. The focus is on respecting and accepting the teen. However, at T18, the focus shifts to viewing the teen as a person to be taught.

I believe that this shift mirrors the increasing amount of caregiving being provided by the sibling over adolescence. If the power differential is increasing as the sibling continues to develop at a faster pace than the teen with a disability, it is likely that the sibling will take on an increased caregiving role. Consequently, the sibling may experience a sense of accountability for the teen as a result of the increased power differential. By the time the teen is 18, as previous research has shown, siblings are realizing the long-term implications of the teen's disability (Eisenberg et al., 1998). This must be considered in concert with the findings regarding increasing role asymmetry in these pairs over time (Orsmond & Seltzer, 2000; Stoneman et al., 1989). It is easy to imagine that with this realization and an increased sense of responsibility, siblings begin to view the teen in a different light. In relation to the impact on the sibling relationship, siblings may be experiencing role strain, or the stress of trying to fulfill multiple roles (Goode, 1960). These siblings are attempting fill sibling, caregiver, and teacher roles all at once. Role strain has been linked to negative sibling outcomes (Coleby, 1995; Cuskelly, Chant, & Hayes, 1998; Gath & Gumley, 1987; Stoneman et al., 1988), which may negatively impact the sibling relationship. Regardless, the relationship between egalitarianism and closeness needs to be further unpacked for sibling pairs in which one individual has a disability.

Siblings also highlighted having learned about more positive characteristics of the teen at T15 than at T18. Yet again, the types of positive characteristics that arose (in the initial codes) were similar at each time point, but they arose more frequently at T15. Interestingly, siblings also highlighted having learned about more negative characteristics of the teen at T15 than at T18. Within each time point, however, there were many more instances of having learned positive characteristics than having learned negative characteristics. This increased level of both positive and negative characteristics identified at T15 may indicate a relationship including conflict within a context of warmth. Therefore, at T15, the increased level of both positive and negative responses about the teen may simply reflect an increased level of affect within the relationship at this time. The decrease in these responses over time, therefore, mirrors the decrease in relationship closeness found in the quantitative analyses. Again, this has not been explicitly studied. It is known that high levels of both warmth and conflict are advantageous for sibling social outcomes (Floyd et al., 2009), but the implications of relative levels of warmth and conflict within the sibling relationship are unclear. The question highlights the importance for the field to define what is meant by a “good” sibling relationship and to examine what relative levels of different aspects within the sibling relationship mean for sibling relationship quality.

Another explanation for the changes in responses has to do, again, with changing roles over adolescence. At T15, siblings may have been placing more emphasis on their role as a sibling but, by T18, there is an increased emphasis on their role as a teacher or caregiver. Consequently, the salient lessons learned at this time point are related to life lessons and lessons learned for themselves, rather than attributes of the teen specifically. At T18, the sibling’s responsibility and accountability for the teen may be more salient, thus highlighting how this role impacts their own interactions with the teen and their life more generally.

In terms of lessons learned for themselves, siblings commented more frequently on the meaning of having a sibling with a disability when the teen was 18 than they did when the teen was 15. In other words, when the teen was 18, the impact of having a brother or sister with a disability appeared to be more salient for the siblings in this study. However, within time points, more siblings emphasized that having a brother or sister with a disability was rewarding in spite of the difficulties at T15 than they did at T18. In other words, siblings at T18 were more likely to highlight that having a brother or sister with a disability was simply difficult rather than both difficult and rewarded as they did at T15. These responses reflect a similar pattern as the one mentioned above. At T18, siblings seem to be more focused on or aware of the negative aspects and experiences of having a brother or sister with a disability. This mirrors the pattern seen in the change in life lessons. Again, this may be a reflection of the change in roles being experienced by the sibling. If the sibling feels more accountable for the teen and is taking on more responsibility, they may be more aware of the teen’s weaknesses and the hardships that are involved in having a brother or sister with a developmental disability.

