

Resilience Levels in Siblings of Children with Developmental Disabilities

By

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*A Thesis
Submitted in Partial Fulfillment of
the Requirements for the Degree of*

Master of Science in Communication Sciences and Disorders

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2017

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This research was supported in part by the UW-River Falls Summer Scholar Program and the University of Minnesota Extension: Driven to Discover Program as well as the UW-River Falls Communication Sciences and Disorders Department.

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Abstract

Families and parents of children with disabilities have been identified as resilient, yet have shared many stressors and threats to that resilience. Limited data attempts to investigate resiliency levels in siblings of children with developmental disabilities, with no known research to date evaluating the relationship of resilience levels in siblings of children with developmental disabilities compared to that of typically developing siblings. *Purpose:* The purpose of this study was to compare resiliency and coping strategies between siblings of children with developmental disabilities and siblings of typically developing children. *Methods:* Subjects were recruited through a mass email and flyer distributed to all families within a community school district and a follow-up study was completed recruiting siblings of children with developmental disabilities at the Minnesota State Fair. Children 9-17 years of age were placed into two groups: 1.) siblings of typically developing children (n=42, mean age= 149.33 months) and 2.) siblings of children with developmental disabilities (n=44, mean age= 158.05 months). Each participant completed the *Resiliency Scales for Children and Adolescents: A Profile of Personal Strengths*. Resiliency areas were assessed by three subtests: sense of mastery, sense of relatedness and sense of emotional reactivity. *Results:* An analysis of variance found no statistically significant differences between groups across all subtests ($p < 0.05$). Scatter plots, box plot analyses and correlational data indicate that scores between both groups were similarly varied and showed trends between variables. This indicates that some aspects of resiliency are interrelated and appear to be similarly represented for siblings of children with developmental disabilities and siblings of typically developing children. *Conclusion:* This study was the first of its kind to analyze resilience levels in siblings of children with developmental disabilities.

Keywords: resilience, siblings, developmental disabilities

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Chapter 1: Literature Review

Resilience Theories and Previous Research

Although the term resilience is fairly new to the research realm, the concept of adaptation and coping amidst hardship has been a longstanding theory. Investigation into this field began with Charles Darwin in the 1800s. Charles Darwin's observations into how certain animals on the Galapagos Islands adapted to their environment through natural selection to promote survival is not only the foundation of biology today, but also laid the foundation for resilience. While he did not use the term resilience in his work, he alluded to its central constructs including adaptation in a series of adverse life events (van Wyhe, 2002). After the underpinnings of adaptation were established by Darwin, in the 1920s Sigmund Freud introduced the concepts of the id, ego, and superego placing emphasis on how aspects of the individual incorporates and adapts into society. According to Freud, the id relates to the "unconscious mind" and is in control of basic life functions such as breathing, hunger, and sexual desires. The ego then controls both conscious and unconscious thought and is the balance between the thoughts of the id, and socially acceptable behavior of the superego. The superego represents the opposite end of this spectrum, focusing more on what is acceptable and moral in society (McLeod, 2013). Freud's work contributed to what was known about adaptation at the time, elaborating on the work by Darwin, to be expanded to include human adaptation to balance basic human desires with what is socially acceptable. Resiliency today is largely centered on this by trying to master personal and social acceptance.

In 1938, B. F. Skinner made his contributions, adding fundamental concepts that carried over into resilience research today. Skinner's applications in behavioral psychology help to explain why humans adapt to behaviors in certain ways. He introduced the concepts of operants

such as reinforcers and punishers. By way of reinforcers and punishers, certain behaviors can either be promoted or diminished. As this applies to human behavior, the response of the environment helps individuals learn how to behave (McLeod, 2007). In resilience, much work has been done, and is still needed, to investigate what behaviors promote positive coping (reinforce) and those that lead to negative coping strategies or maladjustment. This work coupled with that of Freud and the following work by Erikson shed light on human behavior and adaptation and ultimately the investigation into resilience.

After Freud applied resilience to human nature, Erik Erikson furthered this idea in labeling stages of development, or personal adaptation, over the lifespan in the 1950s-1960s. What is especially interesting with Erikson's research is that he began to focus on how one can either respond negatively or positively to life experiences, either facilitating adaptation or maladaptation. Erikson established eight stages of psychosocial development, explaining how the needs of the individual begin to clash with needs in society across different stages of the lifespan. The eight stages are as follows (McLeod, 2008):

1.	Trust vs. Mistrust	Infancy	0-1 ½ years
2.	Autonomy vs. Shame	Early Childhood	1 1/2 – 3 years
3.	Initiative vs. Guilt	Play Age	3-5 years
4.	Industry vs. Inferiority	School Age	5-12 years
5.	Ego Identity vs. Role Confusion	Adolescence	12-18 years
6.	Intimacy vs. Isolation	Young Adulthood	18-40 years
7.	Generativity vs. Stagnation	Adulthood	40-65 years
8.	Ego Integrity vs. Despair	Maturity	65+ years

Table 1. Erikson's eight stages of development. Stages four and five are highlighted as these ages and stages are most pertinent to the present research.

In accordance with Erik Erikson's contributions, Masten, Burt, and Coatsworth (2006) stated that competence, a central concept involved in resilience, manifests itself when a person successfully meets "age-salient developmental tasks" (p. 704). This competence can be challenged when life experiences cause damage to any one, or a combination, of the individual, their relationships, and the surrounding environment which can compromise the ability to successfully adapt at these various stages. Of interest, stages four and five focus on meeting developmental tasks by either finding pride when successfully contributing, or feeling inferior when one cannot meet societal expectations. An individual also begins to assimilate into larger society and identify his/her individual self. When failures happen at these stages, Erikson explained this can lead to an unhealthy and poor self-concept (McLeod, 2008). Resilience is a matter of coping successfully at these various stages, to lend to a positive sense of the self, mastery of difficulties, and positive interpersonal relationships.

Of those who significantly contributed to the psychology world and impacted today's research on resilience and coping strategies in humans, Albert Bandura's research cannot be overlooked. Coming along in the 1960s-1970s, he elaborated on conclusions from B.F. Skinner saying that behavior is not shaped with operant conditioning and reinforcements, but rather humans also learn how to interact in society based on observations. This idea brought into account cognitive functioning as a part of social learning, creating his social learning/cognitive theory which explained that humans think about the connection between their actions and the resultant consequences. Resilience can be discussed not only in terms of behavioral learning, but also in terms of social learning/cognitive theory (McLeod, 2011). Another major contribution to the literature from Albert Bandura included his work on self-efficacy. Self-efficacy concerns individuals' beliefs of their own ability to deal with adverse situations, and plays a major role in

children's overall resilience. In Bandura's report "Self-Efficacy: A Theory on Behavioral Change," he explains that a person's expectations of his/her own self-efficacy fundamentally impacts his/her ability to initiate coping strategies and to maintain perseverance in coping amidst life's hardships. Self-efficacy then is a necessary component to foster positive adaptation. On the contrary, Bandura stated that those who stop coping early on during a time of hardship, are likely to develop "self-debilitating expectations and fears for a long time" (Bandura, 1977, p. 194).

Throughout this literature review, concepts related to resilience and its central constructs will be discussed at large. The general theory of mind is that competence and psychopathology are the criteria for adaptation, and positive adaptation promotes resilience (Masten, Burt, & Coatsworth, 2006). Resilience is the "process and patterns of positive adaptation in development during or following severe threats to adaptation" as defined by resilience specialists Masten, Burt, and Coatsworth (2006, p. 696). Severe threats to adaptation can take a variety of forms including child maltreatment, family problems, disabilities, socioeconomic hardship, violence, and general stressful situations. What is particularly pertinent to the study of resilience is that while these threats to adaptation should produce negative effects, in resilient individuals positive adjustment and success is found. Luthar (2006) explained this idea when she stated that the nature of the word resilience implies "atypical processes that usually lead to maladjustment" (p. 739). It should come as no surprise that when a threat to adaptation is introduced, it can be considered an atypical process as it interrupts the typical lifestyle of the individual or family, and ultimately would lead to poor outcomes. The following studies provide explanations and insights into the impact certain atypical processes have had on familial and individual adjustment and competence.

