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High school siblings of children with disabilities: Five case studies

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HIGH SCHOOL SIBLINGS OF CHILDREN WITH DISABILITIES:
FIVE CASE STUDIES

CUTTILL

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**High School Siblings of Children with Disabilities:
Five Case Studies**

BY

Casey Cuttill

THESIS

SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS
FOR THE DEGREE OF

Specialist in School Psychology

IN THE GRADUATE SCHOOL, EASTERN ILLINOIS UNIVERSITY
CHARLESTON, ILLINOIS

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YEAR

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Abstract

What is life like for a teenager growing up with a sibling who has a disability? Using their own words, five high school students explored, through an interview format, how their experiences, family systems, and identity have been shaped in direct and indirect ways by having a brother or sister with a disability. Several common themes emerged and included how sibling-care responsibilities influenced their ability to participate in social activities outside of the home, reported perceptions of having more household responsibilities than their peers and/or siblings, recognition that the sibling with a disability influenced family members and family life, an apparent lack of embarrassment about their siblings' differences, and a lack of understanding of the exact cause of their sibling's disability. Overall, the high school students interviewed had mostly positive comments to make when describing their perceptions of life with a brother or sister who has a disability. Limitations of the present study, as well as suggestions for future research, are also described.

Acknowledgements

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High School Siblings of Children with Disabilities: Five Case Studies

The family is a powerful and pervasive influence in a child's life, including the families of children with disabilities. Since the mid-1980's, research on the families of children with disabilities has exploded. Most of this research, however, has focused on parents; fewer researchers have studied siblings of children with disabilities. The available research indicates that children can be deeply affected by having a brother or sister with special needs (e.g., Flaton, 2006), but the results of this research have varied. Some studies have found negative effects, such as a higher incidence of emotional and behavioral problems and low self-esteem (e.g., Rossiter & Sharpe, 2001). Other researchers have reported positive benefits, including fewer behavioral problems and more prosocial behaviors in siblings of children with disabilities (Lobato, Miller, & Barbour, 1991). The present study added to this research through interviews with a sample of high school students in order to gain insight into their subjective experiences and perceptions related to having a sibling with a disability and to identify common themes.

This paper begins with a review of relevant theories related to the importance of family members in how children develop. The positive and negative effects of having a brother or sister with a disability reported by previous researchers are presented, including relevant information related to age and sex. Finally, an overview of the main developmental tasks of adolescence is discussed in order to explain and introduce interview questions.

Theories

Bronfenbrenner's Ecological Systems Theory. With a few exceptions, each child grows up in some sort of family system. There are many factors both within and outside the family that can determine success for the developing child, including parents, other siblings, the extended family, the peer group, socioeconomic status, the educational system, and the community, to name a few (Rossiter & Sharpe, 2001). Bronfenbrenner's ecological systems theory is a model of child development that stresses the need to understand people in terms of their everyday environments, as well as in the broad range of situations encountered in their homes, schools, neighborhoods, and communities (Leal, 1999). Bronfenbrenner suggested that in order to understand development properly, we need to describe the total settings or systems in which development occurs.

Bronfenbrenner described development as an interaction between the individual and a series of systems or layers in the environment. In Bronfenbrenner's view, the child's world is organized as "a set of nested structures, each inside the next, like a set of Russian dolls" (Bronfenbrenner, 1979). These structures or layers differ in the amount of direct or indirect contact with the individual child. The layer closest to the child has the most direct influence on development, whereas the layers further away include influences that are more indirect.

The innermost layer or microsystem has the most direct influence on children and their development. This is made up of settings in which the child has direct, face-to-face interactions with others, such as the family home, classroom, and playground (Leal, 1999). Over time, the relative importance of these different interactions may change. For example, interactions with family members may be most important in infancy, whereas

peers and school may become increasingly important in middle childhood and adolescence.

The second layer in Bronfenbrenner's model is called the mesosystem and it encompasses the links among the direct experiences included in the first layer. Such interconnections might include the relationships between the school and the child's family, the family and the healthcare system, health services and school, and church and friends. For example, how well an individual does at school will depend, in part, on the support for school-related activities that the child receives from family members in the home.

The third layer or system is even further away from the child's direct experiences and includes settings in which the child has largely indirect contact. This system or structure is called the exosystem. This layer in Bronfenbrenner's model involves settings that have an indirect influence on the development of the child. These may include extended family members who do not reside in the child's home, a parent's place of employment, friends of family, community services, neighborhoods, legal services, the local school board, and the mass media (Berk, 1991). For example, a parent's work can have an indirect influence on the child. Even though a child may never visit her or his parent's place of employment, if a parent is stressed out at work and has a lot to do, then this may affect the relationship the parent has with the child at home.

The outermost layer or macrosystem surrounds the first three systems and represents societal, cultural, and historical contexts of the time. These are the broader systems in which the family exists, including patterns of beliefs and ideology that distinguish different cultures and subcultures. For instance, how children with disabilities

are viewed and the opportunities available to them may vary based on current values, ideologies, and laws of the society or culture in which the child lives.

Bronfenbrenner's Theory and Children with Disabilities. There are many instances where the different layers or systems in Bronfenbrenner's ecological systems theory can affect a child's development and family life, including the development and family life of children who have a brother or sister with a disability. Just like any other sibling, a child with a disability can have a direct influence on how other children in the family develop (i.e., innermost layer or microsystem in Bronfenbrenner's theory). Because a child with a disability may take up more time and energy than typically developing children, parents, as well as siblings, may feel overwhelmed. In previous research, parents have described how children with disabilities often need so much of their time and energy that they do not feel as if they have enough left for their other children (Phillips, 1999). If this is the case, a sibling of a child with a disability may not receive as much parental attention and may have more responsibility than other children their age, which may impact their relationships with their parents and their siblings.

As suggested by Bronfenbrenner's theory, the interconnection between the parent's work and the home life may also affect the development of the child. Parents who are employed and have a child with a disability often have even bigger problems related to having enough time and energy for everyone and everything. Employed parents of children with disabilities report high levels of stress, work interruptions, and considerable difficulty locating appropriate childcare (Freeman, Litchfield, & Warfield, 1995). As a result, the stress that is related to working and having a child with a disability can affect the relationships at home among all members of the family.

Rosenzweig, Brennan, and Ogilvie (2002) studied employed parents of children with disabilities. They found that the parents reported intensive involvement in both child care and paid employment, where they averaged 39.9 hours worked per week at their jobs alone. These parents also estimated that they were responsible for approximately 70 percent of child care in their homes. Many of these parents also made a transition from full-time to part-time work as a result of caring for a child with a disability. Those who were preoccupied with issues affecting their children frequently noted a lack of focus on their job. This inter-relationship between work and home could potentially cause negative consequences at home as well according to ecological systems theory.

Family Systems Theory. Another theory that stresses the importance of the family setting in how a child develops is family systems theory. Family systems theory emphasizes the interconnectedness of family members, positing that when events impact one member of a family, all family members are changed in some way (Minuchin, 1977). The family systems perspective states that individuals merge to form a family unit, the whole of which is greater than the sum of its parts. The family as a system develops over time and has shared history, values, traditions, goals, beliefs, and priorities (Leal, 1999). How the family functions as a whole at any point in time will determine how family members will deal with or view a child with a disability. For example, one family may approach a disability as a blessing or as a challenge, whereas another family may see the same disability as a catastrophe.

The family is also viewed as a network of reciprocal relationships in family systems theory. Even though the family is considered a whole, there are a series of reciprocal relationships happening within the family. For instance, siblings have a

relationship with one another that is separate and distinct from their relationships with each of their parents. Similar to Bronfenbrenner's ecological systems theory, family systems theory also recognizes that families do not exist independent of their environments, but are considered within a broader social and environmental context (Leal, 1999). Goals that are set by families may be influenced by the larger society based on what is viewed as appropriate at that time. Educational opportunities and educational trends related to children with disabilities are two examples. Finally, families are viewed as multigenerational according to family systems theory. The family systems perspective recognizes that the family unit can overlap with a number of other family units from the past, present, and future (Leal, 1999). For instance, some mothers and fathers may routinely consult with their own parents before making major decisions. Some grandparents are actively involved in the care and upbringing of their grandchildren with disabilities. The intergenerational transfer of caregiving responsibility from parents to children can also occur when adult siblings take over the caregiving role for their sibling with a disability (Krauss, Seltzer, Gordon, & Friedman, 1996).

Family Systems Theory and Children with Disabilities. The family systems perspective suggests that how each family deals with an issue depends on both the individuals who make up the family and the family as a unit. The discovery that a child has a disability, for example, is an event that affects each member of that child's family. According to the family systems theory, how a family responds to the news of a disability also depends on how the family functions as a whole system or unit. A family unit that tends to have a more positive approach may view the news of the disability as a challenge that needs to be addressed; a family with a more negative outlook may see it as a

catastrophe and be unable to respond in an adaptive manner. Research has indicated that families that have adapted successfully to their child with a disability typically demonstrate positive perceptions and report positive experiences as well. Taunt and Hastings (2002) mentioned in the three studies that they reviewed that some families report positive influences as a result of having a child with a disability. These families mentioned such things as pleasure/satisfaction in providing care for the child, the child as a source of joy, a strengthening of the family and or marriage, a new or increased sense of purpose in life, an opportunity to learn and develop new skills, abilities, or career opportunities, expanded social and community networks, a changed perspective on life, and increased spirituality. Other researchers have reported that spirituality plays an important role in understanding and accepting a child with a disability. Some family units use their faith as a way to make sense of having a child with a disability, and some researchers report that these families tend to fair better. They may view their child as a gift from God, or they view the disability as either a blessing or as a test of their faith (Poston & Turnbull, 2004).