The types of lessons siblings learned for themselves showed a similar pattern. Siblings commented more frequently on the meaning of having a sibling with a disability when the teen was 18 than they did when the teen was 15. In other words, when the teen was 18, the impact of having a brother or sister with a disability appeared to be more salient for the siblings in this study. However, within time points, more siblings emphasized that having a brother or sister with a disability was rewarding in spite of the difficulties at T15 than they did at T18. In other words, siblings at T18 were more likely to highlight only the negative aspects of having a brother or sister with a disability than they were at T15. These responses reflect a similar pattern as the one mentioned above. At T18, siblings seem to be more focused on or aware of the negative aspects and experiences of having a brother or sister with a disability. This mirrors the pattern seen in the change in life lessons. Again, this may be a reflection of the change in roles being experienced by the sibling. If the sibling feels more accountable for the teen and is taking on more responsibility, they may be more aware of the teen's weaknesses and the hardships that are involved in having a brother or sister with a developmental disability.

Perhaps the most profound difference observed between T15 and T18 in terms of the identified lessons learned from living with the teen was in relation to the lessons learned about life. On the surface, there were a similar number of siblings who emphasized having learned a life lesson at each time point. Additionally, with the exception of wording arising from the siblings' responses, the initial codes were virtually identical at T15 and T18. However, across time points, the distributions of themes were remarkably different. At T18, there was a heavy emphasis on having gained a new life perspective. This theme was less marked at T15. The siblings who commented on life perspectives at T18 overwhelmingly concentrated on lessons pertaining to finding the silver lining and the unpredictable nature of life. This contrasted to the siblings at T15, who instead emphasized the value of people and life almost exclusively. Similarly, more siblings emphasized learning that they were lucky in some way at T15 then they did at T18. There were an overwhelming number of responses at T15 that discussed the siblings feeling lucky for having the teen, whereas this was much more infrequent at T18. This may reflect another way in which these siblings have learned to value people in their lives, in that they specifically have learned to value the teen.

The differences in these lessons learned suggest that the lessons learned at T18 reflect having experienced some hardship. In other words, looking for a silver lining implies that there is some negative experience that must be re-evaluated. Similarly, emphasizing the unpredictable nature of life indicates that the sibling has experienced life’s ups and downs. It is possible that living with the teen by T18 has impacted the experiences of the siblings in a difficult or stressful way and, thus, altered their life perspectives. In conjunction with findings indicating that decreases in sibling relationship quality are related to negative adjustment in siblings (e.g., Conger & Conger, 1994), this suggests that sibling relationship quality and sibling psychological well-being are closely linked. Again, the direction of this relationship is still unclear, and must be examined further.

Furthermore, at T15, the siblings who identified having learned a lesson about life strongly emphasized learning that everyone is unique, whereas this was much less frequently addressed at T18. When looking at the responses, it became clear that the siblings really picked up on the idea that everyone has different needs, talents, and appearances at T15. At T18, this was less frequent, and the siblings who did remark on learning that everyone is unique stated it as everyone being different, without highlighting the idea that everyone has different assets. In this way, the T15 responses that identified learning that everyone is unique appeared to be much more strength-based, rather than difference-based. Again, this could be reflecting a change in roles from sibling to teacher or caregiver. The differences become more salient at T18 because the differences they see between the teen and typically developing adolescents have defined the sibling relationship and the sibling's role in it.

Trends reflecting sibling development. Slightly more siblings included lessons learned for themselves at T18 than they did at T15. Within the category, however, the themes varied considerably from the first time point to the second time point. First, siblings cited having learned a virtue less at T15 than they did at T18. Although the types of virtues learned (patience, understanding, etc.) remained the same over time, more siblings reported having learned a virtue from living with their brother or sister at T18 than they had when the teen was 15. Furthermore, the types of virtues varied more greatly at T18 than they did at T15, although patience and understanding were the most frequent initial code in each.

Far fewer siblings commented on having learned how to interact with or treat people generally at T15 than at T18. Again, the initial codes were very similar, but siblings remarked more on learning how to treat other people less frequently when the teen was 15 than they did when the teen was 18. However, within this theme, a greater proportion of siblings identified having learned to treat others as they wished to be treated and to never judge a person prematurely at T15 than at T18. These two shifts in sibling responses from T15 to T18 reflect the change in distributions from more emphasis on lessons learned about the teen at T15 to more emphasis on lessons learned for the sibling themselves and about life more generally at T18. Additionally, the responses at T18 seem to highlight how the sibling has learned to behave in interactions globally, rather than on the relationship with the teen specifically.