Of importance for understanding reports of the following resilience studies, one must not only understand what makes resilience (perseverance in spite of negative life experiences) but also how resilience is objectively measured. As discussed previously, adaptation is a sign of resilience and promotes positive coping in the face of adversity. In humans, adaptation can take the forms of social competence, meeting developmental milestones (such as in Erikson's stages of development), good academic performance, and positive relationships. (Luthar, 2006). The sibling resiliency study in particular will focus on mastery of goals (meeting milestones), relatedness (positive relationships), and emotional reactivity as a way to objectively measure adaptation and resilience.

When measuring resilience then, one could picture an equation in which the impact of severe threats to adaptation are quantitatively subtracted from the amount of positive supports equating to either a positive, bonadjustment situation or a negative, maladjustment outcome. Masten (2006) explained that human systems need to be in good working order to thrive even in the face of adversity; if those systems are impaired somewhere along the process of development, then the risk is increased especially if the adversity lasts for a prolonged period of time. Bearing this in mind, Masten (2001) clarified that while resilient individuals used to be referred to as having "extraordinary strength," resilience is truly an "ordinary phenomenon" (p. 227). The mere ordinariness of resilience demonstrates the necessity of research in this area as it is not the few superhuman that this research calls upon, but rather the input of the ordinary man.

Given the groundwork from previous theorists such as Darwin, Freud, Erikson, and Bandura, research in adaptation and resilience began to emerge. Norman Garmezy was noted for further delving into human adaptation in the presence of severe threats. In 1974, he studied parents with schizophrenia and found that some children coped extremely well despite their high

risk for psychopathology (Garmezy, 1974 as cited in Luthar, 2006). His findings then became the solid foundation upon which other research was built. For example, E. James Anthony in 1978 published a book titled *The Invulnerable Child* in which he investigated children of individuals with schizophrenia and found that some children did not succumb to the psychopathology and rather remained compassionate toward their parent. Originally, Anthony termed these children ‘invulnerable’ (Anthony, 1974, as cited in Luthar, 2006). As research progressed, this term did not fit the criteria that resilience is ever changing and an adaptation process throughout one’s lifetime; and was further supported when Masten (2001) and colleagues stated that resilience is rather an ordinary phenomenon as compared to a superhuman strength. Luthar (2006) detailed that the term “invulnerables” suggested a permanent condition; however, the term resilience encompassed the idea that this process is changing and adapting over time (2006).

As developmental psychopathology and resilience research progressed, the researchers began to branch out to investigate in-depth relationships. Here, the focus shifted from defining resilience to identify what role resilience plays in a certain population. To date, resilience has been investigated in families, parents, and children with severe threats (usually presenting as some type of disability). Most relationships to follow are analyzed by evaluating the effects a severe threat (such as schizophrenia) and surrounding supports (such as community help) have on the individual’s and family’s ability to cope and adjust.

Resilience in families. Luthar (2006) reported, parental and caregiver support plays one of the most prominent roles in fostering resilience, especially from a young age. When investigating resilience in family units, the researchers’ main goal was to identify the resources and strategies a family uses to cope with a severe threat and respond in a positive way. Given the two criteria for resilience, a severe threat and a positive support, Greeff, Vansteenwegen, and

Gillard (2012) identified a severe threat to typical development and lifestyle as having a child with a physical disability. Their goal was to quantify information from these families in order to identify 1.) if the family is considered resilient and 2.) if found resilient, what resources and supports helped them to cope so well. Sixty-eight parents and sixty-two children participated in the study. Families qualified for the study if they had a child who was at least 12 years of age, fluent in Dutch, and had a physical limitation such as a cognitive disease, acquired illness, or trauma. Qualifying families were asked to complete a series of five questionnaires to help put an objective number to subjective statements used to discuss resilience. The researchers identified many variables that may impact the results of family adaptation including feeling of control, family commitment, internal and external family resources, and social support. On most scales, low scores indicated that the family was “vulnerable” and at risk for maladjustment. It is important to note that these researchers correlated many of their findings with the McCubbins and McCubbins Model of Family Stress, Adjustment, and Adaptation (McCubbins and McCubbins, 1993) to indicate that the greater the level of adaptation, the greater the family resilience. This model will be discussed at length in the following pages.

Greeff, Vansteenwegen, and Gillard (2012) found that while the family unit as a whole could be termed resilient, the factors affecting that resilience differed between the parent and children within the family unit. Parents found spiritual support, social support, control, and family commitment to be the main components to positive adaptation. Children labeled mobilization of the family, social supports (of family and friends), a passive evaluation of the situation, and family commitment to be the major components to resilient youth. Interestingly, there were also weak to moderately positive correlations identified between a family’s sense of coherence score and the education level of the parent for both the parents ($n=68$, $r=.41$, $p<.001$)

and the children ($n=62$, $r=.24$, $p<.05$). A weak to moderately positive correlation existed for parents ($n=68$) between the family sense of coherence score and family income ($r=.28$, $p<.001$). The authors concluded that family coherence increases as a parent's educational level increases, implying that people with a higher education have more money and more access to resources to promote coping strategies; but overall a strong, committed family is a solid foundation to promote resiliency skills and strategies.

Another factor that has been found to impact family resilience is genetic disorders. Hall, Neely-Barnes, Graff, Krcek, Roberts, and Hankins (2012) led an investigation into the parental stress factors of families of children with genetic disorders. The researchers provided sound reasoning for why they termed a genetic disorder as a stressor in this research design. They explained, "any demand that creates system changes within a family, or has the possibility of creating these changes, is a stressor" (p. 26). Further, changes as such can affect relationships between parents, between parents and children, and between siblings. Hall et al. chose to focus on stress related factors because previous research findings support the conclusion that parents of children with disabilities have shown a higher tendency for stress.

Hall et al.'s (2012) research study was based on the Resiliency Model of Family Stress, Adjustment, and Adaptation developed by Hamilton McCubbin and Marilyn McCubbin in 1993. This model incorporates a variety of factors that promote either bonadjustment or maladjustment in families facing adversity. More specifically, Hall et al. (2012), touched on major concepts from this model including vulnerability, family type, family resources, appraisal of the stressor, family problem solving and coping skills, and the result of either bonadaptation or maladaptation. Appendix A explains how the interplay of the above concepts differs between families of stressed parents and families of non-stressed parents. In this case, the stressor is

considered the genetic diagnosis and can be one of four conditions: autism spectrum disorder (ASD), cerebral palsy (CP), Down syndrome (DS), and Sickle Cell Disease (SCD).

Twenty-five parents of children with genetic disorders were included in this study. These participants were recruited as part of a larger study conducted previously, which indicated that parental stress was a serious threat to coping. Parents completed the *Parenting Stress Index-Short Form (PSI-SF)* (Abidin, 1995) and a demographic form as part of this study. The *PSI-SF* includes 36 questions organized into three subscales set to investigate parental distress, parent-child dysfunction, and difficult child. Upon completion of the *PSI-SF*, parents were categorized into two groups based on their scores: stressed and non-stressed.

The results concluded there were no statistically significant differences in parental stress across groups based on genetic diagnoses. When analyzing individual results, investigators noted some “red flags” concerning vocabulary and phrasing used by the stressed parents as compared to those labeled non-stressed. As an overarching theme, the stressed parents felt that they were ostracized by the community and lacked support (Hall et al., 2012). For those labeled non-stressed, common themes were discussing benefits of the siblings, strengths of the child with a disability, and positive outlooks for the future.

A particularly interesting component of this research included interviews with the parents, extrapolating key themes from these interviews. In examining vulnerability, no signs were noted for the non-stressed group, while ostracism was observed from the stressed group. Across both groups, siblings were identified as keys to a cohesive family type. One parent explained, “You teach the sibling how to help so they can participate and won’t feel left out. And that way you will all be in it together” (Hall et al., 2012, p. 34). When looking at appraisal of the stressor (diagnosis) one non-stressed parent viewed not meeting developmental milestones [as

quickly] as a positive because it gave her the time to appreciate it when it happened. Parents in the stressed category however viewed this as a negative with surmounting frustration. When discussing the siblings, non-stressed parents noted benefits despite the challenges, and the ability of the sibling to “defend” the child with a disability (p. 35). Resources were another key area discussed and included support and communication. Stressed profile parents felt a lack of support and “negativity of other people toward their children” whereas non-stressed profile parents felt open communication and mixed support (p. 36).