The specific disability or characteristics of a child with a disability can also affect the family system. A study by Wang, Turnbull, Summers, Little, Poston, Mannan, and Turnbull (2004) revealed that for both fathers and mothers, the severity of a disability was negatively associated with their satisfaction ratings of family quality of life. The researchers found that children with greater needs really can take their toll on mothers and fathers, increasing their mothers' sense of burden and their fathers' depressive symptoms. Additionally, families whose children have severe and persistent behavioral problems have described how they feel socially isolated, have altered their desired

routines and lifestyle, and are often fearful about problem behavior (Fox, Vaughn, Dunlap, & Bucy, 1997). Even adults with disabilities can impact their family of origin. For instance, Seltzer, Begun, Seltzer, and Krauss (1991) reported that when siblings were actively involved in the care of their adult brother or sister with a developmental disability, this resulted in a positive influence on their aging mother's health and well being.

Summary of Previous Research on Siblings

When a child has a disability, both Bronfenbrenner's ecological systems theory and family systems theory suggest that it is important to see how this affects the family members both as individuals and as a unit. Much research has been devoted to the family, in general, and the mother, more specifically. Compared to mothers, however, less is known about siblings. Siblings can be an important source of support to the family and to the child with a disability. Stoneman (2001) reported that siblings of children with disabilities and comparison siblings without disabilities were similar in the amount of time that they spent interacting together.

Over the years, siblings of children with disabilities have not been studied as much as other members of the family, such as mothers and fathers. Just like parents, siblings can be affected by having a sister or a brother with a disability because of the possible impact on family life. Although siblings in households with a child with a disability may spend just as much time interacting with one another as siblings in households without a child with a disability, the research on the effects of having a sibling with a disability has provided conflicting results. Some researchers have reported positive effects, and others have suggested negative outcomes.

Positive Findings

Some researchers have suggested that a child with a disability in a family does not necessarily adversely affect the development of siblings, and may in fact have a positive influence. Some researchers reported that the relationship between children with disabilities and their siblings is usually positive. In a study of children with autism, siblings reported being proud of their ability to “teach” younger siblings (Stoneman, 2001). Lobato, Miller, and Barbour (1991) observed preschool sibling pairs containing a child with a disability and found that their interactions were more prosocial and nurturing than interactions between comparison siblings. There is other evidence that children with disabilities may have more harmonious relationships with their siblings than other sibling pairs. Carr (1995) compared quarrels in sibling dyads when one sibling, with or without Down syndrome, was 11 years old. She reported that 37 percent of the siblings with Down syndrome had no quarrels, compared to 18 percent of control siblings. The positive relationships between a sibling and her or his brother or sister with a disability often last well into adulthood (Orsmond & Seltzer, 2000). There may be long-term positive outcomes as a result of having a sibling with a disability, such as greater empathy and more appreciation for persons with disabilities (Rossiter & Sharpe, 2001). Many siblings of individuals with disabilities ultimately enter helping professions (Lobato, 1990).

Negative Findings

Other research has shown that siblings of children with disabilities have a difficult time and are affected negatively in some situations. Brothers and sisters of a child with a disability often have concerns about their sibling’s disability, including uncertainty regarding the cause of the disability and its effect on them, uneasiness about the reactions

of friends, and feelings of being left out or being required to do too much for the child with a disability (Dyson, Edgar, & Crnic, 1989). Brothers and sisters may have difficulty dealing with their peers' reactions to their sibling who has a disability. Other children may ostracize and isolate the siblings of children with disabilities. Research has identified some negative consequences to being the sibling of a child with mental retardation, such as increased risk for depression, loneliness, behavioral problems, and low self-esteem (Rossiter & Sharpe, 2001). Fisman and colleagues (1996) found evidence for a greater risk of externalizing and internalizing behaviors in siblings of children with disabilities compared to siblings of typically developing children. Sibling's care responsibilities may be greater when the brother or sister with a disability has fewer adaptive and self-help skills (Stoneman, 2001). This added responsibility can have a negative effect; Stoneman (2001) reported that siblings with greater responsibilities were more likely to develop behavior problems. Damiani (1999) found that sisters were rated higher than brothers on personality traits such as anger, irritability, moodiness, and depression when they interacted frequently with a sibling who had a disability.

Responsibility

Siblings can be affected by the extra care that a child with a disability presents to the family unit. Do children who have siblings with disabilities really have more responsibilities at home than children who do not have siblings with disabilities? The results of research addressing this question have been contradictory. Some researchers have concluded that siblings of children with disabilities have more responsibility, especially sisters (Damiani, 1999). Even though evidence suggests that some siblings have more responsibility, the results have not been supported by all researchers. Others

suggest that the responsibility of siblings does not change when a child with a disability is in the home (e.g., Stoneman, 2001). How much responsibility an individual child has may be related to that child's sex and age.

Sex. Early research suggested that whether the person was male or female played a significant role in the level of responsibility expected of a sibling of a child with a disability. Grossman's (1972) seminal study of siblings revealed that the "most involved" sibling in helping in the care of a brother or sister with a disability was an older sister. More recent research has also suggested that sisters who have a sibling with a disability are more likely than brothers to take on additional caregiving and household responsibilities (e.g., Orsmond & Seltzer, 2000; Stoneman, Brody, Davis, Crapps, & Malone, 1991). Gender role stereotypes, therefore, continue to contribute to whether males or females participate in certain roles. Still today, girls and women are often expected to take on a nurturing role more than boys or men. Damiani (1999) reported that girls continue to have more home and child care responsibility than boys, whether there is a child with a disability in the home or not. So there are some researchers who suggest that girls have more home and child care responsibility than boys, in general, but not necessarily as a result of having a sibling with a disability (Damiani, 1999). On the other hand, it has been reported that brothers of children with retardation tend to babysit more often than their counterparts who do not have a sibling with a disability and, in fact, babysit as often as sisters without siblings with disabilities (Damiani, 1999). Damiani (1999) also reported that boys who have a sibling with a disability have also been expected to do more gender-appropriate active tasks at home, such as yard work and other work outside the house. Orsmond and Seltzer (2000) reported that brothers of

adults with developmental disabilities reported more care responsibility if their sibling with the disability was a brother. Previous research findings provide some evidence, therefore, that siblings of children with disabilities take on more responsibility in some situations and that the type and amount of responsibility may be related to the sex of the nondisabled sibling.

Age. Research also suggests that age may play a role in the amount of responsibility given to a sibling. Age in general is important when talking about responsibility in families because more household responsibility is often expected of children who are older. This is because normal development is regarded as constituting the gradual increase in children's capacity to assume responsibility for themselves (Such & Walker, 2004). Several researchers have suggested that older siblings of children with disabilities, especially older sisters, may be given more caregiving and household responsibilities (Grossman, 1972; Orsmond & Seltzer, 2000; Stoneman, et al., 1988; Stoneman et al., 1991). Siblings who are younger than their brother or sister with a disability may also take on more responsibility when they come to equal or surpass the cognitive or social competencies of their sibling with a disability. Researchers have referred to this as a "role cross-over" in the sibling relationship that results in dominance by the younger, nondisabled sibling and is in contrast to normative childhood patterns of older sibling dominance (Brody, Stoneman, Davis, & Crapps, 1991; Orsmond & Seltzer, 2000; Stoneman et al., 1991). This role cross-over may result in parents assigning more responsibilities to their children without disabilities who are both younger and older than their siblings with a disability.

Developmental Tasks of Adolescence

Adolescence is a bridge between childhood and adulthood. Because of this, adolescence is considered to be a significant, transformative, and distinct phase in life (Schneider, Wedgewood, Llewellyn, & McConnell, 2006). The major developmental tasks of adolescence include cognitive development, identity formation, social development, vocational preparation, and planning for future independence. Adolescence is also a point in development that is marked by greater independence of children from their families. Because of these developmental changes, adolescents may become more conscious of their sister or brother with a disability as “different” (Wedgewood et al., 2006). A brief overview of the developmental tasks of adolescence is presented next.

Cognitive Development. According to Piaget, around age 11 young people enter the formal operational stage when they develop the capacity for abstract, scientific thinking (Berk, 2005). When children enter this stage, they no longer require concrete items and events as objects of thought. Another important aspect of formal operational thinking is propositional thought. This happens when adolescents can evaluate the logic of propositions (or “what if” statements) without the need to refer to real world examples or circumstances (Berk, 2005). Hypothetico-deductive reasoning also results from formal operational thinking. When faced with a problem, for example, the adolescent will start with a general theory of all possible factors that might affect the outcome and then deduce from that specific hypotheses about what might happen (Berk, 2005). Formal operational thinkers, therefore, are able to think first of many possibilities, and then move to reality.

There has been debate on whether all individuals reach formal operations during their teenage years as Piaget expected. People are most likely to think abstractly on tasks with which they have had extensive experience (Berk, 2005). For example, a college student majoring in psychology would be able to abstractly think about different theories and ideas in the psychology field but may have difficulty doing so in another less-well studied area. Another reason adolescents do not always engage in formal operational thinking is because they often fall back on less demanding intuitive judgments.

As adolescents enter the formal operational stage, they may become more argumentative, self-conscious, self-focused, and go beyond the real to the possible. By proposing, justifying, criticizing, and defending a variety of solutions, adolescents move to a higher level of understanding (Berk, 2005). Also in adolescence, children become more self-conscious and self-focused. This is partly due to gains in perspective taking, which cause the adolescents to be more concerned with what others think. Because many adolescents in the formal operational stage can go beyond the real to the possible, they can think of alternative family, religious, political, and moral systems (Berk, 2005). Since they are able to do so, they often want to explore these other possibilities.

While Piaget's theory of cognitive development suggests some major changes in thinking in adolescents, information processing theory also suggests a variety of cognitive changes. Information processing theory emphasizes how information is processed, stored, and recalled. In adolescence, attention becomes more focused on relevant information and better adapted to the demands of the tasks; strategies for storing, representing, and recalling information become more effective; knowledge increases, easing strategy use; and metacognition (awareness of thought) expands, leading to new

insights into effective strategies for acquiring information and solving problems (Berk, 2005).