A likely explanation for these changes observed in lessons learned is that the majority of the siblings in this study were in adolescence (approximately 68%). Therefore, the siblings are still developing. The changes seen in how siblings view the teen with a disability and how they look at life more generally might simply be a reflection of cognitive and social development. Prosocial behavior, moral reasoning, and perspective taking have been identified as central developmental issues during adolescence (Chase-Lansdale, Wakschlag, & Brooks-Gunn, 1995; Eisenberg, Cumberland, Guthrie, Murphy, & Shepard, 2005). The development of these skills likely influence siblings’ ability to recognize broader lessons learned, such as virtues and how to interact with people. Additionally, perspective taking is apt to impact the siblings’ ability to examine how they should treat people. For example, as the siblings mature, they are better able to think about how it might feel to be made fun of as a person with a disability. These lessons may have been prompted by living with a brother or sister with a disability, but the ability to recognize such lessons is likely a result of the sibling’s own development.

Relationship between Sibling Expectations, Pessimism, and Frequency of Discussion and Change in Sibling Relationship Closeness. Results indicated that sibling expectations for the teen's future when the teen was 15 years of age was not significantly associated with a change in sibling relationship closeness. However, sibling pessimism was related at trend level to the change in sibling relationship closeness, so that higher levels of pessimism when the teen was 15 years of age were associated with a greater decrease in sibling relationship closeness over adolescence. Indeed, previous research has shown that, generally, while having a brother or sister with a disability is not inherently deleterious, siblings do tend to report higher levels of anxiety and worry than children in typical families (Eisenberg et al., 1998; Pit-ten Cate & Loots, 2000; Rossiter & Sharpe, 2001). These feelings of pessimism have been found to negatively impact siblings' emotional well-being, and it is easy to imagine how that might transfer to the sibling relationship quality.

There is another explanation for this finding. The sibling's level of pessimism for the teen's future may reflect their recognition of the long-term implications of the teen's disability. This is reflected in the items within the pessimism measure (QRS-SF; Friedrich et al., 1983). For example, items include "It bothers me that my brother or sister will always be this way" and "My brother or sister will always be a problem to us". The very nature of the measure taps into the long-term impact of the teen's disability. Therefore, the sibling's pessimism at T15 might reflect a realization regarding the future, which then is related to how the sibling relationship changes over time. This will be further discussed below. No research to date has addressed how siblings' feelings of pessimism about the teen's future relate to contemporaneous sibling relationship quality or changes in relationship quality. Future research is needed to examine the nuances of this relationship.

Conclusion. To summarize, there are several themes arising within the quantitative data and qualitative data that, I believe, reflect a pivotal change in the sibling relationship that is happening during this period. First, sibling relationship closeness is decreasing between when the teen is 15 years of age and when the teen is 18 years of age. Second, qualitative responses reflect increased cognitive and emotional maturity of the siblings over time, emphasizing the importance that this change in relationship closeness is occurring within a context of sibling development. Third, and finally, this decrease is occurring within a context of the sibling relationship becoming more asymmetrical over time, as is indicated by previous research (Orsmond & Seltzer, 2000; Stoneman et al., 1989), and by trends seen in the qualitative data of this dissertation.

First, there is a decrease in the sibling relationship closeness over this time period. Although the results of the quantitative analyses of this dissertation indicate that this is a small decrease, the decrease is further substantiated in the qualitative results. It seems that a variety of issues may underlie this change. Siblings indicated more hardship and less positivity in their lessons learned at T18 than they had at T15. This was reflected in how siblings came to view life, the teen, and their relationship with the teen at T18 in comparison to T15. Compared to T15, siblings at T15 more often reported difficulty in living with the teen, that having a brother or sister with a disability was hard, and that life was hard and capricious. Any of these in isolation or in concert could impact the sibling's view of sibling relationship closeness. Again, no research to date has examined the impact of sibling pessimism or worry on the actual sibling relationship quality. However, the results from the current investigation suggest that this is a critical area of investigation for future research.

Second, this decrease in sibling relationship quality is occurring within a context of sibling development. The majority of siblings in the current study are also in adolescence, as noted above. The results from the qualitative analysis revealed that changes in lessons learned from living with the teen over time reflected the cognitive and emotional development of the sibling. At T18, siblings focused less on what they learned about the teen, and more on what they learned for themselves. This was illustrated in the increases in having learned virtues and having learned how to interact with and treat people. These changes likely reflect the siblings' development in moral reasoning, perspective taking, and prosocial behavior. The emphasis in sibling responses overall at T18 was on more global lessons about how to live and act in the world, as opposed to only lessons learned for themselves and, specifically, about the teen. By T18, siblings had generalized the lessons they had learned by living with the teen to lessons that were applicable across many relationships and situations in life.