These findings fit well with the McCubbin & McCubbins’ 1993 Resiliency Model of Family Stress, Adjustment, and Adaptation. The key points discussed above were all categorized into a progressing flow chart (Appendix A) that led to either bonadaptation or maladaptation. This research helps to visually and conceptually grasp those factors and resources that can pave the way for a resilient or non-resilient response to a stressor. Based on the qualitative responses and *PSI-SF* scores, stress does not appear to relate to diagnosis as no relationships were identified between the *PSI-SF* scores and the diagnosis of the child. Leading in to the present research study, these authors helped to categorize some key concepts for siblings of children with developmental disabilities in pinpointing that stress may be a contributing factor. However, there remains a necessity to compare the views of the parents of the siblings with the actual thoughts, feelings, and actions of siblings of children with developmental disabilities.

With the emergence of positive psychology and the change in thought from a deficit focused approach to a strengths based approach, Froma Walsh found fault in the idea that families had historically been evaluated based on their contribution to risks, and not constructively to resilience. With this missing link, Walsh began investigating further into family resilience, identifying those factors that helped a family to become “strengthened and more

resourceful” amidst life’s adversities. Over time, she categorized her findings/factors into nine key concepts of resilience that fit under three larger domains. The three domains were identified as “belief systems, structure/organization, and communication processes” (2011, p. 153-155). Some of the nine key concepts of resilience identified by Walsh are discussed in the following paragraph and one will find connections between this theoretical framework and that previously discussed by McCubbin & McCubbin (1993).

Under the first domain, belief systems, Walsh (2011) found common resilience concepts to include making meaning of adversity, stimulating a positive outlook, and spirituality. These ideas involved the family viewing the crisis situation in a positive light, finding hope, and promoting a “can do spirit” (p. 154). This domain in particular shows overlap of common themes between Walsh’s framework and that previously discussed (McCubbin and McCubbin, 1993), elaborating on the importance of some of these features in the resilience process at large. The second domain investigated was family structure and organization. This included concepts such as families being flexible, connected, and using their social and economic resources. Many of these features are self-explanatory in that a family needs to be willing to change and adapt to the surrounding circumstances, using what is available to them. Communication and problem solving is the third domain and it involved concepts including “clarity, open emotional expression, and collaborative problem solving” (p. 154). Walsh’s themes in family resilience helped give researchers a basis for what tools and resources are used for families who are found to be resilient. In identifying these themes, Walsh also established that resilience in families is developmental in nature; it is a process that changes over time. She explained that some families may have a multitude of stressors occur at one time, or stressors may affect families differently based on their previous experiences. Much like Erik Erikson and his developmental stages,

family resilience also goes through a developmental process that will ebb and flow based not only on the current situation, but past and future situations as well.

Based on Walsh's research findings, Bayat (2007) researched families of children with autism, claiming to be the first of its kind to investigate resilience in families of children with a disability. In doing so, he changed the frame of reference from investigating what was not working, to investigating that which is helping these families to work so well despite adversity. This correlated with Froma Walsh's idea of using a strengths based approach. Bayat recruited 175 parents and caregiver participants who had a child between 2-18 years of age and was diagnosed with autism. An autism diagnosis could include autism spectrum disorder, Asperger's syndrome, and pervasive developmental disorder (PDD). Bayat (2007) distributed 3 open-ended questions to participating parents and caregivers asking them to describe the following: "positive and/or negative effects of autism on the family, positive and/or negative effects of autism on the personal life, and to describe the child" (p. 706). With the results, the primary researcher and a graduate student coded the responses and identified trends and common themes among them.

The first conclusion found no relationship between income or racial background and the perceptions of family members on their child with autism. This is particularly interesting as Greef, Vansteenwegen, and Gillard (2012) did find a connection between family SES and the resources necessitated to promote resilience. Secondary to this finding, research by Bayat (2007) collectively organized responses into four groups based on the primary tone in their response: either positive, negative, neither positive nor negative, or both positive and negative. Overall, results showed that more parent and caregivers found autism to have a positive influence (39%) rather than negative influence (21%) on their personal life, but more participants found autism to have a negative impact (30%) rather than positive impact (28%) on the family. While the

researcher did not go into much detail as to why this might be, he did follow up his study with identifying trends in the results that produced these numbers. [The following trends that are discussed at length are only those that coincided with Walsh's 2011 study, for more information refer to Bayat, 2007].

The four emergent themes identified by Bayat (2007) that fit within Walsh's (2011) family resilience framework include: 62% of people identifying pulling resources together/being connected, 63% referenced making meaning out of adversity and a change of worldview, 39% discussed an affirmation of strength, and 45% referenced the importance of a spiritual belief system. For example, one participant referenced bringing siblings closer together as a part of their pulling resources together/being connected. Another participant, when discussing making meaning of adversity and a changed world view, referenced their child with autism as "their teacher" (p. 710). It is particularly interesting to see these points made by parents and caregivers, and to keep them in mind when interpreting the opinions of siblings.

When reviewing the results as a comprehensive unit, Bayat concluded that there was a more positive tone amongst the responses. The general consensus was that individuals felt that they had changed for the better upon having a child with autism, while the impact on the family produced mixed responses. His results helped to show that while families can be viewed as resilient, as many shared common themes discussed by Walsh, overall opinions and insights vary across families as seen in the variety of positive and negative perceptions of the family and on the personal life. These results also help to provide some insight into how parents view the relationship between their child with a disability and other siblings. However, parent assumptions are all that current resiliency research has to investigate when examining the resilience found in siblings of children with developmental disabilities.

A final family resilience study that provides insight into the direction of the current research is a study by Taunt and Hastings (2002) investigating the impact of raising a child with a developmental disability on the family life. The theoretical underpinnings to their research, regarding resilience in families of children with disabilities, centered on the parents creating general positive trends. The author attempted to widen the research base, reaching extended family and siblings. The research protocol involved two samples; one consisting of 14 parents and 2 siblings with at least one other child in the family and primary diagnoses of Down syndrome, autism, and mental retardation. The second sample had 33 parents whom had at least one child diagnosed with a developmental disorder such as cerebral palsy and Down syndrome as well as those less common such as Cri du Chat syndrome, and more than one child in the home. Sample one completed an interview based questionnaire and sample two completed open ended questions via mail-in survey. The questions asked in both samples targeted any positive effects noted on behalf of the siblings or other extended family member. In this research protocol, the phrasing of the questions favored a positive interpretation, thus was biased toward the positives when drawing conclusions. The parents identified major themes and categories in which their child with a disability positively impacted their family. For the purposes of this review, detail will not be given to the overall parental perceptions as the themes identified coincided with findings of previous research including a change in world view and opportunities to grow. Overall, parental perceptions were found to be mostly positive, as was suspected.

A unique aspect of this study was insight into the extended family and the siblings. In general, Taunt and Hastings (2002) concluded that “positive effects on siblings and the extended family were reported to a lesser extent by parents” (p. 414). Important here is that while this information is relevant to the current study, again parental perceptions of the siblings and

extended family are used to report, and not the actual perceptions of the siblings and extended family members themselves. For this reason, the authors suggest interpreting the data with caution. Parents found that siblings and extended family members had increased sensitivity, changed perspective on life, and opportunities to learn. Specifically in discussing the siblings, 50% of parents from sample one noted a positive affect (this theme was not identified for sample 2 specifically). In sample 2, common themes for siblings included a greater sense of responsibility and sticking up for other children with disabilities.

While this research is influential, 50% of the parents labeling their children as having been positively impacted in having a sibling with a disability does raise some questions as to the actual impact it has on other children in the family. Taunt and Hastings (2002) stated, “one problem of contamination is that the parents’ perceptions of positive impact of a child with a disability on siblings are likely to be biased by positive effects they see for themselves” (p. 414). While this research did show general positive trends for families, siblings, and other extended family members, there remained some limitations to the study such as the generalizability of the findings to the target population, the siblings themselves. Yet, there is some ambiguity surrounding the interpretation of sibling results as the siblings’ effects were found to be positive, yet less positive than that of the parents whom were reporting the results. This research then sets the tone for future work to elaborate upon their findings, and ultimately limitations, to broaden the resilience knowledge base.