Identity Formation. Erikson (1968) was the first to recognize identity formation as a major achievement of adolescence and as a crucial step toward becoming a productive, happy adult. Constructing an identity involves defining who you are, what you value, and the directions you choose to pursue in life (Berk, 2005). According to Erikson, young people experience an identity crisis, which is a temporary period of confusion and distress as they experiment with alternatives before settling on values and goals. Although some may have a difficult time finding their true identity, others gradually try out life possibilities, learning different things about themselves and their environment. Through the things that they learn about themselves, they are able to make future decisions. Once a stable identity is formed, the identity continues to be refined throughout life as people reevaluate earlier commitments and choices.

There are several things that may influence identity formation including personality, family, peers, and school and community. When a person is flexible and open-minded, they are more often better in identifying life long goals. Families that offer their children a secure base from which to explore often enhance identity development (Berk, 2005). Children who are encouraged to voice their own opinions often explore more possibilities. Peers also may influence identity formation. As adolescents interact with many different peers and people, their exposure to ideas and values expand (Berk, 2005).

Social Life. As adolescents become older and more independent from their families, peers become more and more of an influence in their lives. Close friendships

provide opportunities to explore the self and develop a deep understanding of another. This helps support the development of self-concept, identity, and perspective taking (Berk, 2005). Close friendships also provide a foundation for future intimate relationships. They can also help young people deal with the stresses of adolescence and can improve adolescent's attitudes toward and involvement in school.

Another aspect of social life for many adolescents is romance. In the U.S. and other Western societies, people tolerate and even encourage early romantic involvements, which begin in junior high and increase steadily over the teenage years (Carver, Joyner, & Udry, 2003). By late adolescence, young people are ready for greater psychological intimacy, and they look for someone who offers companionship, affection, and social support (Furman, 2002). As older teenagers form romantic ties, sensitivity, empathy, intimacy, self-esteem, and identity development are enhanced (Berk, 2005).

Planning for Future/Adulthood. According to Berk (2005), adolescents are in the realistic period in planning for the future and what they want to do with their lives. By late adolescence, the realities of adulthood come into focus, and adolescents start to narrow their options (Berk, 2005). Many do this by exploring the many possibilities out there in the world today, gathering all the information they can that will match their personalities. They then begin to focus on a specific occupation later down the road. Family also influences the decisions that adolescents make regarding the future. For example, an adolescent's vocational aspirations strongly correlate with the jobs of their parents (Berk, 2005).

As a result of abstract, analytical abilities of formal operational thinking, adolescents develop cognitive self-regulation in which they are able to plan what to do

first and what to do next, monitoring progress toward a goal, and redirecting actions that prove unsuccessful (Berk, 2005); these are skills important in planning for one's future. Because of a lack of experience, however, adolescents often do not engage in this rational process of decision making. They may not identify the pros and cons of each alternative, may not assess the likelihood of various possible outcomes, may not evaluate their choice to see if their goals were met or not, and often do not learn from the mistake to make better decisions in the future (Berk, 2005). Since adults have experienced more, they often make better decisions about their problems and future planning, though adolescents' decision-making confidence and performance improve as they get older and experience more in life.

Adolescence and Siblings with Disabilities. As described above, adolescence is a time in development when children make significant progress in their cognitive, social, and personal development. Bronfenbrenner's ecological systems theory and family system theory both suggest that these developmental changes can be directly and indirectly influenced by family members and the family unit. How are these developmental changes in adolescence shaped by having a sibling with a disability? How does growing up with sibling with a disability influence one's identity formation, plans for the future, social life, thinking and cognitive abilities? As summarized earlier, there is considerable research demonstrating that family members can be affected in different ways and in varying degrees, both positive and negative, by the presence of a family member who has a disability. Some of this research, however, contains contradictory findings. Many researchers have studied typically developing siblings' experiences with a brother or sister with a disability during childhood (e.g., Carr, 1995; Damiani, 1999;

Fisman et al., 1996; Grossman, 1972; Rossiter & Sharpe, 2001; Stoneman, 2001), but few, if any, have focused only on the perspectives of adolescents.

The Present Research

The primary goal of this study was to enter into the lifeworld of high school students who grew up with a sibling who has a disability in order to understand this experience and its impact on the development of these individuals. The phenomenological case study method (Ashworth, 2003) was the model used for collecting this information. The phenomenological case study is a qualitative research method that allows researchers to describe the perspectives of individuals without interpretation (Ashworth, 2003). For the present study, this means that high school students explained in their own words their experiences growing up with a sibling with a disability and how they felt this shaped their identity, experiences, thinking, and life choices. Emerging themes related to cognitive development, identity formation, social life, and planning for the future were identified and discussed. A phenomenological case study, therefore, collects descriptive, subjective data that can provide insight into variables that are suitable for future quantitative investigation (Taylor & Bogdan, 1998). Furthermore, results from this study may provide insightful information for parents, siblings, and professionals who work with families.

Research Goal. Bronfenbrenner's ecological systems theory and family system theory both suggest that having a sibling with a disability can influence how a child develops in both direct and indirect ways. The present study collected descriptive data from high school students regarding their perspectives of growing up with a sibling with a disability. Based on the phenomenological case study approach (Ashworth, 2003;

Flaton, 2006), no specific hypotheses are offered. Instead, the goal of the present research was to gain a detailed, subjective picture of how individual adolescents view their sense of self, life, and choices and how having a sibling with a disability influenced these.

Method

Participants

Five of approximately 15 high school students, Amy, Mary, Rachel, Dave, and Zach, participated in this study. All names were changed in order to ensure confidentiality. All five participants have a sibling with a disability and were recruited for the study because they had been identified by their school district as having a sibling with an Individual Education Plan (IEP) in school. All five students were Caucasian individuals. The five high school students all attended the same high school in a Midwestern state. This school district is made up of 3,067 students enrolled in five grade schools, one junior high school, and one high school. The district's operating expenditures per pupil was \$6,546. The district has a low income rate of 38%. The district is made up of predominantly white Americans, 96.2%, with African Americans at .9%, Hispanics at .7%, Asian/Pacific Islander at .8%, and Multiracial/Ethnic at 1.4%.

All five of the high school students have a sibling with a mental impairment. Amy was a 15-year old young girl who has a brother who is 14 years her senior and who has been diagnosed with cerebral palsy and mental impairment. Mary was 14 years old at the time of the interview. Mary has a 13-year old sister with Down syndrome. Another student, Rachel, was a 16-year old high school student who had an older brother with fragile-X syndrome and mental impairment. Zach's story is unique. When Zach was 15

years of age, he went to live with a foster family that included a 19-year old young man diagnosed with autism and mental impairment. Finally, Dave was a 17-year old boy who was 4 years of age when his sister was born with Down syndrome. An overview of the five students is included in Table 1.

Materials

A transcript of interview questions were developed for this study by the examiner (see Appendix A for a copy of this transcript). Demographic or background information was assessed first. Participants were asked their age, sex, and grade in school. Students were also questioned regarding their family structure, including with whom they currently live, marital status of parents, and sex and age of all siblings. The high school students provided information about their sibling with a disability. They were asked about the age, sex, specific diagnosis, age sibling was diagnosed, where this sibling resides currently, and if this sibling was receiving special education and any other interventions or therapies outside of the school setting.

The high school students responded to questions related to their perceptions of how growing up with a sibling with a disability influenced their lives and development. These questions started out general (e.g. "What is it like to have a sibling with a disability?") and then became more specific ("How has having a sister or brother with a disability affected your relationships with your parents?"). Questions also asked about the adolescent's social life, family relationships, household responsibilities, identity formation, thinking and problem solving, and plans for the future. Additionally, students were asked to describe what they considered to be the most positive and the most

negative aspects related to having a sibling with a disability. Appendix A contains the questions that guided the interview process.

Procedure

First, permission to carry out this study was obtained from the participating high school. Parental permission was obtained by asking the school district to send permission letters to the parents of students in high school who have a brother or sister with an IEP (see Appendix B for a copy of this letter). Once parental permission slips were returned, then an appointment was set up to interview each high school student individually. These interviews were approximately 30 minutes and took place at the high school at times that did not interfere with the student's academic goals and when the student had sufficient time to respond to the interview questions.

At the beginning of each interview session, the purpose of the study was described, confidentiality was guaranteed, and consent to participate was obtained from each student (See Appendix C for Child Assent Form). Each student was questioned following the interview protocol in Appendix A; however, follow-up questions were asked as needed to further explore and/or clarify responses (such as "Tell me more about that" or "Give me an example of that"). The interviews were tape-recorded in order to record fully all of the information the students provided. Each student had as much time as needed to answer the questions provided by the interviewer. Once the students completed the interview, they were thanked for their participation. They were also verbally debriefed and reminded about the goals of the present research.

Results

The approach for presenting interview results described by Flaton (2006) was used for the present study. As suggested by this approach, the initial step was to remove all of the interviewer's questions and review the remaining text to omit redundant material. Next was the creation of the case study profiles, which were composed entirely of the participant's words. Flaton (2006) suggested that this approach allows readers to feel, think about, and possibly empathize with the sibling experience first-hand. An overview of the high school students' responses to the interview questions are presented in Table 2. The students' answers to questions related to the most positive and most negative aspects of having a sibling with a disability are also summarized in Tables 3 and 4, respectively.

Amy's Experience

My name is Amy and I am 15 years old. I am currently a sophomore in high school. I live at home with my mom and older brother. My parents are currently in the process of getting a divorce, though it is not official yet. I have two older brothers; one is 18 and in college; the other is my 29 year old brother with a disability. He has cerebral palsy, and I think some kind of mental impairment.

When I was born, my family had obviously already been taking care of my brother "John". I believe he was diagnosed from birth. I am not exactly sure what caused his disability, but my mom told me when I was little that she was sick when she was pregnant, but she is not sure what caused it. He still lives with us now and probably will for a while.

When John was in school, he received special education services because of his disability. I am not exactly sure what that entailed, but he has a mental impairment so he

had special classes. He is not in school anymore, but goes to the workshop at the county mental health association at the YMCA. They work with him there and help him interact better with people. They also make things, like a factory, and John has a chance to earn money. It is kind of like a job for him. He goes from 8:15 in the morning to 3:15 in the afternoon so it is kind of like a school day for him. They provide transportation for him to get there and get back, but someone needs to be home to meet him when he gets home. We have to have a babysitter at the house to watch him until my mom gets home from work at 4:00.

