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Factors Affecting Daily Stress In Siblings Of Children With Special Needs

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FACTORS AFFECTING DAILY STRESS IN SIBLINGS OF CHILDREN WITH SPECIAL NEEDS

being

A Field Study Presented to the Graduate Faculty
of the Fort Hays State University in
Partial Fulfillment of Requirements for
the Degree of Education Specialist

by

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ABSTRACT

For families who have a children with disabilities, a great amount of stress are put on not only the primary caregivers but all members of the family unit. This study examined what factors influence stress experienced by siblings of children with disabilities. These factors included severity of the children's disabilities, gender of the siblings, how much help the siblings provide in the care of the children with disabilities, and the number of people in the families. The purpose was to raise awareness of the participants and pinpoint certain characteristics that affect how frequent and how intense stress is experienced by siblings of children with disabilities. The study also examined situations and characteristics that increased frequency and how much happiness the siblings of children with disabilities experienced because of uplifting experiences. The results indicated that as the participants took on more responsibilities in the care of their siblings with disabilities the less frequent they reported these hassles occurring. The siblings that provided more help in the care of the children with disabilities may no longer perceive these situations as hassles, therefore reporting they occur less often.

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Todd Blackwill

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Introduction

The sibling bond is unlike any other type of relationship developed in a lifetime. The development of this relationship evolves over an extended period of time allowing for a complex emotional attachment and a series of shared experiences (Larson & Richards, 1994). “Sibling relationships outlast marriages; survive the death of parents, and resurface after quarrels that would sink any friendship” (Goode, 1994, p. 7). Unlike friends, sibling relationships are involuntary in nature making them harder to dissolve (Vangelisti, 1993).

Siblings spend more time with each other than with either of their parents (Larson & Richards, 1994). Shared time and experiences strengthen sibling bonds and encourage a unique closeness. In childhood, siblings provide companionship and camaraderie. They act as confidants and mentors. As a result, siblings influence each other’s development, especially in the areas of mental growth, adjustment, and maturity (Stoneman, Brody, Davis, & Crapps, 1987).

As with any kind of relationship, siblings encounter times of hardship and stress. Based on the Theory of Family Systems, any change or hardship that affects one member of the family will affect the group as a whole (Buckley, 1967). Families are in a constant struggle to obtain a period of homeostasis or tranquility (Lazarus & Folkman, 1984). When challenges arise, the theory suggests that families make adjustments in lifestyle and routine in order to return to a period of considered “normalcy.” This theory suggests that children would be affected by stress and hardships faced by other siblings, as well as by their parents. Disability of one child may be one such stressor that causes hardships.

One 9-year-old girl reported being the only person with whom her intellectually impaired sister, Martha, will go the bathroom and the only one able to stop Martha's tantrums (Zatlow, 1992). The girl's parents and teachers relied on her to calm Martha during outbursts, causing her to miss instructional time and time with peers.

In childhood, the presence of regular daily stress has been linked to poorer physical and psychological health (Lazarus & Folkman, 1984). Middlebrooks and Audage (2008) report three types of stress experienced in childhood: positive, tolerable, and toxic stress. Positive stress is experienced when children attempt something unfamiliar that teaches them coping skills. Starting a new school or meeting new people are both examples of positive stress that teaches children skills they will use in the future. Tolerable stress refers to stressful events that are more intense, but the experience is short-lived. A sudden accident, a divorce, and a natural disaster would be examples of momentary stressors that are considered tolerable when occurring with the support of caring adults (National Scientific Council on the Developing Child, 2007). Toxic stress refers to negative experiences that last for extended periods of time (Middlebrooks & Audage, 2008). Experiences causing toxic stress can continue for several months or even years. Children in these types of situations activate their stress response system more often and for longer periods of time than those who experience only positive or tolerable amounts of stress (National Scientific Council on the Developing Child, 2007). A man reflecting on his childhood with a disabled sibling reports,

> "It was grueling; I had no relief, no support, no options. My life revolved around Kevin and his care. If I wanted to go away for a few days, I couldn't. The guilt

> was overwhelming. What do you tell your friends? No I can't go out; I have to feed my brother?" (Remsberg, 1989, pg 10)

The intense strain reported by this man would be classified as toxic stress and can cause stress response system to be activated more than children experiencing either tolerable or positive types of stress.

Each time children feel threatened or overwhelmed, stress hormones are released into the brain (Folkman, 1984). Prolonged exposure to stress hormones occurs in children experiencing toxic stress and can cause impairments in function and development (National Scientific Council on the Developing Child, 2007). Toxic stress damages connections between brain neurons resulting in smaller brains, as well as, disrupting brain circuits during development. This causes children to have a lower tolerance for daily stress throughout their lives. Studies have shown that high levels of the stress hormone Cortisol can damage the hippocampus, an area of the brain responsible for learning and memory (National Scientific Council on the Developing Child, 2004). This damage can cause deficits in children's long-term academic ability (Folkman, 1984).

Families with children who have a disability experience greater stress than similar families without children who have a disability (Hastings, 1984). Stressors in these families put a strain on all the relationships in the household, including a large strain on a marriage (Connors & Stalker, 2002). Parents report the main stressor to be the disability itself. In fact, 46.2% of these parents state the disability as being their main source of stress. Furthermore, 81.7% of parents who have children with severe disabilities report the disability as their main cause of stress. Siblings and parents in these families report lower tolerance to additional life stress and fewer coping skills than that of the general population. Supporting the theory that children who are exposed to large amounts of stress are more reactive and less able to cope with daily challenges.

In some cases where siblings with disabilities need constant care and support, the home environment falls under the Middlebrooks and Audage (2008) definition of toxic stress. During personal accounts of these in-home experiences, siblings of developmentally delayed children indicated that they have more in home responsibility than their peers (Hayden, 1974). Lifetime disabilities are known to provide additional daily stress on the family (Hastings, 1984). Overwhelmed parents with limited resources may be forced to pass responsibilities on to the typically developing children. Studies have shown that parents of children with disabilities perceive their children without a disability as more mature and independent than they would be if they did not have a family member with a disability (Glendinning, 1983). Further, Tozer (1996) found that these parents believe that the siblings of children with disabilities are more selfless and responsible than their peers. These perceptions of parents could lead them to disclose information and entrust responsibilities beyond what typical children would experience. Immediately following the diagnosis of a disability, responsibilities were rededicated and the role typically developing children play in the family begins to change. Research has found that family routines and role distributions for siblings change in a predictable manner to adjust to the birth of children who have disabilities (Blackard & Barsh, 1982).

Featherstone (1980) found that the most important factor in children’s ability to adjust to a disabled sibling is how well the parents adjust. The parents are under extreme pressure to not only care for the children with disabilities, but also do it in a way that sets a good example for the other children. The stress experienced by these parents has been shown to be at such a high level that it can have a long-term negative impact on both their physical and mental health (Mailick, 2009). Indeed, the hormone levels of 82 parents of children with disabilities were much higher levels for stress hormone Cortisol indicating the presence of chronic long-term stress. These levels were comparable to those of combat soldiers returning from war. With such a high amount of chronic stress experienced by the parents, it is not unlikely that the consequences could be felt by the family as a whole (Bukley, 1967).

Juggling the roles of caregiver and financial provider adds further stress to these parents. Three out of five Canadian parents of children who have a disability under the age of 14 years old report always or sometimes experiencing stress when trying to balance their family and work responsibilities (Canadian Census Bureau, 2006). Thirty-eight percent of parents say they work fewer hours as a result of their children's disabilities and are interrupted at work on an average of once every four days. Caregivers of children with disabilities make less than the national average in regards to yearly income. They also have fewer career opportunities and hold jobs with less possibility of career advancement. This is thought to be the result of the parents of children with disabilities having less available time and resources for education.