The missing link. Existing research regarding sibling relationships shows that “older siblings’ competent behaviors at school were linked with increases in younger siblings’ competence over time” (Luthar, 2006, p. 757). The siblings relationship in and of itself, while part of the family system, is a unique bond. While the sibling dynamic can differ based on

familial circumstances, research does support that siblings do have a symbiotic relationship. Researchers have thus begun to investigate this relationship, and the extent to which siblings mutually benefit from one another in their relationship. As one example, Zeltzer, Dolgin, Sabler, Roghmann, and others (1996) investigated sibling adaptation to childhood cancer. The premise of their research stated that siblings were an “otherwise neglected group” from previous studies, and therefore no information has been gathered regarding the siblings’ health status while working through the financial stress, coping, and well-being of having a child with a chronic illness.

Two hundred and seventy nine siblings from seven different pediatric oncology centers across the nation were recruited for this study. Inclusionary criteria included having a living brother or sister diagnosed with cancer 4-42 months prior to the beginning of the study, the sibling between the ages of 4-18 years, and must have been fluent in English. In order to minimize confounding variables, a match to sample was performed to create a control group equal on many accounts. All participants (both the siblings and their parents) then completed a variety of assessments: *Sibling Symptomatic Checklis* (Zeltzer et al., 1996), *Child Behavior Checklist (CBCL)* (Achenbach & Edelbrock, 1983), *Youth-Self Report* (Achenbach & Edelbrock, 1987), personal interviews, and physician observations. The aims of the researchers were to identify if siblings (of children with childhood cancer) differed from the control group on health status, healthcare use, physical symptoms, and health risk behaviors. For the purpose of this review, it is not possible to go into detail with every finding, so a general overview will be provided. Siblings were found to have higher somatization scores on the sibling symptomatic checklist when compared to nonclinical norms. This included statistically significant findings that siblings reported stomachaches, hurt all over, stiff necks, appetite losses, and pains in chest

for which their parents were less likely to bring them to a physician ($p < .001$) (Zeltzer et al, 1996).

Further, while parents and siblings themselves rated the general health of the siblings to be relatively good as identified by a moderately positive correlation ($r = .35$, $p < .001$) parents rated the total number and intensity of symptoms much lower compared to that of sibling self-ratings. When evaluating siblings' somatic scores, "higher levels of sibling reported somatic symptoms associated with higher levels of sibling adjustment difficulties" (Zeltzer et al., 1996, p. 101). The authors also found that there were no differences in symptomatic scores across disability types, similar to findings by Hall et al. (2012). Finally, one unique facet of this research design investigated sibling health status across adaptation reports. Parents and teachers reported on the siblings' behaviors since the cancer diagnosis, identifying three different groups: resilient ($n = 77$), intermediate ($n = 110$), and dysfunctional ($n = 51$). Conclusions determined that adaptation groups differed on symptomatology, meaning that children in the dysfunctional group had higher reports on symptomatic checklists based on parent and self-reports. In general, regardless of adaptation groups, "adolescent male and female self-reports matched the scores of age and gender matched children referred to mental health facilities because of psychiatric problems" (Zeltzer, 1996, p. 104). The research performed brought attention to the "otherwise neglected group" of siblings of children with disabilities drawing the main conclusion that there is a correlation between siblings affect and symptomization. While provided with detailed research and telling results, readers are left to question what that means for these siblings when the focus of care is often on the child with the disability/diagnosis.

Van Riper (2000) is another author who contributed a great deal to what is known in sibling research thus far. She investigated family variables in siblings of children with Down

syndrome. One aspect that is particularly familiar about Van Riper's research is the framework used, McCubbins and McCubbins (1993) Resiliency Model for Family Stress, Adjustment, and Adaptation (Appendix A). Van Riper (2000) stressed the need for her research within this context by stating that what is known about families of children with Down syndrome is like a puzzle, and the information regarding the siblings is currently a missing piece.

Past research has shown a general increase in the research regarding children without disabilities in a family, particularly emphasizing the negative effects and difficulties they experience, with relatively little information existing to explain any positive outcomes. For this reason, Van Riper set out to investigate how family demands, family resources, family problem-solving communication, and family coping imposes upon sibling well-being. The overarching goal was to investigate family adaptation, more specifically, "outcome of family efforts to bring a level of balance, harmony, coherence, and functioning to a stressful situation" (Van Riper, 2000, p. 269). What makes this research notable compared to that done previously in the late 1970s, 1980s, and 1990s is the attempt at finding positive facets, a strengths based approach as brought about by Froma Walsh (2011). A strengths based approach gives particular emphasis to bonadaptation, or achieving a sense of balance and coherence as compared to situations where maladaptation (no balance and coherence) has occurred.

In her research, Van Riper (2000) recruited 41 families of children with Down syndrome via support groups, mailing lists, and referrals. Both the mother and a sibling were asked to complete a questionnaire, with a majority of participating siblings being older (n=30). A variety of assessments were completed by the participants, all of which were approved by the authors of the guiding framework. For the purposes of this review, conclusions discussed will highlight that which directly applied to the siblings' well-being. The siblings completed the *Piers-Harris*

Children's Self-Concept Scale (Piers & Harris, 1986) to assess how they felt about themselves while the mothers completed the *Child Behavior Checklist* (Achenbach & Edelbrock, 1983) to assess the parental perceptions of the siblings' behaviors and social competency. These two assessments then allowed the researchers to not only independently identify siblings' and parents' feelings, but also allowed the researchers to compare the two ratings.

Results showed that on the *Piers-Harris* the siblings in general showed an overall favorable self-concept, as seen by their scores compared to norms. Above average self-concept scores are considered to be 60 or higher, and siblings scored an average of 60.58 (SD =8.53). Despite this, five siblings did score in a clinical range for social competence and behaviors. When applied to the family variables discussed above, significant conclusions were drawn. There existed a moderately positive correlation between family demands and behavior problems ($r = .43, p < .05$); that as more demands were placed upon the family, siblings' behavior problems were noted to increase as well. Family demands were also found to be significantly negatively correlated with social competence ($r = -.34, p < .05$) and self-concept of the siblings ($r = -.35, p < .05$); while having family resources were found to be positively associated with increases in social competence ($r = .47, p < .01$) and self-concept ($r = .34, p < .05$). Finally, Van Riper concluded that there were significant positive associations between family coping and social competence ($r = .39, p < .05$) and between problem-solving communication and social competence ($r = .50, p < .01$). Researchers can then draw from these findings what makes a sibling particularly able to adapt well to his/her environment: resources, problem-solving skills, and coping skills. Furthermore, finding ways to decrease the demands on the family will help to promote positive social competence and self-concept amongst other siblings within a family.

However, when interpreting results Van Riper (2000) stressed the “multidirectional and complex” nature of the findings (p. 281). She concluded that siblings who were found to have higher self-concepts and fewer behavioral problems likely decreased the family demands and inherently helped to increase family resources. This in turn likely promotes positive communication and social competence. In general, the variables in this study were interrelated and affected conclusions that were drawn, which limited applicability. Van Riper (2000) did apply her findings to the clinical setting, stating interventions should also focus on the siblings, particularly checking in to see what types of activities they are involved in, their performance in school, and any behavior problems. In doing so, she referenced one particularly interesting source of information, The Sibling Support Project developed by Donald Meyer, whose input is discussed as follows.

The Sibling Support Project focuses on developing a community for siblings of children with special health, developmental, and mental health needs through sibshops, online supports, books, and workshops based out of Seattle, Washington. One of their contributions, the “What Siblings Would Like Parents and Service Providers to Know” was developed to give insight into these siblings’ lives and minds. For example, the premise of this study says that:

Brothers and sisters share many of the concerns of the parents of children with special needs including isolation, a need for information, guilt, concerns about the future, and caregiving demands. Brothers and sisters also face issues that are uniquely theirs including resentment, peer issues, embarrassment, and pressures to achieve. (Meyer, p. 1)

In producing their narrative, Don Meyer and colleagues allowed others to see what it is that siblings wish others knew about their lives with a sibling with special needs. The following are three examples identified by siblings in the SibShop Program.