Finally, this decrease in sibling relationship quality is occurring within a context of increasing power differentials, or role asymmetry, within the sibling relationship and shifting sibling roles. Many of the trends noted in the qualitative analyses can be understood as reflections of changing sibling roles. Siblings at T18 often spoke about teaching the teen with a disability. This was in stark contrast to their responses at T15, which emphasized interacting with and accepting the teen. This suggests that, over this three-year period, siblings are shifting roles from being just a brother or sister to being a caregiver, teacher, or manger. The sibling of a child with a disability often takes a more dominant role as they teach and assist their sibling. Indeed, role relationships between children with intellectual disabilities and older siblings have been found to be especially asymmetrical, with older siblings assuming frequent teacher, manager, and helper roles, whereas siblings of typically developing children are more likely to engage their brothers and sisters as playmates (Stoneman et al., 1989). Both older and younger siblings of children with disabilities have been found to take on more extensive caregiving roles when compared to their peers who have a typically developing sibling (Cuskelly & Gunn, 2003). Implicit in this explanation is that sibling responsibility and accountability for the teen increase over adolescence as the sibling becomes more like an adult and the power differential increases in the relationship. Furthermore, at T18, siblings focused much more on the hardships involved with having a brother or sister with a disability. This finding suggests that, with shifting roles come shifting responsibilities that may highlight some obstacles or difficulties in living with the teen. The types of interactions that one has in a sibling relationship are necessarily different from the types of interactions one has in a teacher-student type relationship. Once the sibling feels some level of accountability for the teen, it may result in the sibling experiencing increased difficulties and conflict in the sibling relationship.

Having identified the three main trends found in the data, I speculate that all three are closely related. More specifically, I believe that the driving force behind the change in relationship quality over time is increasing role asymmetry, or the increasing power differential. Given that the majority of siblings in this study are in adolescence, and all the siblings in this study are between middle childhood and young adulthood, their development must be taken into account. These siblings are still developing socially, cognitively, and emotionally. In contrast, the teens with disabilities in this study are developing at a much slower pace. Therefore, as time goes on, the gap between the developmental level of the sibling and the teen widens. This increasing role asymmetry has been supported in the literature base (Orsmond & Seltzer, 2000; Stoneman et al., 1989).

This increasing role asymmetry is occurring simultaneously with a shift in roles for these siblings. Prior research indicates that younger siblings of children with disabilities experience a role cross-over at which point they overtake their older brother or sister developmentally (Farber & Jenné, 1963; Stoneman, 2005). In relation to the current investigation, it is impossible to tell when this role cross-over is occurring. However, virtually nothing is known about the nature of sibling roles more generally over time. Previous research has indicated that siblings of children with disabilities take on more caregiving responsibilities than siblings of typically developing children generally (Cuskelly & Gunn, 2003; Gath & Gumley, 1987; McHale & Gamble, 1989; Stoneman et al., 1988; Stoneman et al., 1991). What is not known is the development of this caregiving role over time. It is easy to see how, as the sibling continues to develop skills, it would be natural for them to take over increased caregiving activities. If this is the case, as I suspect it is, siblings are moving from a sibling, peer-like role to a caregiver or teacher role. As mentioned previously, this type of shift would unavoidably require a change in the types of interactions the sibling has with the teen.

This increased caregiving role may result in a decreased sibling relationship closeness over adolescence. I posit that this is not necessarily because the sibling relationship is deteriorating but, rather, that the nature of the sibling relationship is changing. Research has shown that siblings who engage in increased levels of caregiving for their brother or sister with a disability are limited in the time they are able to spend with friends and participating in social activities (Coleby, 1995; Stoneman, 1988). In other words, these siblings experience time constraints in that their caregiving duties take away from time spent with peers. Similarly, it is possible that, within the sibling relationship, when siblings take on increased caregiving responsibility, they no longer have the time to interact with the teen as a playmate or peer. The interactions they have with the teen are now colored by their role as teacher or caregiver. Therefore, I speculate that this decrease does not necessarily reflect that the sibling relationship is worsening over time, but that it is changing to accommodate the role asymmetry and the new role of the sibling and, ultimately, the teen with a disability.