Parents report enormous changes in their lives and caregiving responsibilities following the birth of children with disabilities (Waisbren, 1980). As a result of these drastic life transformations, they also describe feeling prolonged periods of loss, hopelessness, and sorrow (Farber, 1960). Fowle (1968) found that parents of children with disabilities experienced decreases in self-esteem and faced feelings of shame and guilt. These studies focused purely on the negative effects on parents' emotions caused by the presence of children with disabilities. No study to date has examined the positive emotional impact on parents as a result of having children with disabilities.

The parents' emotions toward their children's disability also influence how other family members cope with life changes. Tew and Laurence (1973) found a positive correlation between mothers' mental and physical health and children's ability to adjust their siblings' disabilities. A study of family attitudes regarding children diagnosed with a developmental disability found that siblings will mirror the feelings of their parents (Graliker, 1962). This suggests that if parents have negative attitudes about family member's disability this attitude will spread to the typically developing children in the household.

Similarly, children's first perception of their siblings' disabilities will be identical to the parents' perception (Laboto, 1990). These feelings, however, will change and develop as the children mature. "Children will gain a much richer understanding of themselves and other people as they develop the ability to discriminate their own perspective from their companions" (Selman, 1980, p. 804). According the Selman's Theory of Perspective Taking (1980), children will progress through five stages as they develop the skill to understand others' points of view. As siblings' progress through these steps, their perspectives of their siblings' disabilities will change.

Siblings in the early stages of development have self-centered views of the disability (Klein, 1993). Selman (1980) refers to this stage in the perspective taking process as egocentric or undifferentiated. Children are naive to any other viewpoints besides their own perspective. This stage spans roughly from age 3 to 6 years. Developmentally, these children are not able to understand why their sibling receives more attention and care. Because of this perspective, jealousy is a common feeling associated with by children during this stage (Connors & Stalker, 2002).

In the egocentric stage, children may imitate their disabled siblings in such things as communication and mannerisms. By adopting characteristics of their brothers' or sisters' handicap or disorder, the siblings create their own pretend disability (Klein, 1993). Some experts believe that these behaviors are intended to get the attention of their parents. In contrast, Dyson and Fewell (1989) suggest that siblings of children with disabilities mimic behavior of their developmentally delayed brother or sister because they do not realize that others do it differently. The behavior being imitated is considered to be normal in their eyes.

In a study of 4-12 year olds, children were asked to describe their siblings with disabilities to someone who has never met them (Connors & Stalker, 2002). Of the 26 recruited siblings, only two children made reference to their siblings' disabilities in the description. This may indicate that at these ages the siblings do not regard the disability as part of their brothers' or sisters' identity and consider symptoms of the disability to be normal behavior.

Selman's (1980) stages of perspective taking indicates that around the ages of 6 to 8 years children transition to the social information phase. The children are now able to recognize that individuals have different perceptions. However, they believe this is caused by having different information. As a result, children become aware of contrary attitudes about disability among their peers (McHale, Sloan, & Simeosson, 2003). It is at this age that classmates may begin asking the children questions regarding their siblings' disabilities.

Peer influence and the desire to belong can weigh heavily on children's impression of disability (Vangelisti, 1993). Feelings of embarrassment begin to develop as children gain a better understanding of their friends' views of disability (Orfus & Howe, 2008). A study including children who have siblings with disabilities found most of the children reported that their friends were supportive. Yet, they declined to talk about their own feelings with friends because the children felt peers would not understand what it was like to have a family member with a disability (Connors & Stalker, 2002). The siblings in this phase of perspective taking may believe that peers have a dissimilar opinion of their brothers' or sisters' disabilities because their friends lack information about the disabilities. Therefore, the children did not talk about their feelings regarding their sibling with their friends

Between the ages of 8 to 12 years, children can understand that two people may have different viewpoints, even if both parties have identical information (Selman, 1980). In this period of development, children can distinguish their own opinions from the beliefs of others simultaneously. Children also begin to understand how others develop individual perspectives. This awareness helps the children anticipate third party reactions. Siblings of children with disabilities develop the ability to empathize with both their parents and their siblings. This understanding causes a transition to a less self-centered viewpoint of disability. Siblings now recognize how the disability affects others.

Selman's (1980) next phase, societal role taking, begins after age 12. These adolescents assume that everyone in their peer group holds the perspective that is considered the societal norm. Siblings of children with disabilities begin to make generalizations about other's views. During the societal role taking phase, siblings reportedly begin to understand the full ramifications of having siblings with disabilities (McHale, Sloan, & Simeosson, 2003). This age group starts to become increasingly worried about the future giving them great anxiety (Connors & Stalker, 2002). Adolescence, itself, is a stressful time in people's lives. In this transitional period, teens prepare to leave their parent's house to pursue further education and careers. In some cases, the future needs of siblings with disabilities may greatly impact choices. One participating 16 year-old was quoted, "If Jamie is around when Mum and Dad die, he'll come and live with me if I am able. There is no way he will go into residential care. I've accepted that since I was old enough to think" (Burke & Montgomery, 2001, p. 29).

The thought of growing old is particularly difficult for children of siblings with disabilities. The sibling relationship is considered one that will be important throughout life. Seventy percent of these family members reported being close to their siblings as adults (Cicirelli, 1991). This suggests that siblings provide emotional support and friendship throughout life. Some life experiences affect sibling closeness, improve relations, or increase the frequency of contact between adult siblings. Connidis (1992) found that sibling ties were heightened when divorce, widowhood, or health problems occurred in the family. The disability is a lifelong condition that can strengthen bonds between siblings.

Early research on the topic was led by the theory that ‘a handicapped child’ leads to ‘a handicapped family’ (McComack, 1978). Studies based on this theory made assumptions that siblings were experiencing psychologically damaging effects because of having siblings with disabilities. Research often used parents’ perceptions of how their typically developing children are coping to provide data for their studies. Few researchers have talked directly to siblings of the children with disabilities (Connors & Stalker, 2002). More recently, researchers have begun to survey siblings but have reported mixed results concerning the presence of any negative consequences as a result of having siblings with a disability.

Several studies have taken a retrospective approach, asking adults to look back at how having sisters or brothers with disabilities affected their childhood. Grossman (1972) conducted formal interviews with 83 college students who had siblings diagnosed with intellectual disabilities. Each of the participants was paired with a student who was matched based on sex, socioeconomic class, gender, birth order, and religious affiliation but had siblings without intellectual disabilities. Grossman (1972) determined that 45% of the students benefited but 45% were negatively impacted from having siblings with disabilities . Participants who were classified as benefiting from their childhood experience reported better understanding of and compassion for people who are disabled, a better awareness and sensitivity to prejudice, and a better appreciation for their own good health. Those who were classified as negatively impacted by their childhood experience reported resenting the childhood responsibilities and feelings of guilt, as well as feelings that they had been neglected by their parents to take care of their siblings with disabilities (Grossman, 1972).

A similar study by Cleveland and Miller (1977) indicated that many children benefit more than were negatively impacted by having siblings with disabilities. However, both studies listed several limitations. The use of college students who no longer live in the home may have caused participants to have a selective or more mature view of their childhood, and may not necessarily reflect the feelings they had while living in the situation. In addition, the voluntary nature of the survey may have led to an over-representation of participants who have a positive outlook of their experiences with their family and are more comfortable reflecting on it (Grossman, 1972). Those with painful memories may have avoided participation in the studies (Clevland & Miller, 1977).