In regards to expectations for typically developing siblings, some can set “unrealistically high expectations for themselves” in an attempt to help out the family (as in family demands discussed above) (p.1). This can put a lot of pressure on the siblings in both their personal and academic lives. Another issue identified by siblings was having more opportunities to meet peers in similar situations. The authors related it to the parents in that, “for most parents, the thought of ‘going it alone’ [...] is almost unthinkable. Yet this routinely happens to brothers and sisters” (p. 2) It was this premise that helped to support much of the research done by the sibshops as it provides a network for other siblings of children with disabilities. A final theme identified that interrelates strongly with previous research discussed herein is parent perceptions and their impact on the siblings. “Parents’ interpretation of their child’s disability will be a greater influence on the adaptation of the sibling than the actual disability itself” (Meyer, p. 3) Parents need to be using their resources, supports, and coping mechanisms to provide a positive environment for not only the child with the disability, but to also build a positive mindset for the siblings as well. General conclusions from insight gathered directly from the siblings show that while there are positive attributes, the siblings themselves struggle with many issues that relate to the family, and that are innately theirs. Yet despite this, there remains minimal assistance set up uniquely for their needs.

The general consensus gained from previous knowledge regarding resilience indicates that competency and psychopathology influence one another throughout the process of development, but exactly how they relate to one another has yet to be detailed (Masten, Burt, Coatsworth, 2006). Based on previous trends, research into the family resilience framework has exploded since the 1970s, investigating familial, child, and some sibling resilience. However, as evidenced by the plethora of research and knowledge in existence regarding family resilience,

the lack of information to explain how siblings cope in the face of disability is astounding. Much research claims to investigate the family system as a whole, but will use data reflective of parental input alone or parental perceptions of the siblings themselves. As seen from work by Zeltzer et al.(1996), parental perceptions tend to not be as accurate as those coming from the siblings themselves, leaving out key details that can affect the child's well-being. Further, much of what does exist is deficit focused, in the sense that the research has previously focused on what is lacking or what inhibits siblings, as opposed to what they have gained from having a sibling with a disability. In fact, from the work provided by Masten, Burt, and Coatsworth(2006), there remains a need for "intervention to focus on positive goals and competence achievement in siblings" (p. 726).

Studies to date have shown evidence that based on the resilience model by McCubbins and McCubbins (1993), changes within a family system can either positively or negatively affect the family subsystem as a whole. In doing so, this does not excuse the siblings from experiencing challenges and looking for sources of support to enable them to respond successfully amidst a change in life circumstances. Even more so, Hall et al. (2012) specifically detailed how a change in the family system can directly impact the sibling bond, which Van Riper (2000) explained to be such a strong, unique bond apart from that of the parents. This research along with the conclusion that non-stressed parents saw one of the largest benefits of having a child with a disability as the positive benefit to the sibling, there immediately became a drastic need to further investigate the relationship between siblings. Yet, when attempting to find this research, it remains a missing link between what is known about the family system and what has been assumed about the sibling bond. The following research attempts to lessen the gap between what is known about family resilience, and the lack thereof in sibling resilience and adaptation.

Purpose and Significance of this Research

The purpose of this research was to gather preliminary data investigating resilience levels in siblings of children with developmental disabilities as compared to their counterpart, siblings of typically developing children. No known research to date exists investigating the relationship of resilience levels in this particular population. A preliminary investigation was designed to conduct simple comparisons between the two groups. Based on these findings, a continuation of the study was conducted that further investigated the relationships within the resilience category, by way of expanding the sample size. With no known research conducted prior to this study, hypotheses generated were aimed at identifying if there is a difference in resilience levels between these two groups, as well as further analysis of resilience in siblings of children with developmental disabilities focusing on areas of deficit, areas of strength, and possibilities for future intervention.

Chapter 2: Methods

A between groups comparison research design was used to investigate the resilience levels in siblings of children with developmental disabilities as compared to typically developing siblings. This research involved two phases of study, the second phase a continuation of the first.

Phase 1

The goal of phase one was to gather preliminary data regarding the resilience levels of siblings. The sample population in this study included 29 participants from a local school district. Participants were recruited through residential schools, with approval from the Institutional Review Board and district superintendent.

Screening and Eligibility.

A flyer was sent home with children at school that explained the goal of the research, the inclusionary criteria, and a brief reason for the investigation. Twenty-nine parents responded with interest in having their child participate in the study, and completed a screening form to determine eligibility by way of the inclusionary criteria. Inclusionary criteria included: male and female children between the ages of nine to seventeen years and having at least one sibling. All 29 families qualified for participation, and were placed into one of two groups: 1.) siblings of typically developing children ($n=21$, mean age 138.86 months) and 2.) siblings of children with developmental disabilities ($n=8$, mean age 150.00 months). To identify group placement, parents were asked if any/one of their child/ren has/have an Individualized Education Plan (IEP) or Individualized Family Service Plan (IFSP) through the school district. It is important to note that the participating child, without an IEP or IFSP, was required to be between the ages of nine and seventeen years, whereas the sibling with a developmental disability (as identified by having an IEP or IFSP) could be of any age. Participating parents were also asked to identify the primary

services the child received: physical therapy (PT), occupational therapy (OT), speech therapy (SLP) or other services. Upon qualifying for the study, families were then sent an envelope package containing the parental consent form, instructions, the survey form, and a self-addressed, stamped envelope with which to mail back completed materials to the principal investigators. Participating children were instructed to complete the survey at home at their leisure and parents were encouraged to allow their child to complete the survey independently, to the best of his/her ability.

Phase Two

The aim in phase two was to increase the sample size and add power to the study. An a-priori power analysis was conducted, yielding a result of 80 participants necessary to determine a large effect size. This project was accepted by the University of Minnesota's Driven to Discover program and approved by the University of Minnesota's Institutional Review Board. The Driven to Discover program provides space and marketability for approved researchers to recruit participants and collect data at the Minnesota State Fair.

Screening and Eligibility.

Due to the imbalance in the sample size between groups during phase one, in phase two once an n of at least 40 was reached with group 1 (in total with phase 1), only siblings of children with developmental disabilities were recruited for group 2. For this reason, there is a smaller sample size for group 1 ($n= 21$, mean age=159.81 months) as compared to group 2 ($n=36$, mean age=159.83 months) The same inclusionary criteria and parental consent form were used in phase two (Appendix B). In this phase, more demographic information was obtained. Participating parents completed an intake form asking their child's primary diagnosis, severity of the disability (mild, moderate, severe), and if the parent felt the sibling would benefit from a

sibling support program (Appendix C). Fifty-seven participating siblings completed the survey at the state fair, at a separate desk, and also completed three brief questions regarding any interest he/she would have in a sibling support program. Participants who completed the survey were given a University of Minnesota drawstring backpack for participating.

<i>Phase 1</i>	Sample Size	Mean Age	Female	Male
Group 1	n=21	138.86 months	13	8
Group 2	n=8	150.00 months	3	5
<i>Phase 2</i>				
Group 1	n=21	159.81 months	8	13
Group 2	n=36	159.83 months	17	19
<i>Total</i>				
Group 1	n=42	149.33 months	21	21
Group 2	n=44	158.05 months	20	24

Table 2. Demographic data for the two phases of the study, including a comprehensive total across both phases. Note that the age is listed in months corresponding to data in the RSCA manual.

It is important to note that the total number of participants between the two groups is listed as n=86. However, when reviewing the data during analyses, four participants were excluded due to the participants him/herself having a disability. These scores could not be counted towards the overall statistical analyses as too many confounding variables would be introduced, and there was not a large enough sample size to create a third group. All four participants were removed from group 2.