Having a brother with a disability has been pretty normal. I do have to stay home with him sometimes, though, because he needs someone there to help with things like wiping off his mouth when eating. He usually just lies on the couch and watches television, so it is not too hard. Even though my other brother went to college, I still probably only have to stay home about once a week to take care of John. This is how having a brother with a disability has affected me the most. I think I could possibly do more things if I did not have to take care of him, but I don't think it would make that much of a difference anyway. He is older and not at school with me. When I really think about, I don't really have to take care of him that much.

My dad is not really in the picture when it involves John. Once my parents decided to get a divorce, he has really disappeared from his life and is not really involved anymore. Therefore, all the responsibilities for John and the house have really been put on my mom. She does most things around the house, as well as watches John, cooks him food, changes him, carries him, and does the things that he needs. I really don't have that much to do anymore. I used to have to clean dishes and do laundry, but not since my

parents got a divorce. I am really busy with my extra-curricular activities, so I don't have much time. With John, I really only have to do basic things like wiping off his mouth if he is eating, covering him up on the couch, and turning on the television for him. I actually think I have fewer responsibilities at home than Eric (college-aged brother) did because Eric could drive and had to run errands. I think that I may have to do those sorts of things once I get my license though. Compared to my friends, I think I may have less responsibility because they have to do a lot more things around the house than I do.

As far as my social life goes, I would not say that John has really affected that too much. My friends all know that my brother has a disability. I can't remember exactly how they found out; either I told them or they just saw him with my mom at one of my cheerleading things and asked about him. When I tell them that he is my brother, they may act a little shocked at first, but that is it. I am not embarrassed at all when it comes to John. I just let my friends know who he is and then we are done talking about him. I do have less time to do things though. I don't go out as much as my other friends. People ask me to, but sometimes I am not able to because I have to watch John. Sometimes I get angry at first, but I know that he is a part of my life and that is what I have to do. My friends don't get mad; they understand that this is what I have to do.

When I had a boyfriend, he and John got along well. John never affected our relationship. I am not sure how my boyfriend found out that I had a brother with a disability; I either just told him or he came over and I introduced them. They didn't really have much of a relationship because my boyfriend wasn't around the house much.

My parents have worked all my life. Their working never really affected me that much, other than the fact that sometimes I needed a ride somewhere and they were

working. My mom is in the field of social work, so having John may have actually helped her have a better understanding of the kids she worked with. At times, it may have affected her work negatively if he was sick. If that happened, she would have to miss work and stay home and take care of him. In our family, my mom has really tried to take care of John the most. She stays home with him most nights. Sometimes I may get mad at her if I have to stay home, but I get over it pretty quickly. When Eric was home and lived with us, John didn't affect our relationship too much. Sometimes we fought because both of us would want to go out, but someone needed to stay home with John. We would be mad at each other for a while, but would soon forget about it.

My schoolwork has not been affected by having John as a brother. After high school, I would like to become a doctor or a scientist. My brother John really influenced these plans because I have always wanted to cure types of retardation or cerebral palsy. John has really given me a sense of respect towards life since he doesn't have much of a chance to live. I appreciate and value things more. Just knowing that I have things like freedom and independence, but he can't really function well in life gives me that appreciation for life.

When we get older, I hope to still have a relationship with John. I hope to come and see him, but it might be kind of hard since I don't know where I will be living. I want to visit, but if I am not able to, I will send him some things. John will probably continue with the workshop because he enjoys it. Other than that though, he probably won't be able to be independent or hold a job. I think that it may be difficult for my mom to take care of him the rest of his life because she is getting older and it is harder for her to take care of him and pick him up. She is starting to have back problems. I think he will still

live with her for a while, but soon he will probably live in a home that will be better equipped to take care of him. At some point when I get older, I know I will probably have some responsibilities to help out with John's care. I am not sure what those will be, but I will help take care of him and possibly help out with the financial burden for him to be in a home.

The most negative aspect of having John as a brother has been taking care of him at times and making sure he is always ok. He is my brother though and I love him. He makes me have respect for life and what I have in it. I would say that is the most positive thing about having a brother with a disability.

Mary's Experience

My name is Mary and I am 14 years old. I just started high school this year and am a freshman. Right now, I live at home with my parents, one older brother, and one younger sister. I have two older brothers who are 21 and 19, but they don't live with us because they are in college. Brandon is my older brother that lives with us; he is 17. My younger sister is Becky; she is 13 and has Down syndrome. She was diagnosed before birth, which helped my family prepare for her arrival. I am not sure what caused her to have Down syndrome. I think it was in my parents' genes because no one in the family had it before. My mom was 35 when she had Becky.

At first the doctors told us that Becky would be lucky to be born alive; then once she was born, they told us that she would be lucky to live past the age of 5. Now they believe that she will live a good healthy life. My family lives on a farm, so when she was born, my dad sold some trucks so we could get medical supplies for her. We have a tub of

her medicine that is a foot by half-a-foot big. When I was young, I remember helping her out a lot. I helped teach her to move her mouth, talk, and say the words.

Becky is now in the 6th grade at the junior high. In school, she receives special education services for speech to help her talk. I can understand her speech, but sometimes she doesn't separate her words all the time, so it makes it difficult for others to understand her. Sometimes I even have to help my mom understand what she is saying. She also has some special classes that help her, but I am not sure of what they are. We used to have people come over to help her when she was younger, but not now. My family and I are really involved in Becky's life. We are friends and do a lot together. We just recently started a gymnastics class and are doing that together. She also played basketball for her 6th grade team. My older brother Brandon helped coach her team.

I think that having a sister with a disability has actually improved how I have lived because I have to care about her and I have more responsibilities. If I never had Becky as a sister, I would never have known what it was like to have a sister like her; having her has changed my perspective on life. If I had a "typically" developing sister, then I may have someone to be able to understand me more since we are so close in age, but I would never want to change anything about Becky. I don't really think that my life is really much different from my friends because Becky is just like having a younger sister. We have to take care of her just like other families do with their younger children; Becky just doesn't get any older mentally.

My family lives on a farm, so our whole family has a lot of responsibilities. Personally, I have a lot of responsibilities, but I am used to them. I have all the typical farm-like responsibilities, like taking care of the animals, as well as doing things around

the house. Responsibilities that are directly related to Becky include getting her clothes ready for school in the morning and helping her with her homework after school. Becky is pretty independent, but she still needs help with homework. Her daily living skills are good; she is able to take medications on her own, shower by herself, and feed herself. So other than helping her with her homework and getting her clothes ready, I really don't have to help her with much.

Between my brother Brandon and I, I think we have about the same amount of responsibilities. I am responsible for a lot of things inside the house, such as cleaning, as well as helping Becky with her homework, but he is responsible for all of the outside stuff. I think it pretty much evens itself out in the end. I have been through all of the work that Becky is doing right now, so it really hasn't been too hard for me to help her with her homework. I actually enjoy this responsibility. If I were to compare my own responsibilities to my friends, I would say that I have more just because we live on a farm. Even if we did not have Becky, I think I would have the same amount of responsibilities as I do now.

I do a lot of things during my free time such as cheerleading, track, softball, gymnastics, and guitar. I do as much if not more than other students my age. So the fact that we have Becky has not really affected what I do for fun. As far as my friendships and social life goes, I know that when I have friends over that don't know Becky, then they will have to get used to her. Most of my friends though know her and they are fine with her having a disability. They think she is cute and like hanging out with her. All of my current friends know that I have a sister with Down syndrome. I think that they just found out somehow because I have gone to school with them my whole life. Becky has not

affected the status of my friendships either because my friends are understanding. My friends are from all different groups; my older friends know my brother and my younger friends know me and my sister, so everyone knows about my sister and are fine with it.

I don't believe that my romantic life has been affected by Becky at all. I don't currently have a boyfriend, but I would not go out with someone that is not friends with her. When I did have a boyfriend, Becky did not really affect our relationship. He knew about her and liked her because he went to school with us and would also come over to our house. I would never be with anyone that did not like Becky.

The fact that we have Becky has influenced our family structure. Both of my parents work. My dad works at the house because is a farmer and my mom is a nurse about 30 minutes away from where we live. Sometimes I used to go there and help her, as well as volunteer my services to the hospital. Having a child with a disability that needed more attention did sometimes affect their work. They had to take time off so that they could be aware of where she was. Someone doesn't always have to be watching her, but someone has to be home at all times with Becky. Becky has influenced my relationship with my parents as well. Since they have a lot of responsibilities with Becky, they expect us to be more responsible and have more responsibilities. They expect more from us. I think that this has been good for me though. My parents also let her get away with more stuff too, but I think that is just because she is the baby of the family. My brother and I have a decent relationship that has not really been affected too much by Becky. We still fight like brothers and sisters do, but we have fought about who has to stay home with her at times.

As far as school goes, I am in all of the advanced classes at school. Even with all of my responsibilities on the farm and for Becky, I have plenty of time to finish my own homework. After high school, Becky has influenced my plans in what I want to do for the rest of my life. I used to want to be a scientist to find a cure for Down's when I was little, but now I want to be either a physical therapist or a nutritionist so I can help others. I know that a physical therapist helps people with different sorts of disabilities and nutritionists can help those with diabetes.

Having a sister with a Down syndrome has really influenced my thinking about life. I know that something can happen at any moment and you may not know what it is, but you still need to be prepared for anything. Becky has also helped me figure out who I am. I know that other people my age are still trying to do this, but Becky has helped me realize this because I spend more time with her and have more responsibilities such as caring for her.

Becky is pretty independent and is able to do a lot on her own, but I think that when she gets older, she will still live with my parents. If something happens to them, then my mom has always told me that I will be her primary caretaker since we are so close in age, as well as friends. My family has already decided that there is no way that we will put her in a home, so when my parents get older, she will probably come to live with me. I expect that when I am older, I will not have too many responsibilities for her if she is living with my parents because she will be older and won't have to go to school. If I am the primary caretaker for Becky, then I would be responsible for preparing her medicine and cooking. She is able to cook in the microwave, but not on the stove or in the oven. I am not exactly sure what she will do as an adult, but she has always said she

has wanted to be a Wal-Mart greeter. Our relationship will still be the same when we get older as well. No matter what, she will be my sister and a little kid. We will still see each other a lot and be together.