Mixed results have also been found when evaluating the impact of having siblings with disabilities as it pertains to children’s pathological tendencies. A study of 230 children with siblings diagnosed as having cystic fibrosis, cerebral palsy, or multiple disabling conditions were evaluated against a control group of 1,034 siblings using the Psychiatric Screening Inventory and maternal reports (Breslau, Weitzman, & Messenger, 1981). Results from the study indicated that overall inventory scores between the groups were not significantly different. However, children who had siblings with disabilities illustrated significantly less pathology in the subscale of isolation and significantly more pathology in the subscales of social problems, fighting, and delinquency.

Gath (1972, 1973) conducted two similar studies, one using a group of siblings of children with cleft palettes compared to a control and the other using siblings of children diagnosed with Down syndrome compared to a control group. While procedures of the two studies were identical, varying only by the diagnosis of the target child's sibling, the two studies found very different results. Both studies used parent and teacher ratings of deviance. The study of the siblings of children with cleft palettes found no significant differences in the target population and the control group (Gath, 1972). The study of siblings of children with Down syndrome found that the target population was twice as likely as the control group to be rated as deviant by both their teachers and their mothers (Gath, 1973). This may indicate a relationship between the severity of the disability and siblings' ability to cope. Children who have disabilities more severe in nature may need more assistance in performing activities of daily living, putting more responsibility on the family as a whole. The psychological community highly criticizes this finding and other studies for the use of parent reports that lack objectivity. Maternal impressions of how well their children are coping with a siblings' diagnosis with disabilities has been shown to weigh heavily on how the mothers are coping (Carr, 1974).

Criticism of parents objectivity has led the psychological community to pursue other avenues of gathering information on the topic. Siblings of children with spinal bifida were evaluated on school conduct and adjustment by their teachers (Tew & Laurence, 1973). The study matched each sibling with children of the same age, geographic location, sex, and family size to form a control group. The results indicated that children with siblings who have spinal bifida were four times more likely to have adjustment problems in school than the control group.

The use of teachers to evaluate siblings of children with a developmental disability has also been criticized due to research indicating that knowledge of having a family member with a disability lowers the expectations held by others of siblings' social adjustment and achievement (Blackard & Barsh, 1982). The use of school personnel is reliable if the evaluator is not aware that the student has a family member with special needs. This, however, may be difficult when the siblings attend the same school.

An early study by Farber (1959) examined the role of tension in families who have children with intellectual disabilities. This study examined the roles and routines of the typically developing siblings and the parents. Measurements were taken to identify how often the two roles remained consistent and how often they were at odds with one another. Families of less dependent and higher functioning children who have intellectual disabilities reported better adjustment and lower role tension than families of lower functioning children with intellectual disabilities.

While the conduct these children display in school is important, many of the effects of having siblings with disabilities can only be seen at home. Watching the interaction between the typically developing children and other family members can show how well the children are coping. Siblings of children with intellectual disabilities were evaluated on role tension based on gender and birth order. Female participants who were older than their sibling with intellectual disabilities had the highest role tension with their parents (Farber, 1960). The research indicated that male participants had significant less role tension than did female participants. This was believed to be a result of fewer caretaking responsibilities and lower parental expectation. Female sibling role tension with parents decreased because of children's placement outside the home (in-resident care), whereas male sibling role tension actually increased when the children with disabilities were placed in residential treatment.

The oldest female appears to be the most adversely affected by the presence of siblings with disabilities (Grossman, 1972). The first-born females generally take on more responsibilities than first-born males or the later-born females, a trend that has been shown to occur across all socioeconomic classes. As a result, it is logical that a greater amounts of responsibilities go to these children in families with siblings with disabilities. Indeed, the degree to which the oldest daughter was negatively impacted by the presence of siblings with an intellectual disability was more pronounced if the children were more physically dependent on others (Grossman, 1972).

In the process of conducting research, researchers have to choose which perspective model of disability they want to use for the development of their study. In his book, *Brothers and Sisters of Disabled Children*, Peter Burke (2004) uses two of the most popular models of disability. The Medical Model of Disability views disability as something to be cured; it is pathological in orientation and consequently is indicative of people with disabilities who have medical problems that have to be remedied (Gillespie-Sells & Campbell, 1991). This definition directly stated that a disability is something in need of being cured. This implies that there is something abnormal or wrong with people with disabilities. In contrast, the Social Model of disability indicates that environmental factors exasperate barriers experienced by individuals with handicapping conditions (Burke, 2004). This model indicates that the disability is not within the individuals but in their interactions with the environment.

Using a combination of the two models Burke (2004) created his own model as it applies to the families of individuals with disabilities. Burke (2004) coined the Model of Disability by Association, which refers to the effect of the neglect that children may experience in the home due to the overwhelming needs of siblings with disabilities. Neglect, as referred to in the Disability by Association Model, does not match the definition as presented in federal law. The Federal Child Abuse Prevention and Treatment Act label neglect as, "Any recent failure to act on the part of a parent or caretaker which results in death, serious physical or emotional harm, sexual abuse or exploitation; or failure to act which presents an imminent risk of serious harm" (42 U.S.C.A. §5106g). In the Disability by Association Model, neglect is referred to as different levels of care and attention of siblings in families of children with disabilities that may not equate with the needs of the siblings without disabilities (Burke, 2004). In this case, neglect is a result of competing pressures on caregivers rather than a deliberate act.

The social exclusion portion of the Disability by Association Model refers to the "deliberate prohibition or restriction which prevents a sibling from engaging in activities shared by others, often as a result of segregation of oppression." Burke (2004) uses the model to show how having siblings with disabilities become part of these children's self-concept (Burke, 2004).

Present Study

Raising children has always a huge responsibility for any parent. In our culture, it is generally accepted that older children in a family help care for their younger brothers and sisters. Typically when the younger siblings mature, the help the older sibling provides decreases as the younger brothers and sisters learn to care for themselves. In families with children who have disabilities, often caring responsibilities of the typically developing siblings will follow them through childhood and maybe even alter the direction of their lives. Unintentionally, feelings of siblings of children with disabilities go overlooked. These siblings may often feel like the care is an obligation to the family rather than a choice. One adult sibling reported, "It was always a given that I would take responsibility over when my parents got older. When I set a strict boundary: No, he cannot live with me, my parents felt I let the family down," (Fish, 1993, p. 26)

Much of the research in this area is dated, and while it is still relevant, the research community has not received much new research to spark curiosity and renew interest in the topic. Ultimately, the best way to help siblings of children with disabilities is to increase awareness in the local community. This research study was conducted in a rural community in western Kansas that currently provides no registered support group for siblings of children with disabilities. The Sibling Support Project is the largest organizer of support groups for siblings of children with special needs . As of 2012, 346 registered chapters are in the United States, none of which are located in Kansas (Meyer

& Vadasy, 2012). This study aimed to evaluate a need for support services to the population existed by examining the Intensity and Frequency of Daily Hassles causing hardship in local children's lives.

While community awareness and renewed interest in research is important, this study was intended to provide a direct impact for the research participants. The study was conducted to increase awareness in parents of participants by having them think about the responsibilities and stress their typically developing children may have been experiencing. Often, siblings in these families believe that they need to keep their thoughts and feelings from their overwhelmed parents. Study participation offered the families an opportunity for discussion of stress as a result of having family members with disabilities, following the completion of the survey.

The study was conducted with the purpose of identifying the feelings and stressors siblings of children with disabilities that may go unintentionally ignored. Through the information the children provided, the most stressful hassles were identified. With this information, parents, educators, and other important individuals can target the most stressful hassles and work to make the day-to-day lives of siblings of children with disabilities easier.

By collecting demographic information such as socioeconomic status, gender, age, and severity of their sibling's diagnosis, data analysis hoped to identify subgroups at-risk for higher levels of stress. This helped show the populations that are most in need of support from others. Using the information gathered by the uplift scale, parents can balance the daily stressors experienced by the siblings of children with special needs with the uplifting situations shown to bring the siblings the highest level of happiness.