Finally, around the time the teen is 18 years of age, siblings have begun to recognize and come to terms with the long-term implications of the teen's disability (Eisenberg et al., 1998). This is also likely a result of the siblings' development and a result of the increasing role asymmetry. It is possible that sibling development and increasing role asymmetry in the sibling relationship result in this realization that, in turn, triggers the sibling to adjust his or her role in the teen's life accordingly. Additionally, the findings regarding pessimism and the sibling relationship support this hypothesis. Higher levels of pessimism at T15 relate to larger decreases in sibling relationship closeness over adolescence. However, the pessimism measure taps into the realization that the teen's disability has life-long implications. Again, I do not believe that the sibling's level of pessimism is related to a deterioration of the sibling relationship, but simply is associated with a change in the sibling relationship. Therefore, it is extremely likely that the change in sibling relationship closeness over the adolescent period is driven by two main factors: the siblings' development and increasing role asymmetry. Further research needed to investigate this matter will be discussed later in this chapter.

Limitations

The current investigation has several limitations. First, the EICS sample is largely homogenous. As mentioned previously, the sample is primarily white and middle class. Therefore, it would be difficult to generalize these findings to families of variable backgrounds. Both sibling and family processes are likely to differ as a function of ethnicity and culture (Weisner, 1993).

Second, the data used in the current study focuses only on one period of development. Examining sibling relationships in adolescence makes an extremely important contribution to the existing literature base, as very little previous work has been done on this topic. However, sibling relationships change over time, as previous research and some results from this dissertation show. Although it is important to note that this investigation does examine sibling relationships over a period of three years, it is equally important to indicate that changes over mid-adolescence cannot be generalized to changes in adulthood, childhood, or even other periods of adolescence. This relationship continues to change (Cicirelli, 1995). Families and sibling pairs face a variety of changing experiences and challenges throughout the life course.

Third, it is important to note that this study is a correlational design. Thus, the direction of effects as well as causality cannot be inferred. The use of more sophisticated statistical analyses may yield more detailed results in future studies. The relationships reported in this dissertation likely reflect transactional multidimensional processes within the family **(**Sameroff & Chandler, 1975). This is especially true when working within a family systems framework (Minuchin, 1985; 1988). Unfortunately, this type of methodological approach was beyond the scope of the current study. Furthermore, shared variance was a potential problem in the quantitative models, as multiple measures were based on sibling report (e.g., sibling relationship quality, pessimism, roles, and expectations). As siblings reported multiple measures, the models may also be vulnerable to bias. However, it is important to note that substantively, there is some strength to using primarily sibling self-report. First, as this is a scantily researched area, it is important to understand how siblings’ feelings and experiences themselves impact the sibling relationship. Second, having primarily sibling report facilitated the mixed methods approach of this dissertation. As siblings reported on the quantitative and qualitative measures, I was able to elucidate a much more complete picture of the siblings’ experiences over this time. That being said, further research should aim to examine this phenomenon through the triangulation of multiple reporters. This is especially important, as the sibling relationship is situated within a multidimensional, dynamic family system.

Additionally, this study gives only one perspective of the sibling relationships in families of children with disabilities, as it did not capture the voice of the target adolescent. This was compounded by the fact that when there were multiple siblings in the family, mothers were asked to nominate the sibling that was closest emotionally to the target teen. This suggest that the data in this sample may be artificially exaggerated, so that sibling responses are more positive than they may be in the larger population of siblings of teens with DD. Within the larger T18 sample in this study, 36% of the teens only had one sibling, while 64% had multiple siblings. Within the smaller paired sample, 50% of the teens had only one sibling and 50% had multiple siblings. In both these samples differ from the national distribution in which only 5% of families with children have more than two children, and 37% of families had two children (U.S. Census Bureau, 2010). Therefore, while the current study likely captures the experience of the siblings most involved in the teen's day-to-day life, it does not address the experiences of all the siblings. Furthermore, in comparison to the population of families as a whole, this sample may not be representative in terms of number of children in the household. Future research must strive to capture both the voices of all the siblings within households and the voice of the teen with a DD. This approach would result in a fuller and more accurate representation of sibling relationships in these families. Moreover, future research should determine potential differences in family constellation between typically developing families and families of children with disabilities.

Finally, this dissertation was working with a small sample size. While a sample of 49 siblings is large for a qualitative analysis, it is quite small for quantitative analyses.