Becky is a great sister, though the most negative aspect of having a sister with a disability has been having to clean up after her because she changes her clothes so many times a day. The most positive aspect of having Becky as a sister is everything else.

Rachel's Experience

I am 16 years old and my name is Rachel. I am currently a sophomore in high school. I live with my parents, older brother, and my younger sister and brother who are twins. My twin siblings are 12 and my older brother, Mark, is 18. Mark is my brother with a disability. He has fragile X syndrome, which also resulted in mental impairment. I believe he was 7 when it was diagnosed, but I don't really remember that well. I am not exactly sure of the cause of fragile X, but I do know that he had problems when he was born. He was born with green fluid all over him and was not breathing. The doctors said that he had pooped inside my mom and it got into him. He had several surgeries and went through all kinds of trouble. Right now, he is dependent on us for everything.

At school, Mark receives special education services to help him function better in the school setting. He is in the same room everyday for all of his classes. All of his classes are special ed. He is able to do basic math and reading and they help him work on his life skills. I believe he also receives speech therapy as well, though I don't know if he receives any therapy outside of school. During the summer, Mark attends summer school where they work with money and do a lot of math.

Having a brother with a disability like fragile X syndrome has been kind of cool. I don't really think that anything is wrong with him. He is a person too. It is nice to see that kind of person in my family and see who he is. I wish that more people had a chance to have people like him in their families because if they had someone around like him, then maybe they would understand people with disabilities more. I enjoy him a lot; he is funny, entertaining, and fun to hang out with. It has been kind of different to have Mark in our family, though because we have to stay with him all the time and help him with a lot of things. I have to help him with his outfits for the day, get him dressed, get him ready to go to school, and give him his medications every day.

At home I am responsible for a number of things. I do a lot of cleaning around the house, do different things that my mom asks me to do, and sometimes cook supper, but I don't really have set chores that I need to do. I also have to help Mark with several things such as getting him ready for school, getting him ready for the shower, and just helping him with different things. He is able to get into the shower on his own, but he likes for us to get the water ready and those sorts of things. Compared to my younger twin siblings, I believe that I have more responsibilities because I am the second oldest and am really the only one that can take care of my older brother and do that kind of stuff. When I think about what my friends do in regards to responsibility, I believe that I may have less than them because they have more set chores that they are supposed to do, whereas I don't.

Socially, Mark has affected what I do in my free time or what I do for fun as well. Sometimes I have to take him out with my boyfriend or friends when my parents are not home. It doesn't affect my evening much though. It is actually cool to have him around. All my friends and boyfriend know that I have a brother with a disability. Either I told

them or my mom said something to them because sometime he acts up and is mean. If that happens, my mom just tells them that he has a disability. My boyfriend doesn't mind having him around at all. He thinks that Mark is neat and enjoys him as well. They even kind of have their own relationship. Sometimes Mark is mean to him and my boyfriend may be mean back by saying "Mark don't do that". Other than those little things, my boyfriend likes Mark and everything is fine. I wouldn't say that our relationship has been negatively affected at all.

Mark and I get along very well, which is kind of weird since some people have said that it should be more difficult for him to get along with girls in the house. With Mark though, that is not the case. He doesn't get along well with my dad. Sometimes Mark gets mad over silly stuff and yells a lot. This causes him and my dad to fight a lot. Both of my parents work during the day, so they are home during the night time when all of the children are there. I don't think that Mark has really affected my relationships with my parents or my other siblings. My siblings and I fight, but not because of Mark.

Having Mark as a brother has not really affected my thinking, planning, or problem solving abilities, however I do feel more responsible because I have to take care of him. If I ever have a kid like Mark, I will know how to raise him. After high school I would like to go to college for bowling and to be a computer technician. These plans were not really affected by having Mark as a brother, however, I do wish that he would come and watch me bowl, but he doesn't like to go to anything like that. He just likes to stay at home.

In the future when we are both adults, I hope to see him a lot and still get along well. He is a good friend. He is my buddy and I love having him around. Mark is

dependent on those around him, so I believe that he will still live with my parents when he is older, though he does have a girlfriend. She has the same disability, but is more independent than him. He talks about getting married and living together. My mom says that it is ok if they do, but we will see if it happens. Hopefully, at some point, Mark will be able to hold a job like bagging groceries. I think he would be good at doing that. I don't see him doing much else though; if that doesn't happen, then he will probably just stay at home and do nothing. I believe that I will continue to have responsibilities for Mark, but my load will increase if my parents were to die. I would probably have to take care of him and he would probably come to live with me. My responsibilities at that point would include feeding him, getting him bathed, helping him shave, cooking, and transportation. He does not have his license, but he is trying to get it. He wants to drive but is not able to pass the written test.

I would have to say the most negative thing about having a brother with a disability is that he yells a lot. He gets mad at people over silly stuff. Like I said before, he and my dad fight a lot because of this and he often takes things the wrong way. It is only ever verbal fights; he has never hit anyone before, though sometimes you think that he might. The most positive thing about Mark is that he is really funny. If you are upset or sad about something, he can cheer you up. He can tell a random joke and make you smile. He is really good at that kind of stuff.

Zach's Experience

My name is Zach and I am 16. I am in tenth grade at the high school. I currently live with my foster dad, my sister, and two foster brothers. My sister and my foster brother are both 14 years old, and my oldest foster brother Nick is 19. Nick has autism

and is mentally impaired. I moved in with my new foster family a year ago. I am not sure what age he was diagnosed or what caused his disability. Right now, though he does live at home with us.

He goes to the high school as well. He has special education classes that he attends. He also has his own aide that helps him gradually get better in some of the stuff he is not good at. I know they work on some daily living skills, but they also work on reading as well. He stays in one classroom with the same students all day. I don't think he receives any therapy or intervention out of the classroom though.

Moving into a new situation with Nick who has autism has been really good for me because you get to know those types of people better. It helps me learn what is wrong with him and people like him. I am able to teach him new things, as well as learn how to treat people like him. Before I came to live with this family, I didn't live with a person with a disability. Having Nick has made it easier for me to get to know and learn about disabilities. I have learned a lot about what they can and can not do. Sometimes it is hard, though, because I want to do something, but Nick is not able to, so I won't be able to do it either. That was hard to get used to. When I think about how my life is different from my friends, I think life is easier for them. It is hard to get used to having a brother with a disability. If I were to go into a situation with "typically" developing siblings, then I think it would have been easier to get used to. It was really hard to understand him talk, but now I am good at it. Now I think that I have gotten used to Nick and I liked working with people with disabilities anyway. I had previously worked at a camp with children with disabilities and enjoyed it.

At home, I have a lot of responsibilities around the house, but none that really have to do with Nick. I have to feed the dog, clean my room, vacuum the house, and sometimes I have to do the dishes. At times, when I want lunch on the weekends, I usually cook my own. My friends really don't have that much to do at home. They really depend on their parents for a lot of things, so I think that I definitely have more responsibilities than them.

Nick has had a good impact on my social life as well. It has actually been better since I went to live with Nick and my new family. Over time, I got to know his friends and he got to know mine. He has friends that I like and I have friends that he likes. All of my friends know about my new brother Nick. At first I talked to them about it and let them know about Nick and then I let them meet him. They were kind of weird at first, but then got used to it. They like him a lot and think that he is really cool. At times, he may say weird things in front of them, but they don't mind. Sometimes the fact that Nick is around affects what I do for fun or in my free time. There are some things that he can not do like shooting baskets in basketball. It is hard for him to play that, but he does like to do other things, like play baseball. I have to choose what I can do based on what he can do.

The relationships in my life haven't really been affected too much by Nick. I have never had a girlfriend since I have lived with my new family, so I don't really know how Nick would affect that relationship, however I don't think that he would make much of a difference. At home, my other siblings and I get along pretty well. We used to get in fights, but they were not about Nick. As far as my foster dad goes, Nick really did affect my relationship with him especially when I first moved in with them. When I moved

there, I wanted to get know Nick more than my dad. It is getting better now though, because now that I know Nick more, I am getting to know my dad better. My dad works doing painting jobs, so that has somewhat affected my life. He is often gone at work and if we don't have school, we have to go with him and help him sometimes. My dad's work has been somewhat affected by having a son with a disability. Sometimes Nick has to go with him too, which can result in him getting in the way of my dad and his painting. Nick often gets hurt when he comes.

Since I went to live with Nick and my new family, it hasn't really affected my school work or performance at school all that much. It has though, influenced my understanding of myself and what I value. I have gotten to know what I can do and what I can't do better. I realized I can take care of siblings and help them learn things that they need to know. After high school, I would like to go to college for building or carpentry. I would not say that Nick has really influenced this decision at all.

As Nick gets older and gets out of high school, he will probably live with my dad or someone else will take care of him. My dad's older daughter may take care of him as well. I don't think that he will be able to work; he will probably just stay at home. I think that I will have more responsibilities for him then, than I have now. I think my dad's daughter will probably have more, but I may have to watch him if someone is not home. If that is the case, then I would also have to help him with stuff around the house such as helping him with food and bringing it to him. Hopefully, though, my relationship with Nick will be better when we do get older. After spending more time with him, I will be able to understand him and get to know him more when we are adults.

It is hard to come up with anything that is negative about having Nick as a brother. He has been a real positive influence on my life. Having him has given me the chance to get to know him, as well as his friends that have some of the same disabilities, as well as different disabilities. I have learned more about them and how to help them.

Dave's Experience

My name is Dave and I am 17 years old. I am a junior in high school and live at home with my parents and younger sisters. My sisters are 13 and 14 years old. My sister Emily has Down syndrome. She is in 6th grade at the junior high. She was diagnosed with Down syndrome before she was born, but I was only 4 when she was born, so I don't remember any of it very well. I am not sure what caused Emily to have Down syndrome. It has something to do with an extra chromosome. It was probably from my dad's genetics because my dad's sister has a problem like Emily's but it is not exactly the same.