Hypotheses

A review of literature indicated that severity of the children's disabilities impacted the stress experienced by the family (Gath, 1972). Therefore, it was hypothesized that (A) the amount of assistance the children with disabilities need would positively correlate with both overall Frequency and Intensity of Hassles reported by siblings without disabilities. It is also hypothesized that (B) a significant positive correlation would be seen between the amount of help the siblings provided their families and both the Frequency and Intensity of Hassles reported by siblings without disabilities. Based on the research that reports females take on more caring responsibilities (Grossman, 1972), it was hypothesized that (C) females would report significantly higher Frequency and Intensity of Hassles than males.

Using the Theory of Perspective Taking (Selman, 1980), (D) it was hypothesized that siblings prior to the mutual role taking phase, below the age of 10, would report significantly higher concern for hassles directly affecting them than that of other age groups. The theory was also used to hypothesize that (E) siblings in the societal role taking phase, above the age of 12, would report embarrassment and public perception as a more intense and more frequent hassle than siblings under the age of 12.

Based on the idea that more children will bring more stress to a family, it was hypothesized that (F) the participants' stress levels would positively correlate with the number of children in each family. According to Buckley (1967) a stress felt by one family member will be felt by the family as a whole. With this in mind, it was hypothesized that (G) children in single parent homes would experience a higher Frequency and Intensity of Daily Hassles when severity is controlled for. Using the same research, it was hypothesized that (H) children's would reported Frequency and Intensity of Daily Hassles would vary on levels of SES when controlling for Severity of the Disability.

Methods

Participants

The study included 29 families with siblings of children with disabilities. The siblings ranged from 7 to 16 (*M*=12.78 *SD*=5.36) years of age. One family was excluded from the study due to not fully completing the survey. Of the remaining families, 20 of the siblings of children with disabilities were male and eight were female. Of the 28 children with disabilities, 22 were male and 6 were female. The number of children in the participating families ranged from 2 to 6 (*M*=3.17, *SD*=1.12). For estimated yearly income each level was coded by giving each range a value starting with the \$0-14,999 (N= 0) range given the value of 1, \$15,000-24999 (N=4) given a value of two, \$35,000-49,999 (N=4) given a value of three, \$50,000-74,999 (N=9) given a value of four, and 75,000+ (N=11) was given the value of five.

Table 1
Demographic Information Collected from the Parent Survey

	Minimum	Maximum	Mean	SD	N
Age of the Participant (Years)	7	16	11.82	2.88	29
Age of the Sibling with a Disability (Years)	3	24	12.12	5.36	29
Number of Children in the Family	2	6	3.17	1.12	29

Operational Definitions

A disability for this study was operationally defined as children who qualify for services under the Individuals with Disabilities Education Act (2004):

> A child with a disability means a child evaluated in accordance with Sec. 300.304 through Sec. 300.311 as having mental retardation, a hearing impairment (including deafness), a speech or language impairment, a visual impairment (including blindness), a serious emotional disturbance (referred to in this part as "emotional disturbance"), an orthopedic impairment, autism, traumatic brain injury, other health impairment, a specific learning disability, deaf-blindness, or multiple disabilities, and who, by reason thereof, needs special education and related services. 20 U.S.C. 1401(3); 1401(30)

Siblings were operationally defined as multiple members of the same family who do not hold parental roles. The definition of family was adopted from Poston et al. (2003) stating family as “two or more people who regard themselves to be a family and who carry out the functions that family typically perform” (p. 313). The definition allowed for the participation of step, foster, and biological siblings. The siblings did not have to live in the same household, as long as contact was being established on a regular basis.

Recruitment

Several methods were used to recruit participants due to the limited accessibility of the population. The first method of recruitment was from local schools. Permission was obtained by the administration to have access to student files. Parents of children who were receiving special education services were contacted by phone by the researcher.

The second method was through a snowball procedure. Parents or legal guardians of participants were asked if they knew any other families who would be willing to participate in the study. If the parents indicated they knew of possible participants, they were asked to either provide the researcher with a way to contact the prospective families or provide the prospective family with the contact information of the researcher.

Measures

The Daily Events Scale for Siblings of Children with a Disability or Illness (Giallo & Gavidia-Payne, 2006) was adapted from the Daily Life Stressor Scale for Children (Kearney, Drabman, & Beasley, 1993) to evaluate stressors and uplifts felt by these siblings. Participants rated the frequency and intensity of 43 hassles and 24 uplifts on a 5 point scale. Frequency was measured on the following scale: 1 = never, 3 = sometimes, and 5 = always. The Intensity of Hassles was measured on the following scale: 1 = not bothered or upset, 3 = a little bothered or upset, and 5 = very bothered or upset. The Intensity of Uplifts which captured how happy uplift experience made the participants, was measured on the following scale: 1 = not happy, 3 = sometimes happy, and 5 = very happy. Higher scores on the scale indicated greater frequency and greater Intensity for both Hassles and greater positive affect associated with Uplifts. In the study, a Cronbach's α analysis of the Hassles-Frequency ($\alpha = 0.88$), Hassles-Intensity ($\alpha=0.92$), Uplifts-Frequency ($\alpha = 0.88$), and Uplifts-Intensity ($\alpha=0.93$) indicated a high internal reliability of the scale (Giallo & Gavidia-Payne, 2006).

Reliability alpha for the entire scale was α=.94 (Orfus & Howe, 2008). That study reported a daily hassles frequency mean of 1.69 with a standard deviation of .63 and an intensity mean of 2.05 with a standard deviation of .64. The most frequently reported daily hassle was "my brother or sister with a disability cries, screams, or yells when he/she doesn't want something" (*M*=3.00, *SD*= 1.46). The most stressful hassle was "my brother or sister with a disability embarrasses me when my friends come over," (*M*=3.00, *SD*=1.50). Analysis of the uplift scale resulted in a frequency mean of 2.13 with a standard deviation of .50, and an intensity mean of 3.38 with a standard deviation of .19. The most frequently occurring uplift was "my brother or sister with a disability gives me a hug or kiss" (*M*=2.59, *SD*=1.08). The uplift with the highest intensity was "playing together with my brother or sister with a disability" (*M*=3.64, *SD*=.67).

A *Demographic Survey* was constructed by the researcher to test patterns in participants' responses. The survey collected age and gender of both the children with disabilities and the participating siblings, estimated yearly income of the family, parent education level, and type of parental relationship: single parent, dual biological parents, dual step/biological parent, or other. The survey also had the parents rate the children with disabilities verbal skills, skills to form peer relationships, skills to form adult relationships, and skills to perform activities of daily living.

Results

To better understand the data collected, a Pearson Correlation was conducted to test if there is a relationship between any two subscales of the Revised Sibling Daily Hassles and Uplifts. A significant correlation was found between Frequency of Hassles and Intensity of Uplifts, $r(28) = -.43$, $p<.05$). In this sample, the more frequent the hassles occurred the less happiness the participants experienced from the uplifts described in the survey.

Another significant correlation was found between the Frequency and Intensity of Uplifts, $r(28) =.39$, $p<.05$). The more frequent the uplifts occurred, the happier it made the participants. No other significant relationships were found between the other subscales (Table 2).