Instrumentation

The Resiliency Scales for Children & Adolescents (RSCA): A Profile of Personal Strengths (Prince-Embury, 2007) was used to assess resilience levels. The scale is designed as a “brief, user friendly preventive screening tool to assess personal attributes in adolescent populations before the emergence of psychopathology” (Prince-Embury, 2008, p. 42 and 2011, p. 672-673). Specifically, it has a sound basis on numerous theoretical constructs discussed previously and its creator, Sandra Prince-Embury (2011), states it provides a “practical link to intervention” (p. 672). For example, in a sample of 100 male and female children between the ages of 9-14 years who completed this inventory, the following results were found. For males, positive correlations were found between emotional reactivity scores and bullying. For females, low personal resources were found to be positively correlated with bullying, as well. The RSCA includes assessment of three subtests targeting different areas of resilience: 1.) sense of mastery, 2.) sense of relatedness, and 3.) sense of emotional reactivity. Each subtest contains approximately 25 items based on a Likert scale, with a 0 indicating “Never” and a 4 indicating “Almost Always.”

The three subtests examine, “threats to human development, those that jeopardize adaptation process systems including brain development, caregiver-child relationships, regulation of emotion and behaviors, and motivation for learning and engaging in the environment” (Masten, 2001, p. 234). The sense of mastery subtest was designed to assess one’s self-perceptions and view of the world, evaluating the motivation for learning and engagement explained above. An example question includes, “I can make good things happen.” The sense of relatedness subscale looked at how one valued relationships with others and asked items such as,

“I can depend on people to treat me fairly.” On the sense of mastery and sense of relatedness subtests, higher scores were indicative of higher resilience.

The final subtest, emotional reactivity, evaluated one’s ability to “regulate” his/her emotions, asking questions such as “It is easy for me to get upset.” Emotional reactivity was inversely related with resilience, in the sense that a lower score on the subscale indicated higher resilience. In previous studies, these subtests have been found to have correlations with frequency of “substance abuse, sexual behavior, self-harm ideation, and sensation seeking;” in which scores on the sense of mastery and sense of relatedness subscales were negatively correlated while scores on the sense of emotional reactivity were positively correlated with said maladaptive coping behaviors (Prince-Embury, 2011, p. 678). The *RSCA* subscales have been found to have high reliability: sense of mastery ($\alpha = .85$), sense of relatedness, ($\alpha = .89$) and emotional reactivity ($\alpha = .90$) and have been proven to be an effective tool for measuring resilience (Prince-Embury, 2007).

Demographic Information

The parent intake form was used to gather demographic information regarding the participating children, and it is depicted in figure 1 below. The pie chart represents the various types of disabilities categorized in group 2, with an $n=36$. The sample size used to create this pie chart is equal to the sample size for group 2, phase 2, because these data were not obtained from group 2 participants in phase 1 of this study. Investigators did note some difficulty with quantifying the results of this qualitative question (the disability type question was an open-ended response), as some parents put more than one response. In this case, investigators used the disability that most likely represented the primary diagnosis.

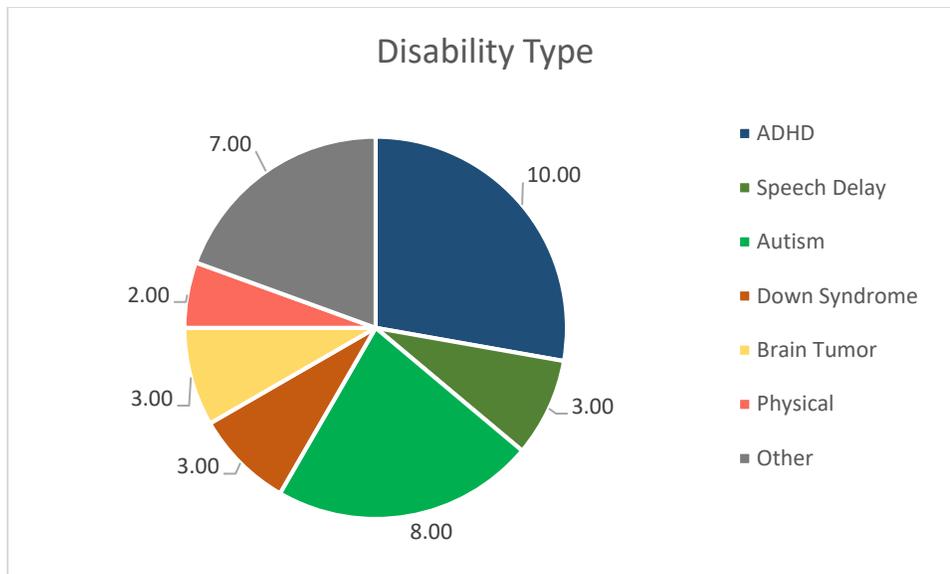


Figure 1. Variability in disability type across participants in the phase 2, group 2 study (n=36).

Hypotheses

Due to this investigation gathering preliminary data, little information was available to derive directional hypotheses. H_0 stated that there would exist no statistically significant differences on *RSCA* scores between groups on the three resilience subscales for siblings of children with developmental disabilities and typically developing children. H_1 stated that there would exist a statistically significant difference on *RSCA* scores between groups on subscale measures for siblings of children with developmental disabilities and typically developing children.

Outcome Measures

Both phases' sets of data were analyzed using the Statistical Package for the Social Sciences (SPSS). Descriptive statistics were calculated for both groups' across phases of study. An Analysis of Variance (ANOVA) was conducted to compare group differences on the three subscale scores. Correlations and confidence intervals were also used. Results obtained from the descriptive and statistical analyses were interpreted in relation to previous research.

Chapter 3: Results

The null hypothesis was accepted. No statistically significant differences were noted on resilience scores for siblings of children with developmental disabilities and typically developing siblings. Comparative and visual analysis provided indications of possible differences existing in scores between the groups.

A one-way between groups ANOVA was computed using the SPSS Software to compare mean scores on the *RSCA* subscales between groups 1 and 2. Higher scores on the sense of mastery (MAS) and sense of relatedness (REL) subtests were indicative of higher resilience, while lower scores on the sense of emotional reactivity (REA) were indicative of greater resilience. In the MAS subscale, group 1 scored lower (59.52 ± 7.67) than group 2 (62.10 ± 8.62), but these differences did not reach statistical significance ($F=2.05 (1, 80), p= .156$). In the REL subscale, group 1 scored (77.41 ± 10.07) almost equal to group 2 (77.18 ± 12.21), and very minimal differences were observed, not reaching statistical significance ($F=.009 (1, 80), p= .926$). In the REA subscale, group 1 scored higher (24.02 ± 12.81) than group 2 (22.11 ± 10.40), and these differences did not reach statistical significance ($F= .547 (1, 80), p= .462$). Table 3 provides a numeric representation of descriptive statistics regarding scores on the subtests between groups. Again, the total sample size is 40 participants for group 2, as four scores were omitted before statistical analyses due to contradictory inclusionary criteria. The following bar graph (figure 2) provides a visual representation of the average scores across subtest areas.

Descriptives							
						95% Confidence Interval for Mean	
						Lower Bound	Upper Bound
	1.00	42	59.5238	7.66760	1.18314	57.1344	61.9132
	2.00	40	62.1000	8.62257	1.36335	59.3424	64.8576
	Total	82	60.7805	8.19971	.90551	58.9788	62.5822
	1.00	42	77.4048	10.06578	1.55318	74.2680	80.5415
	2.00	40	77.1750	12.20527	1.92982	73.2716	81.0784
	Total	82	77.2927	11.09164	1.22487	74.8556	79.7298
	1.00	42	24.0238	12.80908	1.97648	20.0322	28.0154
	2.00	40	22.1125	10.40309	1.64487	18.7854	25.4396
	Total	82	23.0915	11.66538	1.28823	20.5283	25.6546

Table 3. Descriptive data for groups 1 and 2 according to subscale scores. MAS = sense of mastery, REL= sense of relatedness, and REA= sense of emotional reactivity.