Emily attends the junior high where she receives special education services. She is in a different class called resource. This helps her with her work and different homework that she may have. Her other classes are with "normal" kids though. Emily doesn't receive any intervention or therapy outside of school.

Having a sister with a disability is different because someone always has to help her out. We can't leave her at home by herself. I have a lot of responsibilities at home, including those that I am responsible for around the house. I even helped coached her 6th grade basketball team every day after school, except for Friday. Even though I have all of these things to do, it has always been my life and I don't know any different. One thing that may have been different if I didn't have a sister with a disability is the fact that I may not have played any sports. The main reason right now that I play sports is so she can

watch me because she enjoys that. I don't think that my life is too different from my friend's lives. They all like her a lot. She is outgoing and easy to be around.

My responsibilities around the house include doing things on our farm, like feeding the animals, as well as doing things in the house, like cleaning the house, my room, and the dishes. Because Emily needs supervision and more attention, there are things I need to do for her as well. I coached her basketball team, watch her at home, cook, and drive her around a lot. I pick her up from school and try to get there early to miss the traffic. I think that my responsibilities for her are important so that I can help make her life better. Compared to my other sister, I think that I have more responsibilities around the house and with Emily because I have the whole upstairs to myself. I have to take care of all of the rooms up there. I also drive Emily around a lot. I think that if Melissa (other sister) had her license though, she would have more responsibilities than I do. I also think that I have more responsibilities than my friends do just because most of my friends are either only children or just don't have that much to do around the house.

Socially, Emily might have even improved my social life. I like having Emily as a sister because everyone is always wondering how she is doing. All of the basketball players like her and are always asking about her, even though I wasn't able to play basketball this year because I coached her basketball team. In my free time, I like to play video games with Emily sometimes. She got a Nintendo Wii for Christmas and loves to play it because she is able to move with the game, so we play that together. Because I have to watch her a lot, I probably do less than my friends do. All of my friends know that I have a sister with a disability, because when they come over, they see her. I think it was fine when they saw her for the first time. It wasn't weird or anything. There were a

couple of kids in my school that had Down syndrome, so when they saw her, they already knew about it and were ok with it. Emily hasn't affected any of my friendships because my friends all know the responsibilities that I have and just know that it is a part of my life.

As far as my romantic life goes, Emily has not really had any influence on that. I do not currently have a girlfriend, but I have had one in the past. Emily did not affect our relationship in any way, other than the fact that some nights I was not able to do things because I had to watch her. It was ok though, because I, as well as my girlfriend, knew that was my responsibility.

My family has really shown a team work attitude when it comes to working with Emily and providing the help and supervision she needs. Melissa and I have worked together when it comes to helping Emily. We each take turns staying home to watch her. So that hasn't really caused any problems; we really haven't had too many fights about that. It also depends on the activity as to who will be staying with Emily. If it is a school sport, then that person will go to that event, but if it is a hobby, then that isn't as important.

I have never really gotten mad at my parents for having to stay home. I think that they (parents) have made us more responsible because when they have to go to work, we have to help out. My parents have also paid more attention to Emily, but we know that she needs more, so we do not mind. Both of my parents work, so when they are at work, one of us has to stay home with Emily. My mom was actually not even going to go back to work after Emily was born and didn't for a couple of years, but eventually she had to go back to work for financial reasons.

Regarding school, I think Emily may have made my school work and performance better. I noticed what she couldn't do and what I could do, so that made me try harder. She has also helped me notice that she doesn't have what I have. This has also caused me to try harder with my schoolwork. After high school I would like go to college to become a dentist. I have always wanted to be a dentist or a veterinarian so I don't really think that Emily has influenced those plans.

When Emily becomes an adult, I think that she will probably live with my parents until they get too old to take care of her. She will then probably move in with a sibling; probably more Melissa because they relate more since they are both girls. She will probably never be able to live on her own; however, I think that she may be able to have a job. She has always said that she wanted to be a greeter at Wal-Mart. I don't know what our relationship will be like when we are both adults. I am sure we will still have one though. I know that I will have at least some responsibility for her, but probably not as much as I do now. If she lives with me, I would have a lot, but if not, I will help out with anything she needs, such as money or transportation, as well as help to buy her medications because she has to take a lot.

I don't really think about the negative aspects of having Emily as a sister, but I guess when I want to do something and can't because I have to watch her, it kind of pulls me back. The most positive thing about having a sister with a disability is the fact that she makes me try harder at school and in things I am doing. Before I was not in any advanced classes, but now I am. I am also more active in sports because of Emily as well.

Discussion

Overall, the high school students interviewed in the present study had mostly positive comments to make when describing their perceptions of life with a brother or sister with a disability. The students also suggested in their responses how their siblings influenced identity formation and their family systems in both direct and indirect ways. Several common themes emerged and included how sibling-care responsibilities influenced their ability to participate in social activities outside of the home, reported perceptions of having more household responsibilities than their peers and/or siblings, recognition that the sibling with a disability influenced individual family members and family life, an apparent lack of embarrassment about their siblings' differences, and a lack of understanding of the cause of their sibling's disability.

Influence on Social Activities

As adolescents become older and more independent from their families, peers typically become more and more of an influence in teenagers' lives. The high school students sampled in the present study indicated that it was sometimes more difficult for them to socialize with friends or boyfriends/girlfriends because of responsibilities associated with their sibling with a disability. For example, Rachel stated that she often had to take her brother with her when she went out with her friends or her boyfriend. Both Amy and Dave mentioned that they had to stay home to take care of their sibling at times when they could have gone out with friends or engaged in other social activities. Amy also described how she and her typically developing brother and her mother sometimes disagreed on whose responsibility it was to stay home with her brother who has cerebral palsy. However, the students also indicated in various ways that they felt

responsible for the care of their siblings. Amy noted that although there are times where she may get angry because she has to stay home, she described her brother as an important part of her life and she indicated that caring for him is what she "has to do."

Perceptions of Responsibilities in the Home

Over the years, several researchers have reported that siblings of children who have disabilities have more household responsibilities than other children (Damiani, 1999; Grossman, 1972; Orsmond & Seltzer, 2000; Stoneman, et al., 1991; Stoneman, 2001). This may be especially true for girls (Grossman, 1972; Orsmond & Seltzer, 2000; Stoneman, et al., 1991). Rachel, Mary, and Amy all reported that they had additional responsibilities as a result of having a brother or sister with a disability. Rachel, for instance, reported that because she was the oldest "typical" child in the home, she was expected to do more at home than her younger siblings, including taking care of her brother with fragile X syndrome. Rachel's perception was that she had less household responsibility than her friends, but had more responsibilities related to her brother's care. In addition to cooking and cleaning when asked to do so by her mother, Rachel also was responsible for getting her brother ready for school in the morning, getting him ready for his shower, and taking him places with her. Mary was also the older sibling to her sister with Down syndrome and she reported that she was responsible for common household chores, taking care of her sister when no one was at home, helping her sister with her homework, and with getting her sister ready for school in the morning.

Amy's experience with responsibility was somewhat different because she described her mother as responsible for the bulk of her brother's day to day care. Because Amy was involved in several extracurricular activities, she reported that she did

not have much time each day to take care of her older brother. Even though Amy was 14 years younger than her brother, role cross-over appeared to have occurred based on Amy's description of having to stay home at least once each week to "baby sit" her older brother. Role cross-over occurs when younger siblings take on more responsibility and dominance when they come to equal or surpass the cognitive or social competencies of their older sibling with a disability (Brody, et al. 1991; Orsmond & Seltzer, 2000; Stoneman et.al., 1991).

Brothers of children with disabilities may also be assigned more responsibilities than their counterparts who do not have a sibling with a disability (Damiani, 1999). Research has shown that brothers of children with disabilities tend to babysit more often than their counterparts who do not have a sibling with a disability, and may in fact babysit as often as sisters without siblings with disabilities. Damiani (1999) also reported that boys who have a sibling with a disability have also been expected to do more gender-appropriate active tasks at home, such as yard work and other work outside the house. Dave's experience supports the research findings of Damiani (1999). Dave stated that he had to watch his sister when no one else was home, coached her basketball team, drove her where she needed to go, and did things outside of the house, such as feed the animals and other farm-like activities.

Although Zach described his many responsibilities around the house, including feeding the dog, cleaning his room, vacuuming, doing the dishes, he was the only student to report that he had not been given any responsibilities for his sibling with a disability. This may be because Zach's home situation was unique—he moved in with a foster family who already had a child with autism.

Even though the adolescents reported an increased amount of household and child care responsibility, they seemed to agree that the added responsibility was a positive aspect of their lives and identities. Taunt and Hastings (2002) also found that many parents reported things such as pleasure/satisfaction in providing care for the child with a disability, a new or increased sense of purpose in life, an opportunity to learn and develop new skills, and a changed perspective on life. This appeared to be the case for the siblings interviewed. In the present study, for example, Mary noted that she enjoyed helping and taking care of her sister. Mary described how she taught her sister to speak and appeared proud of her success.

Other research findings have suggested, however, that greater responsibility may have a negative impact on the behaviors and mood of siblings of children with disabilities (e.g., Damiani, 1999; Stoneman, 2001). This did not appear to be the case for the high school students interviewed in the present study. For the most part, they indicated they had more responsibilities than their siblings and friends; however, they described their extra responsibilities as a part of their life and identities and did not appear angry, upset or negative in their descriptions. Dave said it best when asked why he had been given his responsibilities for his sister, "...to make her life better."