Table 2
Pearson Correlation Matrix among Subscales of The Revised Sibling Daily Hassles and Uplifts

	Frequency of Hassles	Intensity of Hassles	Frequency of Uplifts
Frequency of Hassles			
Intensity of Hassles	-.10		
Frequency of Uplifts	.00	-.04	
Intensity of Uplifts	.43*	-.18	.39*

*$p < 0.05$

To measure severity of the disability, an index was created by taking the mean of the parents' ratings of the children with disabilities' ability to perform activities of daily living, verbal ability, academic ability, ability to form relationship with peers, and ability to form relationships with adults. The information was coded so that a three represented that the children's abilities matched their peers, below three represented that the children's abilities were below their peers and above three indicated that the children's abilities were above their peers. For example on verbal ability, a response of one or two represented that the children with disabilities had a verbal ability below the level of their peers. A response of three indicated that the children with disabilities had verbal ability at the same level as their peers. Responses of four and five indicated that the children with disabilities has a verbal ability above their peers.

Hypothesis A

The amount of assistance needed for the children with disabilities (*M*=1.57, *SD*=1.03) was expected to correlate significantly with either overall Frequency of Hassles (*M* =2.66, *SD*=1.08*)* or Intensity of Hassles (*M* =2.31, *SD* =.60) reported by the participant. The severity variable was used as a way to assess how much assistance the child with a disability needs.The parent's rating of severity of the disability did not correlate with either Frequency or Intensity of Hassles (Table 3).

In exploratory analyses, it was also found that the severity of the disability correlated with Intensity of Uplifts (*M*=3.86, *SD=.57)* experienced as a result of uplifts (Table 3). This would indicate that the less severe the disability the more happiness the participants experienced from the uplift events.

Table 3

Pearson Correlation Matrix among Severity, Amount of Help, and Subscales of

	Frequency of Hassles	Intensity of Hassles	Frequency of Uplifts	Intensity of uplifts
Severity Index	-.02	-.10	.00	.43*
How much help does the sibling provide	-52**	.14	.12	-.38

*p< 0.05

**p < 0.01

Hypothesis B

A series of Pearson Correlations were used to test the relationship of how much the siblings helped care for their brothers or sisters (*M*=2.75, *SD*=1.04) with disabilities on the Frequency of Hassles (*M*=2.66, *SD*=1.08) and Intensity of the Hassles (*M*=2.31, *SD*=.60) reported. The parents rated how much the siblings helped on a scale with one being no help, three being some help, and five being helps a lot. A significant negative correlation was found between how much help the sibling gave and the Frequency of Hassles the sibling reported (Table 3). Indicating that the more the siblings helped the less frequent the siblings reported the hassles. No significant relationship was found between Intensity of Hassles and how much siblings help care for their brothers or sisters with disabilities. Nor was a relationship found between Frequency of Uplifts (*M*=3.12, *SD*=.34) or Intensity of Uplifts (*M*=3.86, *SD*=.46) and the amount of care the sibling provided (Table 3), which were conducted as an exploratory analysis.

Hypothesis C

Hypothesis C answered the research question of whether male siblings of children with disabilities (N=22) differed from female siblings of children with disabilities (N=8) on their ratings of Frequency and Intensity of the Hassles and Frequency and Intensity of Uplifts. To analyze this, independent sample *t*-tests were run for each subscale. Results from the test showed that the Levene's Test of Equality of Variances was not violated, and equal variances were assumed. The test indicated that none of the results from the independent *t*-test were significant (Table 4). Therefore, it was concluded that for this sample, gender did not make a difference in the siblings' responses for Frequency and Intensity of Hassles and Frequency and Intensity of Uplifts. However, these results should be interpreted with caution due to the inequality of the number of male and female siblings in the sample.

Table 4

Independent Sample t-tests for Gender

	Levene's Test of Equality of Variances		*T*-Test of Equality of Variance		
	F	Sig.	*t*	*df*	Sig
Frequency of Hassles	.053	.81	1.46	26	.15
Intensity of Hassles	1.3	.25	-.623	26	.54
Frequency of Uplifts	1.80	.19	-1.18	26	.25
Intensity of Uplifts	1.75	.19	1.02	26	.32

Hypothesis D

To test this hypothesis, participants' scores of intensity on 17 hassles that directly affected the participants were compiled and averaged to form a Direct Effect variable. These included such things, as "My parents do not have time to talk or play with me."

Using this variable, it was tested if participants prior to the Mutual Role Taking Phase (Selman, 1980) or participants below the age of 10 (N=10) and participants in the Mutual Role Taking Phase or above the age of 10 groups (N=18) would differ on Direct Effect variable. The results indicated that the Levene's test of equality of variances was not violated, $F(2, 26)=.20$, $p<.05$ and there were no significant difference between participants below 10 (M=2.55, SD=.55) and above 10 (M=2.39, SD=.59); $t(26)=-.69$, $p>.05$. It was concluded that there was no significant difference between participants prior to the Mutual Role Taking Phase and in the Mutual Role Taking Phase on the responses to Frequency and Intensity of Hassles directly impacting the participant.

Hypothesis E

This hypothesis tested if public perception of hassles were more intense for siblings in the Societal Role Taking Phase (Selman, 1980) above the age of 12 (N=12) than for siblings not in the Role Taking, below the age 12 (N=16). Of the Revised Sibling Daily Hassles, 12 hassles were selected to evaluate the intensity of public perception. These hassles included such things as "people asking questions about my brother or sister with a disability" or "people stare at my brother or sister with a disability" These hassles were compiled and averaged to create a public perception variable. Using this variable, an independent t-test was used to compare the above 12 participants (M=2.10, SD=.74) and the below 12 participants (M=2.11, SD=.90). The results indicated that the Levene's Test of equality of variance was not violated , F(2, 26) = .14, $p>.05$, and that there was no significant difference between the age groups, t (26) =-.006, p>.05. Concluding that there was no difference between participants prior to the Societal Role Taking Phase and participants in the Societal Role Taking Phase on the responses of hassles dealing with how the public perceptions affect the participants.

Hypothesis F

This analysis was performed with the purpose of finding how the number of siblings impacted the participants' responses on the four variables of the Revised Sibling Daily Hassles Scale. A Pearson Correlation was conducted and indicated that there was a significant relationship between the number of children in the family and Frequency of

Hassles the siblings reported, *r*(28) = -44, *p*<.05. This suggested that the fewer children in a family the more frequent hassles occurred for siblings of children with disabilities. No significant relationship was found between the number of children in the family and the other three variables: Intensity of Hassles *r*(28)= -.14, *p>.05*, Frequency of Uplifts *r*(28)=.3, *p*.>05, and Intensity of Uplifts *r*(28)=-.12, *p*>.05.

Hypothesis G

Hypothesis G intended to examine the differences between the sibling responses among the four different parent relationship statuses: single, dual biological, step-parent/biological parent, and other, using and ANOVA. However, due to the composition and size of the sample this was not statistically possible. The sample contained 3 single parent families, 22 dual parents, 1 step/biological parent family, and 1 other parent relationships.

An independent *t*-test was run by combining single parents, step/biological, and other parent relationship into a group labeled as non-dual biological parents with 6 participants and comparing them with the dual biological parents group with 22 participants. Dual biological parents were compared with non-dual biological parents on scales of: Frequency of Hassles (*M*=2.66, *SD*=1.08), *t*(26)=*.456, p*>.05 , Intensity of Hassles (*M*=2.31, *SD*=.60)*, t*(26)=.80*, p*>.05, Frequency of Uplifts (*M*=3.12, *SD*=.35), *t*(26)=1.54, *p*>.05 and Intensity of Uplifts (*M*=3.86, *SD*=1.08), *t*(26)=.02, *p*>.05. No significant relationships were found between Revised Sibling Daily Hassles Scales and the two parent groups.

Hypothesis H

This analysis assessed if there was a correlation between estimated annual income of the families and the participants' responses on the four scales of the Revised Sibling Daily Hassles Scale when controlling for variances in severity of the disability. However, this sample did not provide enough variance in severity to control for it in a partial correlation. As a result, the bivariate correlations were run without any controlling variables.