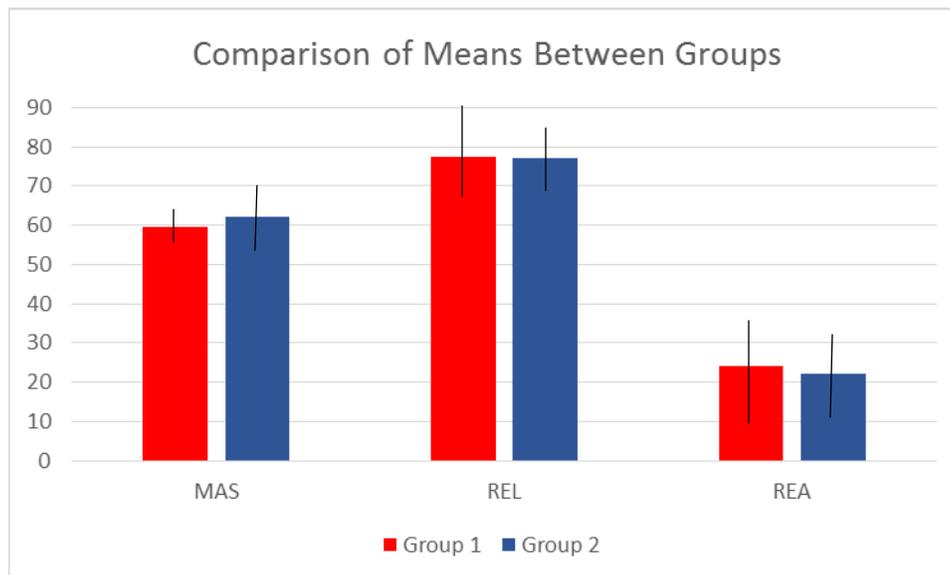


Figure 2. Comparison of mean scores between groups 1 and 2 on the three subscale scores. No statistically significant differences were observed between group mean scores.

Correlational analyses were conducted to better investigate the type of relationship that existed between group scores on the mastery subscale due to its score being the closest of the three to statistical significance. A Pearson product moment correlational analysis (r) was used to assess the type of relationships that existed between the subtests of the sense of mastery subscale

(self-efficacy, adaptability, and optimism) within groups. These subtests contained the summation of scores on certain questions from the subscale that pertained to these three resilience components. The results are depicted in table 4 below. For group 1, there existed weak positive correlations between optimism and self-efficacy ($r=.142$, $n=42$, $p=.368$) and optimism and adaptability ($r = .245$, $n=42$, $p=.118$), neither approaching statistical significance ($p<.01$). There also existed a weak positive correlation between self-efficacy and adaptability ($r = .220$, $n=42$, $p=.161$). Again, no statistical significance was reached indicating that simply having one mastery trait did not imply the others were existent as well.

Group 2 evidenced stronger relationships between scores on the subtests. Optimism showed a moderately positive, statistically significant correlation with self-efficacy ($r = .533$, $n=40$, $p=.000$), and adaptability ($r = .617$, $n=40$, $p=.000$). Self-efficacy showed a moderately positive, statistically significant correlation with adaptability ($r = .483$, $n=40$, $p=.002$). Overall, only group 2 produced statistically significant correlations between mastery subtests ($p <.01$). All Pearson correlation values are in the positive direction, implying that increases in one variable resulted in similar increases in the other variable. For group 2, these positive, statistically significant correlations support the conclusion that if one trait was present, so were the other two traits.

MAS Correlations					
Group			Optimism	Self-Efficacy	Adaptability
		Pearson Correlation	1	.142	.245
		Sig. (2-tailed)		.368	.118
		N	42	42	42
		Pearson Correlation	.142	1	.220
		Sig. (2-tailed)	.368		.161
		N	42	42	42
		Pearson Correlation	.245	.220	1
		Sig. (2-tailed)	.118	.161	
		N	42	42	42
		Pearson Correlation	1	.533**	.617**
		Sig. (2-tailed)		.000	.000
		N	40	40	40
		Pearson Correlation	.533**	1	.483**
		Sig. (2-tailed)	.000		.002
		N	40	40	40
		Pearson Correlation	.617**	.483**	1
		Sig. (2-tailed)	.000	.002	
		N	40	40	40

** . Correlation is significant at the 0.01 level (2-tailed).

Table 4. Correlation matrix depicting subtests of the mastery subscale compared between groups. Pearson correlations that are closer to 0 are considered weak relationships, those that are closer to .5 are considered moderate relationships, and those that are closer to 1 are considered strong relationships between the variables. All correlations are in the positive direction.

Given that the aim of the research was to compare resilience scores between siblings of children with developmental disabilities and typically developing children, researchers created scatter plots to visually interpret the data. The scatter plots are depicted in figures 3-8 below. Visual interpretation of the data showed the scores were similarly varied about the trend line for both groups, in each subtest area. REA was found to be the most variable across both groups. Visual analysis concluded that no significant outliers existed.

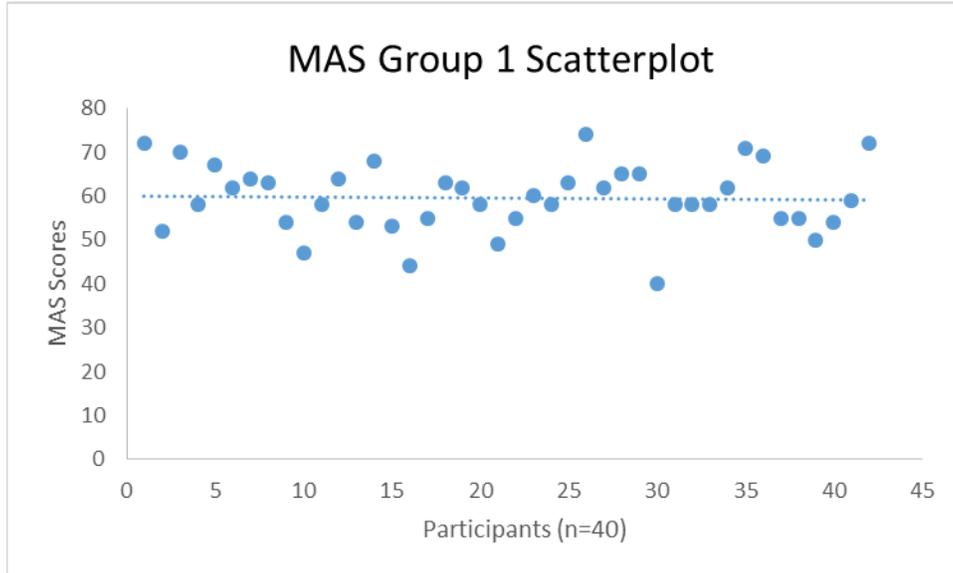


Figure 3. Variability in sense of mastery scores for group 1 about a trend line. No significant outliers noted.

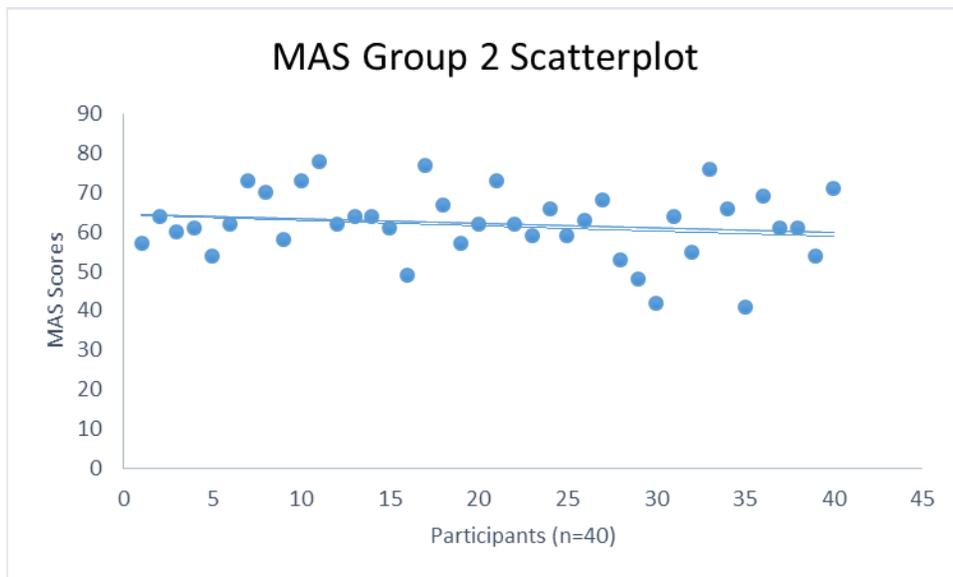


Figure 4. Variability in sense of mastery scores for group 2 about a trend line. No significant outliers noted.