Therefore, some of the variables included in the analyses may make meaningful contributions to sibling relationship quality, but for reasons of power were not statistically significant in this investigation. As noted in Chapter 3, for a power equal to .80 with a large effect size and an alpha of .05, a sample size of 45 is needed for a two-tailed test (Cohen 1988; 1992). However, using the same specifications, to detect a moderate effect size, a sample of 97 is needed. Therefore, the current models were only able to detect large effect sizes, although there may be other important relationships. Future research should aim to replicate these models with larger samples to determine if any other variables contribute to sibling relationship quality significantly.

In spite of these limitations, the findings from this investigation yield a fuller and more complex understanding of the sibling relationships of adolescents with disabilities within the context of future planning.

Future Research and Implications

The current dissertation makes several invaluable contributions to the literature base on the sibling relationship and future planning. First, it addresses how future planning issues impact the sibling relationship. To date, studies have only examined the predictors of siblings' involvement in future planning and siblings' worries about the future (e.g., Davys et al., 2010; Davys, Mitchell, & Haigh, 2011; Griffiths & Unger, 1994; Rawson, 2010). Nothing is known about how future planning in families of children with disabilities impacts the actual relationship between the sibling and the child with a disability. Further research is needed in this area to determine a more comprehensive understanding of this phenomenon. There are many aspects of planning for the future and many ways in which the process of preparing for the future could impact various relationships within the family, not only the relationship between the sibling and the child with a disability. Additionally, more research is needed to determine when siblings are aware of and become a part of planning for the future in order to accurately examine how this impacts various aspects of sibling well-being and the sibling relationship over time. This dissertation provides a glimpse into this process, and highlights the need to truly understand how families negotiate this process together as a family, as well as the impact that this process may have on the individuals within the family.

Second, this dissertation addresses the sibling relationship within the period of adolescence. To date, there has been very limited empirical work that has investigated determinants of sibling relationship quality in families of children with disabilities. Within that already small literature base, very few studies have examined the sibling relationship in adolescence. Therefore, the findings in this dissertation contribute a great deal to the understanding of sibling relationship quality during this developmental period. Much more future research is needed to understand the sibling relationship during this time more comprehensively. Ideally, research will address the role asymmetry and role changes occurring throughout adolescence as discussed in this dissertation. Additionally, this dissertation is especially valuable in that it taps into the future planning process at an early point in the life of the typically developing sibling. All studies to date have only examined aspects of the future planning process in adult siblings of adults with disabilities. Arguably, issues around future planning may be particularly salient to older sibling pairs, as the reality of aging parents may prompt discussion of future guardianship or caregiving responsibilities. However, it is clear from the data in this dissertation that the future planning process begins much earlier than adulthood and, indeed, discussion around the teen's needs in the future is important for sibling relationship quality. As mentioned above, future research should strive to determine the nature of this process over time, as well as the differential influences of this process over time.

Third, this dissertation contributed to the existing literature base greatly in that it examined sibling relationship quality in these pairs over a three-year period. No studies to date have looked at sibling relationship quality over time in sibling pairs in which one individual has a disability. This dissertation is the first study to show any sort of change in sibling relationship quality over time for these sibling pairs. Future research should extend these findings by examining changes in the sibling relationship over childhood through adulthood. While the findings reported here suggest a change in sibling relationship quality over three years in adolescence, the sibling relationship in early childhood is qualitatively different than that in adolescence, and continues to change throughout adulthood (Cicirelli, 1995). Furthermore, this investigation examined determinants of changes in relationship quality over time. Specifically, pessimism was negatively associated with changes in sibling relationship quality over adolescence so that high levels of sibling pessimism at T15 were associated with a larger decrease in sibling relationship closeness. Further research is needed to determine what pessimism really means for these siblings and the mechanism through which it impacts the sibling relationship. I suspect that pessimism is related to the sibling's recognition of the life-long implications of the teen's disability.