A significant relationship was found between estimated annual income (M=4.82, SD=1.36) and Frequency of Hassles (M=2.66, SD=1.08), $r(28)$=.50, p<.01. This indicated the higher the income the more frequent stressors occurred. No significant relationship was found between the other three scales; Intensity of Hassles, Frequency of Uplifts, and Intensity of Uplifts. These results should be interpreted with caution, as there are an unequal number of participants in each income range.

Exploratory Analyses

To examine specific hassles and uplifts, a series of exploratory correlations were examined.Table 5 indicates the frequency of the hassles occurring among different demographic information. A significant positive correlation was found between how much help the participants provided to their siblings with disabilities (M=2.74, SD=1.06) and how much the children worried about doing something wrong (M = 2.64, SD= 1.25), $r(28)$= -.41, p<.05. The more help the sibling provided in caring for their sibling with a disability the less the sibling worried about doing things wrong.

Another significant correlation was found between the siblings' ages (M= 11.82, SD= 2.88) and how much they worry about their siblings getting older (M=2.50, *SD*=1.41), *r*(28)= -.42, *p*<.05. As the children with disabilities age, the siblings worry less about how the disabilities will affect the children in the future

Table 5
Exploratory Pearson Correlation Matrix with Frequency of Hassles and Demographic Information

	Age of the Child with a Disability	Amount of Assistance Needed	Sibling's Age	How much help does the Sibling Provide
I worry about doing something wrong	.15	-.04	-.29	-.41*
I worry about my brother or sister getting older	-.14	-.03	-.37*	-09
My brother or sister with a disability understands me	-.42*	.01	.08	-.73
I have to talk to my friends about my sibling with a disability	-.47*	-.13	.11	.08

*$p< 0.05$

Table 6 shows a series of correlation among how bothered or upset the siblings reported being by hassles. A significant correlation was found between the ages of the children with disabilities (*M*=11.96, *SD*=2.79) and how bothered or upset the siblings we when the parents fight (*M*=2.65, *SD*=1.30), $r(28)=.39$, $p<.05$. How much the siblings worry about their parents negatively correlated with how much help the siblings provide with their siblings with disabilities, $r(28)= -.40$, $p<.05$. Also negatively correlated were the severity index and how bothered the siblings was by not being able to do things other siblings can do, $r(28) = -.42$, $p<.05$.

Table 6
Exploratory Pearson Correlation with Intensity of Hassles and Demographic information

	Age of the Child with a Disability	How much help the sibling provides	Sibling's Age	Severity Index
There are arguments or fights in my family	.39*	.27	-.09	.15
We can't do things other brothers and sisters can do.	-.13	.20	.09	-.42*
I worry about my parents	-.01	-.40*	-.13	.38

*$p< 0.05$

Table 7, shows correlations between selected demographic information and how happy the uplifts made the siblings. Having a friend over negatively correlated with the amount of assistance the children with disabilities needed, $r(28) = -.44$, $p <.05$. This indicates as the amount of assistance the children with disabilities need increases, how happy the siblings are as a result having a friend over decreases.

Doing something fun as a family negatively correlated with the siblings' ages, *r*(28)= -.44, *p* <.05. How much help the sibling provides to their brother or sister with a disability negatively correlated with Intensity of Uplifts as a result of their sibling doing something funny *r*(28)= -.43, *p* <.05, doing something fun as a family *r*(28)= -.45 *p*<.01, and a parent helping the sibling with something *r*(28)= -.40, *p* <.05. The more help the siblings provide in the care of their brothers or sisters with disabilities, the less happy they become as a result of spending time with family, children with disabilities doing something funny, and parents helping the siblings with something.

Table 7
Exploratory Pearson Correlation with how happy uplifts make participants and Demographic Information

	Age of the Child with a Disability	Amount of Assistance Needed	Sibling's Age	How much help does the Sibling Provide
Having a friend over	-.13	-.44*	-.31	-.20
Doing something fun together as a family	.16	.17	-.44*	-.43*
My brother or sister with a disability does funny things	-.02	-.15	-.23	-.45**
My Parents help me with something	-.01	-.28	-.15	-.40*

**p*< 0.05

***p*<.01

Discussion

Severity of the Disabilities of the Siblings’ Effect on Reported Hassles and Uplifts

Contrary to what was anticipated by the literature review, parents’ severity ratings of the disabilities did not correlate with the Intensity of Hassles the siblings reported. Based on the research found (Gath, 1973), it had been thought that the more severe the disability the more frequent the sibling would report hassles. One explanation is an inconsistency in the composition of this sample and samples in prior research. A majority of this sample included children with mild disabilities as reported by the parents. Without all ranges of severity of disabilities equally represented, there is no way of knowing if the results of the correlation are accurate or the result of a scewed sample.

The exploratory analysis indicated that the more severe the disability more bothered or upset the siblings are not able to do things as a family because of their brothers or sisters with disabilities. Although the frequency of the hassle was not significant, it seems logical that the more severe the disability the more things the family cannot do due to the disability. The social exclusion portion of the Disability by Association Model (Burke, 2004) states that restrictions that prevent siblings from engaging in activities shared by others is a -form of segregation of oppression and becomes part of the siblings’ self-concept. Participants reporting being bothered by not being able to do things as a family coincide with this model. It is possible that the more severe the disability the more activities that cannot be done as a family and the more often segregation of oppression occurs, making it more of a hassle for siblings of these children with more severe disabilities, who need more assistance to preform activities of daily living.

The Effect of How Much Help the Siblings Provide

The negative correlation between how much help the siblings provides and how often the hassles occur was contrary to what was hypothesized. A possible explanation for this could indicate that the more the participants helps their siblings with disabilities, the less the participants perceive the daily occurrence as a “hassle”. It is interesting that the sibling who helps their parents more with the care of their sibling actually worried about their parents less frequently than those who provided less care. An explanation may be that the siblings are worried because they want to help but do not know how.

The amount of assistance the sibling provided negatively correlated with uplifts like doing things as a family and having a parent help them with something. This could be explained by using the neglect portion of the Disability by Association model (Burke, 2004) which states the different levels of care of the children in the family may not equate to the needs of the siblings of a children with disabilities. While the siblings may always be aware of the different levels of care, it could become more apparent to them when time is spent together as a whole family in situations where the siblings cannot remove themselves from the situation when they get upset. Another possible explanation for the negative correlation is when the participants do things with their families, they may take on some responsibilities of care for their sibling, thus making the experience less enjoyable.

Changes in Perception as the Sibling and Child with a Disability Age

The participants' age negatively correlated with how often they worry about their sibling with a disability and how often they worry about their sibling getting older . A probable explanation is that as the siblings of children with disabilities age, they are able to fully realize how significant the disabilities are and how it will affect both their life and the life of their brothers/sisters. Since a majority of the participants had siblings with more mild disabilities, they may be more optimistic about the future than siblings of children with more severe disabilities would be and have seen their siblings make progress in caring for themselves. It could also be that the siblings have adapted to what kinds of responsibilities they take on and no longer see them as something upsetting.

A significant negative correlation between children with disabilities' ages and how bothered the siblings are by family fights. This would indicate that as the brothers or sisters with a disabilities ages the siblings are less concerned with family fights. There are several explanations for this. It could be that as the children with disabilities age so do the siblings. As you grow, family fights tend to be less traumatic. Farber (1959) found that the more severe the disability the more role-tension in the families. Fights are more common as in families with higher role-tension. Since a majority of the participants in this study had more mild disabilities, it could be that role tension may be high at first when the children with disabilities have more needs and the families are still adjusting. As both the siblings and the children with disabilities grow older, there may be less role-tension in the family due to the families being fully adjusted and the level of care need for the children with mild disabilities decreases.