Influence on Family Members and the Family as a Unit

According to both ecological systems and family systems theories, a child with a disability can have direct and indirect influences on how other children in the family develop (Leal, 1999). Based on the responses to the interview questions in the present study, siblings with disabilities influenced the high school students' thoughts about life, what they did for fun, their school experiences, and their plans for the future, all of which

contributed to their developing identities. Rachel stated that because she takes care of her brother, she feels like a more responsible person and is prepared if she should ever have a child with a disability. Dave stated that having a sister with a disability motivated him to accomplish more. He indicated that his main reason for playing sports was so that his sister could watch him. Zach mentioned that because of his new-found relationship with his foster brother, he was more aware of his own strengths and limitations. Mary reported that her relationship with her sister has helped her plan her future career goals and contributed to her positive outlook on life. As a result of Amy's relationship with her brother, Amy felt she had a greater respect and appreciation for life, freedom, and independence.

In general, the adolescents did not report that their relationships with their other siblings were affected because they had a sibling with a disability. Amy was the only one to mention a negative influence when she described how she and her typically-developing brother sometimes argue over who is responsible for taking care of their brother with cerebral palsy. On the contrary, Dave stated that he and his sister actually work together as a team and take turns staying home with their sister with Down syndrome.

The high school students in the present study described several ways in which their relationship with their parents was affected because of their sibling with a disability. Mary stated that her parents expected more of her and her brother because of her sister with Down syndrome. Amy stated that she gets angry with her mother when asked to stay home to watch her brother, but she reported that she gets over her upset quickly and did not feel that this has affected her overall relationship with her mother. Zach reported that having a foster brother with a disability did initially affect his relationship with his

foster father because he wanted to get to know his new brother and this limited his interactions with his foster father. As time passed, however, Zach described his relationship with his new dad as becoming better. Phillips (1999) suggested that children with disabilities may take up most of parents' time and energy and Dave specifically addressed this in his interview. Dave noted that his parents gave his sister with Down syndrome more attention, but he went on to explain that it was appropriate because she needed their attention more.

The students also recognized in various ways how having a child with a disability has influenced their parents' lives. Rachel mentioned that her father and brother with fragile X syndrome tend to argue and have verbal conflicts. Mary described how her father had to sell his truck in order to purchase medical supplies for her sister with Down syndrome. Amy noted that her mother has back problems and this makes it difficult for her mother to pick up her adult brother with physical disabilities due to cerebral palsy. Amy and Mary reported that their parents have needed to take sick days away from work in order to be home with their sister or brother with a disability. Amy also noted that her mom works in the field of social work and that having a child with a disability has helped her mother have a better understanding of the children with whom she works. This contrasts with Zach's foster father. Zach reported that when his brother was off from school and his foster father had to work, his father would have to take his brother with autism to the job site and this sometimes interfered with his father's painting job. Dave reported that initially his parents' work schedules were affected greatly as a result of having a child with Down syndrome. His mom actually stayed home for a couple of years, but eventually went back to work for financial reasons.

Previous research by Fox, et al., (1997) found that families whose children have severe and persistent behavioral problems have described how they feel socially isolated, have altered their desired routines and lifestyle, and are often fearful about problem behavior. Rachel was the only participant to address an issue like this in her responses. She stated that her brother frequently yells and can become upset and angry over inconsequential things, sometimes in public places. Rachel described her experiences and her brother more positively than what Fox, et al., (1997) reported. She did not indicate that her family felt socially isolated and did not describe any curtailment of outings or other activities because of her brother's behavior. Rachel did mention that her mother explains her brother's disability when he acts out in public settings.

Lack of Embarrassment about Sibling Differences

Early researchers suggested that brothers and sisters of a child with a disability often have concerns about their sibling's disability, uneasiness about the reactions of friends, feelings of being left out, and difficulty dealing with their peers' reactions to their sibling who has a disability (Dyson et al., 1989). The interview results in the present study do not confirm this previous research. Although two students indicated that friends may initially respond in an unusual manner when meeting their siblings, none of the students indicated any embarrassment associated with their sibling who has a disability. In fact, they viewed their siblings positively and reported in a variety of ways that they included their sibling in their interactions with friends.

Lack of Understanding about the Cause of the Sibling's Disability

All of the students indicated that they were not sure of the exact cause of their sibling's disability, similar to previous results reported by Dyson et al., (1989). Amy said

that her mom told her that she was sick during her pregnancy, but that was all Amy knew. Mary thought that maybe the cause of her sister's disability was in her parents' genes; however, she also reported that there was no history of Down syndrome in her family. Dave was also not sure about what caused his sister's Down syndrome, however, he knew it had something to do with an extra chromosome. He thought it may have a genetic or inherited cause because his father's sister had a problem similar but not identical to his sister's. Rachel elaborated the most when asked what caused her brother's disability. Although Rachel's brother had been diagnosed with fragile X syndrome, an inherited genetic disorder that runs in families and could include Rachel as a carrier, she attributed the cause of her brother's disability to prenatal complications.

Unlike previous suggestions that teens with siblings who have disabilities may be worried about the possibility of having a child of their own with a disability (e.g., Dyson et al., 1989), the high school students in the present study expressed little concern over their lack of understanding about the cause of their sibling's disability and its possible future effect on their own children. Rachel was the only student to mention the possibility of having a child with a disability and did so in the context of mentioning that she felt prepared if this should occur because of her experiences taking care of her brother. It was not clear from the students' responses if most of them had not considered the possibility that they might have a child of their own who has a disability or if the prospect of having their own child with a disability was not perceived as a negative outcome and, therefore, not worthy of concern

Overall Positive Feelings

Researchers have reported positive benefits, including fewer behavior problems and more prosocial behaviors, in siblings of children with disabilities (Lobato, et al., 1991), as well as greater empathy and appreciation for persons with disabilities (Rossiter & Sharp, 2001). Research has also indicated that families that have adapted successfully to their child with a disability typically demonstrate positive perceptions and report positive experiences as well (Taunt and Hastings, 2002). This seems to be true for students in the present study as they all indicated many perceived positive benefits. As mentioned earlier, Dave reported that having a sister with Down syndrome influenced his academic and extracurricular motivation in a positive way. Rachel described her life as full of enjoyment as a result of her older brother with fragile X syndrome. She attributed her brother with making her a more responsible person and with giving her care taking skills. Amy reported that she appreciates life and plans to become a physician or scientist as a result of her experiences with her brother with cerebral palsy. Zach reported that being a part of his new foster family has made his life better. He indicated that he has gained insight into his ability to care for and teach others. Mary reported that she felt better prepared to deal with whatever comes her way and that she has a better understanding of herself as a result of having a sister with Down syndrome. She also indicated that this has influenced her plan to go into a helping profession.

Previous researchers have indicated that a positive relationship between a sibling and her or his brother or sister with a disability often last well into adulthood (Orsmond & Seltzer, 2000). The participants in the present study all noted that they hoped to still

have a good relationship with their siblings when adults and indicated some plans for future responsibilities associated with their siblings.

Rossiter and Sharpe (2001) suggested that long-term positive outcomes as a result of having a sibling with a disability can include greater empathy and more appreciation for persons with disabilities. The high school students interviewed displayed these empathetic qualities, as well as their appreciation for persons with disabilities throughout the entire interview process. They appeared proud of their siblings, as well as happy to have them in their lives.

Limitations of the Present Study

There are several limitations to keep in mind related to the present study. First, the phenomenological case study method (Ashworth, 2003) was the model used for collecting the information reported in the present study. A phenomenological case study collects descriptive, subjective data and can provide insight into variables that are suitable for future quantitative investigation. The phenomenological case study is a qualitative research method that allows researchers to describe the perspectives of individuals without interpretation (Ashworth, 2003). The goal of qualitative research is exploration in order to understand, not solution or truth (Flaton, 2006). Because some researchers (e.g., Flaton, 2006) contend that the scientific method and its tendency to categorize has led to labeling and stigmatization of people with disabilities, the present study did not collect quantitative or statistical evidence about the lives of siblings with disabilities. It is descriptive only.

Because the goal of the present research was to gain insight into the subjective life experiences of high school students who have siblings with disabilities through an

extensive interview, this limited the number of participants. The small sample size limits any generalizations that can be made.

Another limitation of the present study is the fact that the students who volunteered to participate may not be representative of all high school students who have siblings with disabilities. The students were sampled from one high school in a Midwestern state and therefore are not representative of all high school students and their families.

A possible self-selection influence on who volunteered to participate is another possible limitation. For instance, it is possible that adolescents who have accepted their role as a sibling with a brother or sister with a disability would be more likely to volunteer to be interviewed about their experiences than those teens who have not yet accepted the fact that they have a sibling who has a disability. High school students who have had more positive experiences as a result of having a sibling with a disability may also be more likely to be willing to talk about their lives. For many reasons, therefore, the individuals interviewed in the present study may not be representative of the life stories of all high school students who have siblings with disabilities.

Another limitation is that students with typically developing siblings only were not interviewed for comparison purposes. For instance, it is possible that most high school students, whether or not they have a sibling with a disability, feel that they have more household responsibilities than their peers or their siblings. Future research could include interviews with a more representative sample of all high school students.

Future Directions

Responses from the high school students in the present study suggest several areas for future researchers to explore. For example, previous quantitative research studies have also reported that siblings of children who have disabilities tend to have more household responsibilities than other children (e.g., Damiani, 1999; Stoneman, 2001), but numerical data or follow-up questions related to whether or not the respondents themselves viewed this added responsibility in a positive or negative manner was not collected or explored. Based on the positive responses of the high school students interviewed in this present qualitative research study, this type of follow-up may be necessary in order to gain a better understanding of the life experiences of children with a sibling who has a disability.

Interestingly, no student mentioned grandparents or other extended family members in their responses. It is not known if this was because of the specific questions asked of the students in the present study or because their family systems lacked influence from extended family members. Future research could explore this in further detail.

It is rare to find longitudinal research related to families with children who have disabilities. This is especially true for research on siblings. An interesting follow-up would be to continue to interview siblings periodically into adulthood to better understand how their changing development and life circumstances might influence their perspectives of having a sibling who has a disability.

Additionally, more samples representative of the population at large are needed in order to understand more thoroughly how a sibling with a disability affects the life and development of all children.

Conclusions

In telling their life stories, the high school students in the present study described how their sibling with a disability has shaped in both direct and indirect ways their experiences, identities, and family systems. Overall, they displayed mostly positive attitudes when discussing their perceptions of life with a brother and sister who had a disability. They appeared proud of their siblings and happy to have them in their lives.