Next, the largest contribution that this dissertation makes to the literature base is revealed in the mixed methodology. This is the first study to date to examine both sibling relationship quality and future planning issues using both quantitative and qualitative methods. This approach was ideal for the phenomenon of interest, and virtually nothing was known about how future planning issues impact the sibling relationship in adolescence. Indeed, the combination of quantitative and qualitative analyses revealed some interesting and significant relationships. I believe the most significant contribution that this work makes to the existing discussion surrounding sibling relationship quality in adolescence for these teens is the set of findings around role asymmetry and changes, sibling development, and sibling relationship quality. No research has ever examined sibling roles or caregiving over time. Cross-sectional research has suggested that roles filled by the sibling are varied and are sometimes linked to the stages of the individuals involved (Bigby, 1998; Kramer, 2008). Studies of adult siblings indicate that the nature and characterisitcs of these relationships vary over time, often diverging as siblings develop and determine adult lives away from the family home and then converging later in adulthood as siblings age (Jokenin, 2008). Additionally, for siblings of individuals with DD, this research has indicated the sibling relationship is apt to change in importance throughout different stages of life (Evans et al., 2001). However, longitudinal studies following the same siblings have not been investigated, especially not in adolescence. This research suggests that these aspects of the sibling life and sibling relationship may be changing quite a bit over the teen's mid-adolescence. In addition, no research has ever taken into account the sibling's development over time and used that to explain the sibling relationship. These two areas of inquiry are critically important. No sibling relationship is static; the sibling relationship is constantly in flux and must be investigated as a dynamic relationship. Additionally, within the sibling relationship are two individuals who are changing over time. To date, all research has ignored the sibling's cognitive, social, and emotional development. This dissertation emphasizes the importance of considering growth of the sibling as a factor in their reports of the sibling relationship quality.

Future research must tease apart the relationship between power differential, role changes, and sibling relationship quality. First, basic regression analyses should determine if these constructs are statistically significantly related in quantitative models. Second, regression analyses could also be used to determine if role changes (i.e. increased caregiving responsibilities) mediate the relationship between role asymmetry and sibling relationship quality. Structural equation modeling (path analysis) could be used to more effectively determine which of these constructs are directly related, and which are indirectly related. Finally, and most importantly, longitudinal studies are needed to determine which of these, if any, is the driving force in the relationship. Multi-level modeling would be an ideal approach, as this method allows for testing of the relationship between changing power differentials, changing roles, and sibling relationship quality.

Finally, the current investigation contributes to a more comprehensive and accurate understanding of developmental family processes. Hauser-Cram and colleagues (2001) asserted that the exclusion of atypical populations (particularly children with disabilities and their families) from the typical developmental literature reflects prejudice and “results in a skewed and incomplete science” (p. 4). This investigation applied the bioecological model (Bronfenbrenner, 1986) and Family Systems Theory (Minuchin, 1985, 1988) to an empirical study of siblings of teens with disabilities, thus strengthening the ability of these theories to explain family processes in more diverse populations. Consequently, this dissertation contributes to a more comprehensive science that is able to both embrace and clarify developmental differences.

The findings suggest that interventions aimed at supporting families and siblings during adolescence may be effective for targeting potential deleterious effects of the changing sibling relationship. As discussed previously, I do not believe that the decrease in the sibling relationship over adolescence necessarily reflects a deterioration of the relationship but, rather, just a change in the nature of the relationship. Additionally, the change in sibling responses analyzed in the qualitative content analysis portion of this study emphasizes these shifting roles as well as the sibling’s own development. Therefore, to some extent, I do not posit that intervention is necessary. More specifically, the changing sibling relationship during this time is in part due to the sibling growing up and in part a natural adaptive response to the needs of the teen with a disability. Therefore, the fact that the nature of the relationship changes, in itself, does not require intervention efforts. Additionally, this dissertation only looked at one aspect of the sibling relationship over time quantitatively. As the sibling relationship is multifaceted, future research should examine multiple aspects of the sibling relationship over time.

However, there are findings in this dissertation that may be cause for some concern. Higher levels of pessimism were related to a larger decrease in sibling relationship closeness over time. As previously discussed, pessimism may reflect a natural and important recognition of the long-term implications of the teen's disability. If this is indeed the case, this may reflect a natural progression of the relationship. However, future research is needed to determine the difference between this realization and potentially detrimental levels of stress and worry. Given previous research examining the relationship between high levels of anxiety and concern about the future in these siblings and poor social and mental health outcomes, this distinction is an important one (Damiani, 1999).