Although there was no significant difference between frequency and severity of public perception among participants below and above the age of twelve, due to the unequal distribution of severity a conclusion cannot be drawn. Most of the participants had siblings with mild disabilities. Therefore, public perception may be less of a hassle for both age groups because the disability may not be easily visible to the general public. Unlike siblings of children with more severe disabilities, people stopping and starring, adults and children asking questions, and the children with disabilities inadvertently embarrassing their siblings by drawing attention to the family is less common to the participants of this study. It is these types of occurrences that would make public perception more of a hassle for some siblings of children with disabilities.

The Impact of Family Factors

The data found that there was a significant correlation between the parents' estimated annual income and Frequency of Hassles. The positive correlation indicates that as income increases, the number of hassles also increases. This was contrary to what was expected and could be due to the inequality among the groups within the study. It is also possible that there is an unequal distribution of severity level of the disability among the levels of income. If more children with disabilities in the families in the higher income groups have severe disabilities than the children in families in the lower income groups it may explain the results.

Another possibility is that there are different public expectations for different economic classes. People in of higher economic classes may feel pressure to provide care for their family members with disabilities without outside assistance. Since families with children who have disabilities experience more stress than similar families (Hasting, 1984), accepting community assistance and assistance from others is a way to reduce the strain placed on these families (Connor & Stalker, 2002). Since some community assistance qualifications are based on income, community resources may not be available and siblings in these families may have more caring responsibilities.

The significant negative correlation between how much help the siblings provide and how much they worry about doing something wrong can be explained by exposure. Siblings of children with disabilities were found to be more mature than sibling of children without disabilities (Glendinning, 1982). Children who have more caring responsibility may be even more mature than those children who taken on less caring responsibilities of the siblings with disabilities. The more often the children provide care for the siblings, the more confident the children become and the less they worry about doing something wrong.

Limitations

There are several limitations to the present study. The small sample size along with the lack of power of the study, prevents the results from being generalizable to the population as a whole. The sample was also largely uniform on several demographic characteristics. A large majority of the sample were male siblings coming from dual households that make over $50,000 a year and have highly educated parents. The sample provided insufficient data for drawing conclusions on the effects of gender and age of the sibling, as well as the income of the family, limiting one of the studies goals of finding demographic factors that would be more vulnerable to experience greater amounts of stress when having a sibling with a disability. The unequal distribution and small sample size limited finding a target population for future research.

The final limitation was the possibility of parental bias when rating the severity of the children's disabilities. If this was the case, the parents' responses may represent how they perceive their children disability than how severe the disability is changing how the study would need to be interpreted. While conclusion were drawn, the chance of bias leads to question results.

Future Research

Future research should be on a larger scale with a greater number of participants with a smaller target population. This study covered a large population with very few participants. In future studies, researchers should target a specific population, such as siblings of children with similar disabilities. This study would provide participants with siblings with varying levels of disability severity, but a similar population could allow the research to draw more meaningful conclusions that are easily generalizable.

Implications

Due to the size of the sample, the impact the study has on the topic is limited. However, it does illustrate a need for further research on the topic and how the psychological and educational communities need to serve not only the children with disabilities but also the siblings that will be affected by disabilities.

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APPENDIX A

Ethics Board Approval

FORT HAYS STATE
UNIVERSITY
Forward thinking. World ready.

OFFICE OF SCHOLARSHIP AND SPONSORED PROJECTS

DATE:	October 20, 2011
TO:	Todd Blackwill , BS
FROM:	Fort Hays State University IRB
STUDY TITLE [199957 2]	Factors Impacting the Level Stress Experienced by Siblings of Children with Special Needs
IRB REFERENCE #:	12-007
SUBMISSION TYPE:	Amendment/Modification
ACTION:	APPROVED
APPROVAL DATE:	October 20, 2011
EXPIRATION DATE:	October 19, 2012
REVIEW TYPE:	Full Committee Review

Thank you for your submission of Amendment/Modification materials for this research study. Fort HaysState University IRB has APPROVED your submission. This approval is based on an appropriate risk/ benefit ratio and a study design wherein the risks have been minimized. All research must be conducted in accordance with this approved submission.

This submission has received Full Committee Review based on the applicable federal regulation. On the Parent Demographic Survey, under *Questions regarding the sibling*, the word "their" needs to be"your" or "the" (preferably your). That is the only item that should be addressed.

Please remember that informed consent is a process beginning with a description of the study And insurance of participant understanding followed by a signed consent form unless documentation of consent has been waived by the IRB. Informed consent must continue throughout the study via a dialogue between the researcher and research participant. Federal regulations require each participant receive a copy of the signed consent document. The IRB-approved consent document must be used. Please note that any revision to previously approved materials must be approved by this office prior to initiation. Please use the appropriate revision forms for this procedure. All SERIOUS and UNEXPECTED adverse events must be reported to this office. Please use the appropriate adverse event forms for this procedure. All FDA and sponsor reporting requirements should also be followed.

Please report all NON-COMPLIANCE issues or COMPLAINTS regarding this study to this office.Please note that all research records must be retained for a minimum of three years.

Based on the risks, this project requires Continuing Review by this office on an annual basis. Please use the appropriate renewal forms for this procedure.
If you have any questions, please contact Leslie Paige at 785-628-4349 or lpaige@fhsu.edu. Please include your study title and reference number in all correspondence with this office.

APPENDIX B

Permission Letter for Assessment Measure

Todd Blackwill <tjblackwill@gmail.com>

Rebecca Giallo (Linkedin Requests) <requests-noreply@linkedin.com>

Wed, Feb 23, 2011 at 12:23 PM

To: Todd Blackwill <tjblackwill@scatcat.fhsu.edu>

LinkedIn

INMAIL: ACCEPTED

Rebecca Giallo has accepted your request.
Email: rgiallo@parentingrc.org.au
Title: Daily Events Scale
Hi Todd,

Thanks for your message and interest in the Daily Events Scale for siblings. You are more than welcome to use the scale. I will send to your email address.

Kind regards,

Rebecca
On 2/23/11 4:11 PM, Todd Blackwill wrote:

I am a graduate student in school psychology from Fort Hays State University in Hays, Ks. I am doing my graduate thesis on stress of siblings with special needs and was hoping to get your permission to us your Daily Events Scale for Siblings of Children with Special Needs. It would be so grateful. If you could get back to me either way I would really appreciate it.
Thanks for your time,
Todd Blackwill

View this message

APPENDIX C

Parent Demographic Form

Parent Demographic Form

As part of this study, we would like to obtain some general information. The answers you provide will help us interpret the responses your child provides. However, if at any point you would rather not reply to the question, please feel free to leave them blank.

Question about your family

Does your child with a disability have regular contact with the child participating in the study?

Yes No

How many children are in your family? _______

Last year's estimated household income (circle one)

$0-$14,999 $15,000-24,999 $25,000-34,999

$35,000-49,999 $50,000-74,999 $75,000+

My children primarily live with:

A single parent
Dual biological parents
Step parent/biological parent
Other (specify) _______________

Highest academic degree completed (if applicable):

Yourself:

Some High School
High School/GED
Associates
Bachelors
Post Graduate

Your partner:

Some High School
High School/GED
Associates
Bachelors
Post Graduate

Questions regarding your child with a disability

Child's Age: ___________

Child's Gender: Male Female

Amount assistance your child needs to perform activities of daily living, such as using the bathroom, getting dressed, and using a fork.

1	2	3	4	5
No Assistance	Very Little Assistance	Some Assistance	A Lot of Assistance	Total Assistance

Circle the response that indicates your child with a disability's abilities when compared to other children of the same age.