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Appendix A

Interview Questions

Background Information

What is your age?

What is your current grade in school?

With whom do you currently live?

What is the marital status of your parents?

How many brothers and sisters do you have?

How old are they?

Background Information on Sibling with Disability

What is the sex of your sibling with a disability?

How old is she/he?

How many years have you lived with her/him?

What is her/his diagnosis/disability?

At what age was she/he diagnosed?

What's the cause of your sister/brother's disability?

Where does she/he live right now?

Does she/he receive special education services in the school? If so, what are these?

Does she/he receive interventions or therapies out of school? If so, what are these?

Does she/he attend a special school?

Interview Questions

1. Tell me, what is it like to have a sister/brother with a disability?

2. How do you think having a sister/brother with a disability has affected or changed your life?
3. How do you think your life is different from your friends' who do not have a brother or sister with a disability?
4. How do you think your life would be different if your brother/sister did not have a disability?
5. What responsibilities or chores are you responsible for at home?
 - a. Do you think you have more or less home responsibilities than your other siblings? Why?
 - b. Do you think you have more or less home responsibilities than your friends? Why?
6. What responsibilities do you have at home that are directly related to your sister/brother with a disability?
 - a. Why do you think you have been given these responsibilities?
7. How has having a sister/brother with a disability affected what you do for fun or in your free time?
8. Tell me how your social life has been affected by having a sibling with a disability?
9. Do your friends know you have a sister/brother with a disability?
 - a. If no, why not?
 - b. If yes, how did your friends find out your brother/sister has a disability?
10. How has having a sister/brother with a disability affected your friendships?
11. How has your romantic life been affected by having a sibling with a disability?
12. Do you currently have a boyfriend or girlfriend?
 - a. If yes, how did your boyfriend/girlfriend find out your sibling has a disability?
 - b. How has having a sister/brother with a disability affected with relationship?

13. How has having a sister/brother with a disability affected your relationships with your other siblings?
14. How has having a sister/brother with a disability affected your relationships with your parents?
15. Do your parents work?
 - a. If yes, how did your parent's working affect your life?
 - b. How did having a child with a disability affect their work?
16. How has having a sibling with a disability affected your school work or your performance at school?
17. How has having a sibling with a disability influenced your thinking, planning, or problem solving abilities?
18. How has having a sister/brother with a disability influenced your understanding of yourself – who you are, what you value, what you want out of life, etc.?
19. What do you plan on doing after you finish high school?
 - a. How did having a sibling with a disability influence these plans?
20. Where do you think your sister/brother with a disability will live as an adult?
21. What do you think your sister/brother with a disability will do as an adult?
22. What will your relationship with your sister/brother with a disability be like when you are both adults?
23. Do you think you will have any responsibility for your brother/sister with a disability when you are an adult?
 - a. If yes, what will these responsibilities be?
 - b. If no, why not?
24. From your perspective, what is the most negative aspect of having a brother/sister with a disability?
25. From your perspective, what is the most positive aspect of having a brother/sister with a disability?
26. Do you have any questions for me?

Appendix B

“High School Siblings of Children with Disabilities: Case Studies”

Your child in high school has been invited to participate in a research study conducted by Casey Cuttill from the School Psychology department at Eastern Illinois University. Casey is completing her internship in Mid-State Special Education and could use your help in collecting data for her thesis. Please ask questions about anything you do not understand before deciding whether or not your child can participate.

I understand the following points regarding this study:

1. Your child in high school has been identified as a possible research participant because she/he has been identified as having a sibling with an Individual Education Plan (IEP) at school. The purpose of this particular study is to interview high school students who grew up with a sibling who has a disability in order to understand this experience.
2. If your child volunteers to participate in this study, she or he will be asked a number of questions about having a sibling with a disability, including how having a sibling with a disability has affected family and social life, identity formation, thinking and problem solving, responsibilities, and plans for the future. Completion of the interview should take around 30 minutes and will take place during a time that does not interfere with instruction at your child's school. The protocol of the interview will be available upon request.
3. These interviews will be tape-recorded to ensure that each student's response is recorded in its entirety.
4. There are no anticipated short-term or long-term risks involved for your child within this particular study. If any unforeseen and unlikely adverse reaction should occur, then the participant will be referred to an appropriate professional for consultation (the school psychologist, school counselor, or school social worker).
5. Your child will benefit from this research by allowing the researcher to obtain valuable information regarding the lives of children who have siblings with disabilities. Furthermore, results from this study may provide insightful information for parents, siblings, and professionals who work with families.
6. All data that is collected over the course of the study will remain confidential. The researcher will be the only individual to have access to the research information and will not use any names or identifying information when describing the results.
7. Your child's participation in this research is voluntary and is not a requirement. If your child volunteers for the study, he or she may withdraw at any time without consequences of any kind.

8. If you have any questions or concerns about this research study, please contact:

Casey Cuttill, Principal Investigator or Dr. Linda Leal, Faculty Sponsor
(217) 454-6583 (217) 581-2158

9. If you have any questions or concerns about the treatment of human participants in this study, you may call or write:

Institutional Review Board
Eastern Illinois University
600 Lincoln Ave.
Charleston, IL 61920
Telephone: (217) 581-8576
E-mail: eiuirb@www.eiu.edu

You will be given the opportunity to discuss any questions about your child's rights as a research subject with a member of the IRB. The IRB is an independent committee composed of members of the University community, as well as lay members of the community not connected with EIU. The IRB has reviewed and approved this study.

Thank you for your time.

Casey Cuttill
School Psychologist Intern
Mid-State Special Education

I voluntarily agree to allow my child to participate in this study. I understand that my child is free to withdraw consent and discontinue participation in the study at any time. I have been given a copy of this form.

Name of Guardian

Name of Child

Signature of Guardian

Date

If you agree to allow your child to participate in this study and would like a summary of the results, please put your name and address on the lines below. The summary of results will be available and sent out at the end of the school year.

Name: _____

Address: _____

***Please have your child turn the bottom section of this form back to their teacher!**

Appendix C

Child Assent Form

I agree to be interviewed by Casey Cuttill concerning my thoughts and experiences related to having a brother or sister with a disability and to having my responses tape recorded. I understand that my name will not be used and that any identifying information will remain confidential. I also understand that I can stop participating at any time without penalty.

Student's Printed Name

Student's Signature

Date

Table 1

Overview of Participants

	<u>Amy</u>	<u>Mary</u>	<u>Rachel</u>	<u>Zach</u>	<u>Dave</u>
Age	15	14	16	15	17
Birth Order (compared to sibling with disability)	Younger	Older	Younger	Younger	Older
Sex of Sibling with Disability	Male	Female	Male	Male	Female
Diagnosis of Sibling	Cerebral Palsy	Down syndrome	Fragile X	Autism	Down syndrome
Both Parents in Home?	No (mom only)	Yes	Yes	No (foster dad only)	Yes
Reports of What Caused Disability	"Not sure"	"Not sure"	"Not sure"	"Not sure"	"Not sure"
Reports of Current Treatments	Special ed.	Special ed. Speech therapy	Special ed. Speech therapy Summer school	Special ed. Classroom aide	Special ed.

Table 2
Overview of High School Students' Responses to Interview Questions

	<u>Amy</u>	<u>Mary</u>	<u>Rachel</u>	<u>Zach</u>	<u>Dave</u>
Has Sibling Affected Your:					
Social Life?	Yes	No	Yes	Yes	Yes
Romantic Life?	Not much	No	Yes	Don't think it will.	Yes & No
Family Life?	Yes	Yes	Yes	No	Yes
Future Career Plans?	Yes	Yes	No	No	No
Your Future Responsibility for Sibling	Help with care & finances.	Live with me.	Probably live with me.	Help watch him.	Whatever she needs.
Perceived Level of Household Responsibilities	Less than friends'.	More than friends' (live on farm).	More than younger siblings' but less than friends'.	More than siblings' friends'.	More than siblings' & friends'.

Table 3

Overview of the Positive Comments of Having a Sibling with a Disability

Positive Comments

Amy

"I have a respect towards life, since my brother is not able to do the things that I can"
 "I value and appreciate things more"
 "He is my brother and I love him"

Mary

"Having a sister with a disability has improved my life because I have to care for her"
 "I know now that something can happen at any moment and you have to be prepared for that"
 "I have been able to figure out who I am because of my sister"
 "Everything is great about having a sister with a disability"

Rachel

"He is cool, funny, entertaining, and fun to have around"
 "He can cheer you up if you are upset by telling a random joke"
 "He can make you smile"
 "He is a good friend and my buddy"

Zach

"He helps me learn about different disabilities and what those persons can and can't do"
 "My social life is better because he has friends that I like and my friends like him"
 "He has helped me realize what things I am good at, as well as what things I struggle with"
 "I have realized that I can help take care of my siblings, as well as how to help people with disabilities"

Dave

"She has helped me realize what I am able to do and what she can't do; that has made me try harder"
 "I am in advance classes and am more active in activities and sports because of my sister"
 "I am a more responsible person because of my sister because I help her with a lot of different things"

Table 4

Overview of the Negative Comments of Having a Sibling with a Disability

Negative Comments

Amy

"I have to care for him and make sure he is always ok, which takes up some of my time"
 "At time I will get mad at my mom if I have to stay home with my brother, but not for long"
 "My friends get to do more things and have more freedoms"

Mary

"At times, my brother and I have gotten in a few little fights about who was going to stay home with my sister"
 "My parents expect me to be more responsible"
 "I always have to clean up after her because she changes her clothes many times a day"

Rachel

"He yells all the time and gets mad over silly things"
 "At times, my dad and brother don't get along because my brother will get mad over nothing"

Zach

"Sometimes I want to do things that he can't do so I am not able to do them"
 "Life is easier for my friends because it is hard to get used to a brother with a disability"
 "At first, having a new brother with a disability affected my relationship with my dad because I was trying to learn more about my brother"

Dave

"Sometimes I may want to do something and I can't because I have to watch her"