Some additional findings to ponder are the relationship observed between increased teen functional skills and increased sibling cooperation as well as the relationship between the level of frequency siblings discuss the teen's needs with their parents and sibling cooperation. First, the relationship between teen functional skills and sibling cooperation indicates that sibling pairs where the teen has low functional skills may be especially at risk for poor relationship quality. Consequently, this is the population to be targeted with any intervention efforts. Second, the relationship between frequency of discussion with parents and sibling cooperation indicates that family discussion around the teen's needs and future are critical for sibling relationship quality. It is possible that lack of discussion about the teen contributes to siblings' worry and anxiety about the future, thus negatively impacting the sibling relationship. However, further research is needed to determine the nuances of these relationships.

Taken together, the findings of this study suggest that, overall, these siblings are not in need of an "intervention" in the most literal sense. The results of this study do not indicate that these sibling pairs are in crisis. However, I do believe that these siblings could benefit from extra support. Some programs have been implemented which aim to provide siblings with social and family support, as well as information about disability (Lobato & Kao, 2002; Lobato & Kao, 2005; Williams et al., 2003). Each of these programs included parents in the sibling groups and, thus, took a family-centered approach. Each of these programs also found success over a range of sibling ages in terms of sibling adjustment and sibling knowledge of the disability. Programs such as these would be useful to mitigate the stresses felt by siblings, especially when the child with a disability is in adolescence. Additionally, it may be particularly helpful to assist siblings in their changing roles as both the teen and the sibling themselves grow and develop. Many studies have found that siblings of children with disabilities display higher levels of maturity (e.g., Lardieri et al., 2000). However, it is not known how siblings arrive at this place of maturity, and qualitative studies suggest it is likely that this outcome is related to their increased caregiving responsibilities and the difficulties they encounter as siblings of a child with a disability (Mulroy et al., 2008). Sibling support groups and family groups may be an effective way to assist families of children with disabilities in negotiating the role changes that accompany shifts within the sibling relationship.

In this sample, nearly 25% of the siblings spoke to their parents “hardly at all” or “not too much” regarding the teen’s needs. Additionally, only 20% of the siblings reported having discussed legal guardianship with their parents. This was compounded by the fact that none of the siblings who reported being concerned about what would happen to the teen if their parents died had discussed legal guardianship with their parents. This points to the importance for parents to include the sibling in the discussions around future planning, although many are reluctant to do so (Heller & Caldwell, 2006). This corroborates studies that have highlighted the discrepancy between what parents have discussed regarding the future, and what siblings are aware of and are comfortable with (Davys et al., 2010; Griffiths & Unger, 1994). This is further complicated by the fact that siblings are less effective in their caretaking roles if they have not been included in the future planning process (Heller & Kramer, 2009).

Clearly, planning for the future in an explicit way as a family has an impact on the sibling, the child with a disability, and the sibling relationship. The discussion around future plans for the family and the child with a disability are critical for healthy family functioning as the child with a disability grows. The discussion of a clear and concrete plan may lead to more effective caregiving for the child with a disability, a more positive sibling relationship, and increased emotional and mental health for the sibling. Family programs can provide a safe and structured environment in which siblings and their parents can discuss the options and issues surround the teen’s future. Currently, there are no widespread supports for siblings of children with disabilities. Although future work is needed to determine the most effective supports for these siblings, more resources are needed for these siblings to successfully negotiate their sibling relationships.

Conclusion

The findings presented in this study suggest that future planning is a critical factor in sibling relationship quality when the child with a disability is in adolescence. Additionally, the mixed methods nature of the current investigation reveals trends that suggest siblings may be negotiating their own development in concert with increasing role asymmetry and changing role responsibilities. These changes over time likely reflect a natural and adaptive response to the teen's disability, but increased levels of pessimism and worry may be a cause for concern.

Continued design of family-based interventions targeting the sibling relationship and sibling adjustment should address planning for the future explicitly for these families. The current programs are not nearly widespread enough or accessible enough to meet the needs of this population. It is clear that siblings of children with disabilities generally are not being included in the family discussion around future plans for the child with a disability. Further work is needed to create a safe and structured environment in which to hold these discussions.

In summary, the results of this dissertation underscore the importance of the relation between future planning issues and the sibling relationship. Additionally, it highlights that sibling development and changes in the sibling roles over adolescence may influence how the sibling relationship progresses over time. This dissertation provides the first step to understanding how the sibling relationship, sibling roles, and sibling responsibilities may be changing over adolescence while taking into account the planning for the teen’s future.

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