Verbal Ability:

1	2	3	4	5
Below Peers		Same as peers		Above Peers

Academic Ability:

1	2	3	4	5
Below Peers		Same as peers		Above Peers

Ability to form Relationships with Peers

1	2	3	4	5
Below Peers		Same as peers		Above Peers

Ability to form Relationships with Adults:

1	2	3	4	5
Below Peers		Same as peers		Above Peers
		Peers		

<u>Questions regarding the sibling</u>

Child's Age___________

Child's Gender: Male Female

How much does your child help you care for their child with a disability?

1	2	3	4	5
no		Helps		Helps
Help		some		a lot

APPENDIX D

Revised Sibling Daily Hassles and Uplifts Scale

Revised Sibling Daily Hassles and Uplifts Scale (Giallo & Gavidia-Payne, 2008)

Things that bother, upset or stress you out

Everyone has problems or hassles that bother them from time to time. Below are some things that can make you feel upset, bothered or stressed out. For each problem, we would like to know:

	How often does this happen?					**How bothered or upset does this make you feel?**				
	Never		**Sometimes**		**Always**	**Not bothered or upset**		**A little bit bothered or upset**	**Very bothered or upset**	
I feel like I have to help around the house a lot.	1	2	3	4	[✓ 5]	1	2	[✓ 3]	4	5

	How often does this happen?					**How bothered or upset does this make you feel?**				
	Never		**Sometimes**		**Always**	**Not bothered or upset**		**A little bit bothered or upset**		**Very bothered or upset**
1. I feel like I have to help around the house a lot.	1	2	3	4	5	1	2	3	4	5
2. I worry about when my brother or sister gets older.	1	2	3	4	5	1	2	3	4	5
3. I worry about doing something wrong.	1	2	3	4	5	1	2	3	4	5
4. I feel I don't have time to myself.	1	2	3	4	5	1	2	3	4	5

5. I worry about my brother or sister with a disability.	1	2	3	4	5	1	2	3	4	5
6. I worry about my parents.	1	2	3	4	5	1	2	3	4	5
7. My brother or sister with a disability cries or gets upset.	1	2	3	4	5	1	2	3	4	5
8. My brother or sister with a disability is sick or hurt.	1	2	3	4	5	1	2	3	4	5
9. My brother or sister with a disability hurts, hits, pushes, scratches or kicks me or others.	1	2	3	4	5	1	2	3	4	5
10. My brother or sister with a disability touches or takes my things.	1	2	3	4	5	1	2	3	4	5
11. Not being able to do what I want to do without upsetting my brother or sister with a disability.	1	2	3	4	5	1	2	3	4	5

12. My brother or sister with a disability acts strange or does weird things.	1	2	3	4	5	1	2	3	4	5
13. Having to do things for my brother or sister with a disability.	1	2	3	4	5	1	2	3	4	5
14. My brother or sister with a disability doesn’t understand me.	1	2	3	4	5	1	2	3	4	5
15. We can’t do things other brothers and sister can do.	1	2	3	4	5	1	2	3	4	5
16. I feel guilty when I get upset about my brother or sister.	1	2	3	4	5	1	2	3	4	5
17. We can’t do things as a family.	1	2	3	4	5	1	2	3	4	5
18. We have to change our plans as a family because of my brother or sister with a disability.	1	2	3	4	5	1	2	3	4	5

19. There are arguments or fights in my family.	1	2	3	4	5	1	2	3	4	5
20. My parents won't let me do something because my brother or sister can't.	1	2	3	4	5	1	2	3	4	5
21. My parents tell me off for something, but don't tell my brother or sister with a disability off too.	1	2	3	4	5	1	2	3	4	5
22. My parents have to do things for my brother or sister with a disability.	1	2	3	4	5	1	2	3	4	5
23. My parents don't have time to talk or play with me.	1	2	3	4	5	1	2	3	4	5
24. People ask questions about my brother or sister's disability or illness.	1	2	3	4	5	1	2	3	4	5

25. People don't understand about my brother or sister's a disability or illness.	1	2	3	4	5	1	2	3	4	5
26. People look or stare at my brother or sister with a disability.	1	2	3	4	5	1	2	3	4	5
27. People ignore my brother or sister.	1	2	3	4	5	1	2	3	4	5
28. My brother or sister with a disability gets upset when we go out.	1	2	3	4	5	1	2	3	4	5
29. My brother or sister with a disability embarrasses me when I have friends over.	1	2	3	4	5	1	2	3	4	5
30. My brother or sister with a disability bothers me when I have friends over.	1	2	3	4	5	1	2	3	4	5

31. My friends don’t understand about my brother or sister’s disability or illness.	1 2 3 4 5	1 2 3 4 5
32. I have to talk to my friends about my brother or sister’s disability or illness.	1 2 3 4 5	1 2 3 4 5
33. My friends look or stare at my brother or sister.	1 2 3 4 5	1 2 3 4 5

Things that make you happy

There are good things that happen in our lives that make us happy. Below are some things that can make you feel happy. For each event, we would like to know:

1. How often does the good thing happen?
2. How happy does this make you feel?

This is how to fill it out:

	How often does this happen? **Never** **Sometimes** **Always**	**How happy does this make you feel?** **Not very happy** **A little bit happy** **Very happy**
I get time to do something I want to do.	1 2 [✓ 3] 4 5	1 2 3 [✓ 4] 5

	How often does this happen?					How bothered or upset does this make you feel?				
	Never		Sometimes		Always	Not happy		Sometimes		Very happy
1. I get something special.	1	2	3	4	5	1	2	3	4	5
2. I get time to do something I want to do.	1	2	3	4	5	1	2	3	4	5
3. My brother or sister with a disability learns something new.	1	2	3	4	5	1	2	3	4	5
4. My brother or sister with a disability tries hard at something.	1	2	3	4	5	1	2	3	4	5
5. Helping my brother or sister with a disability.	1	2	3	4	5	1	2	3	4	5
6. My brother or sister with a disability gives me hugs or kisses.	1	2	3	4	5	1	2	3	4	5
7. My brother or sister with a disability does funny things.	1	2	3	4	5	1	2	3	4	5
8. Spending time and playing together with my brother or sister with a disability.	1	2	3	4	5	1	2	3	4	5
9. Spending time together as a family.	1	2	3	4	5	1	2	3	4	5

10.	Going out somewhere together as a family.	1	2	3	4	5	1	2	3	4	5
11.	Doing something fun together as a family.	1	2	3	4	5	1	2	3	4	5
12.	My parents help me with something.	1	2	3	4	5	1	2	3	4	5
13.	Spending time with my parents by myself.	1	2	3	4	5	1	2	3	4	5
14.	Going out somewhere with my parents.	1	2	3	4	5	1	2	3	4	5
15.	Having a talk with mom or dad about things.	1	2	3	4	5	1	2	3	4	5
16.	When parents are in a good mood.	1	2	3	4	5	1	2	3	4	5
17.	People help my brother or sister with a disability.	1	2	3	4	5	1	2	3	4	5
18.	People show interest in my brother or sister with a disability.	1	2	3	4	5	1	2	3	4	5
19.	Having a friend over my house.	1	2	3	4	5	1	2	3	4	5
20.	My friends and I play with my brother or sister with a disability.	1	2	3	4	5	1	2	3	4	5

21.	I talk to my friends about my brother or sister with a disability.	1	2	3	4	5	1	2	3	4	5
22.	Spending time with friends doing something fun.	1	2	3	4	5	1	2	3	4	5
23.	When I meet other siblings who have a brother or sister with a disability.	1	2	3	4	5	1	2	3	4	5

Appendix E

Vita

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