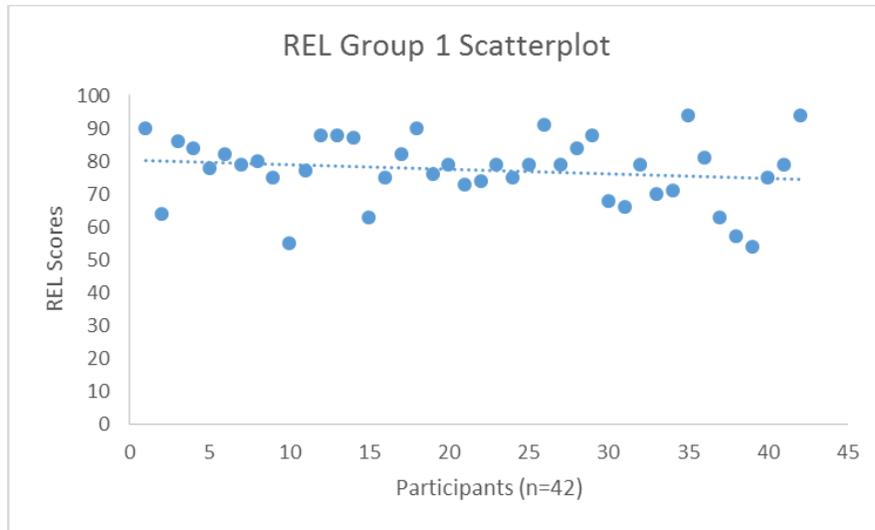


Figure 5. Variability in sense of relatedness scores for group 1 about a trend line. No significant outliers noted.

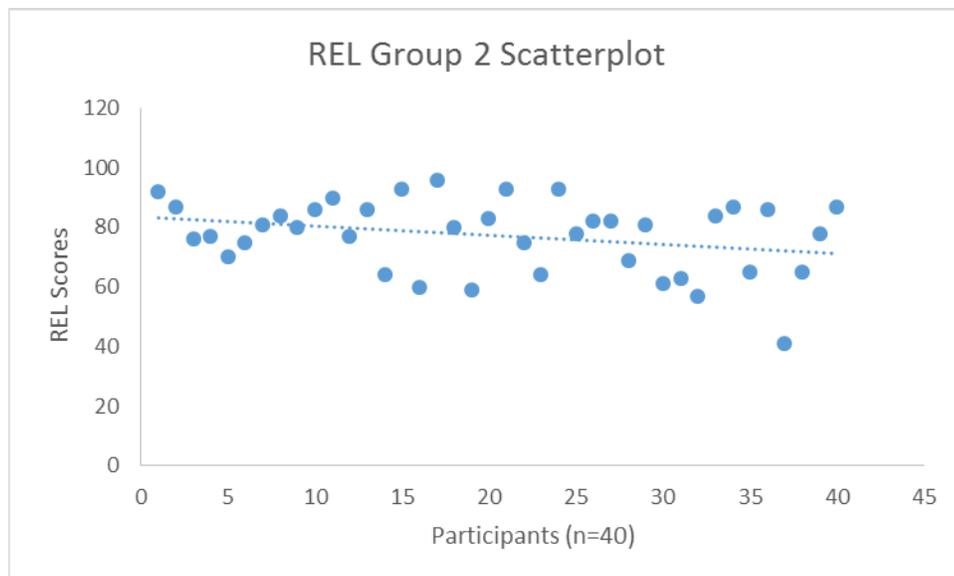


Figure 6. Variability in sense of relatedness scores for group 2 about a trend line. No significant outliers noted.

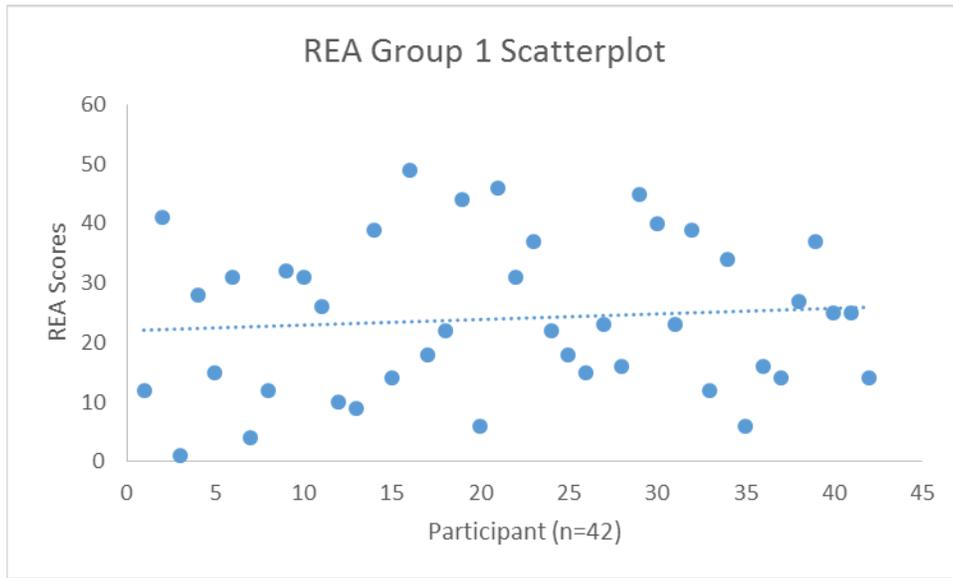


Figure 7. Variability in emotional reactivity scores for group 1 about a trend line.

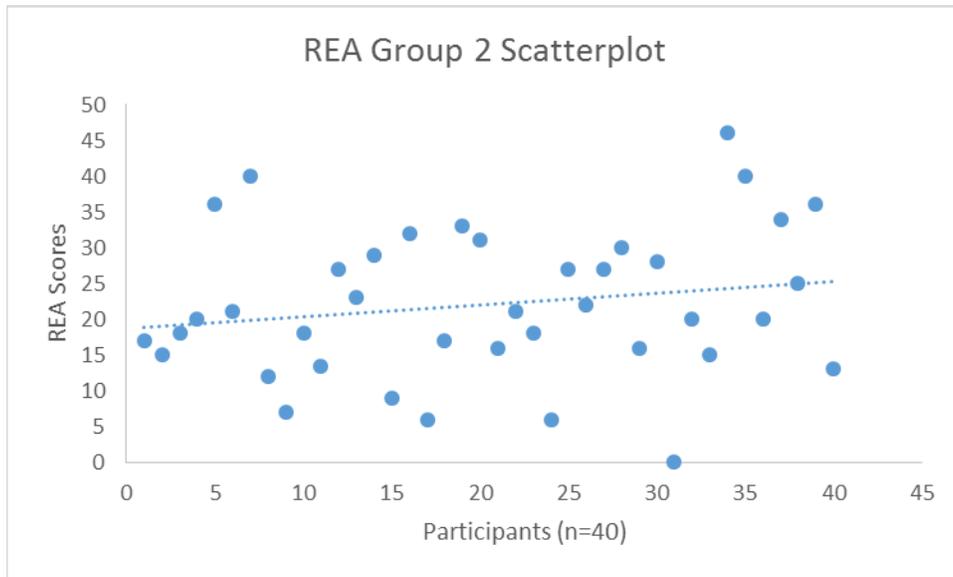


Figure 8. Variability in emotional reactivity scores for group 2 about a trend line.

Box plot analyses were computed using the range of scores for group 2, compared with the 95% confidence intervals for group 1. Group 1 scores were used as a normative range for this study. Group 2 scores were compared to the normative range using 95% confidence intervals, stating that one is 95% confident that should a child in group 1 be given the *RSCA* assessment again, his/her scores would be within the given range. Visual inspection of this comparison indicates that all group 2 scores would be likely to be within the normative range of group 1 scores, and there would not likely be a difference in scores observed if given the assessment again. For all three boxplot comparisons, the group 2 scores were within the group 1 normative range, indicating similarity with resiliency levels between groups. No outlier scores were found, and no trimming of means was necessary. Box plot analyses supported the assumption that there are no statistically significant differences between the two groups' scores.

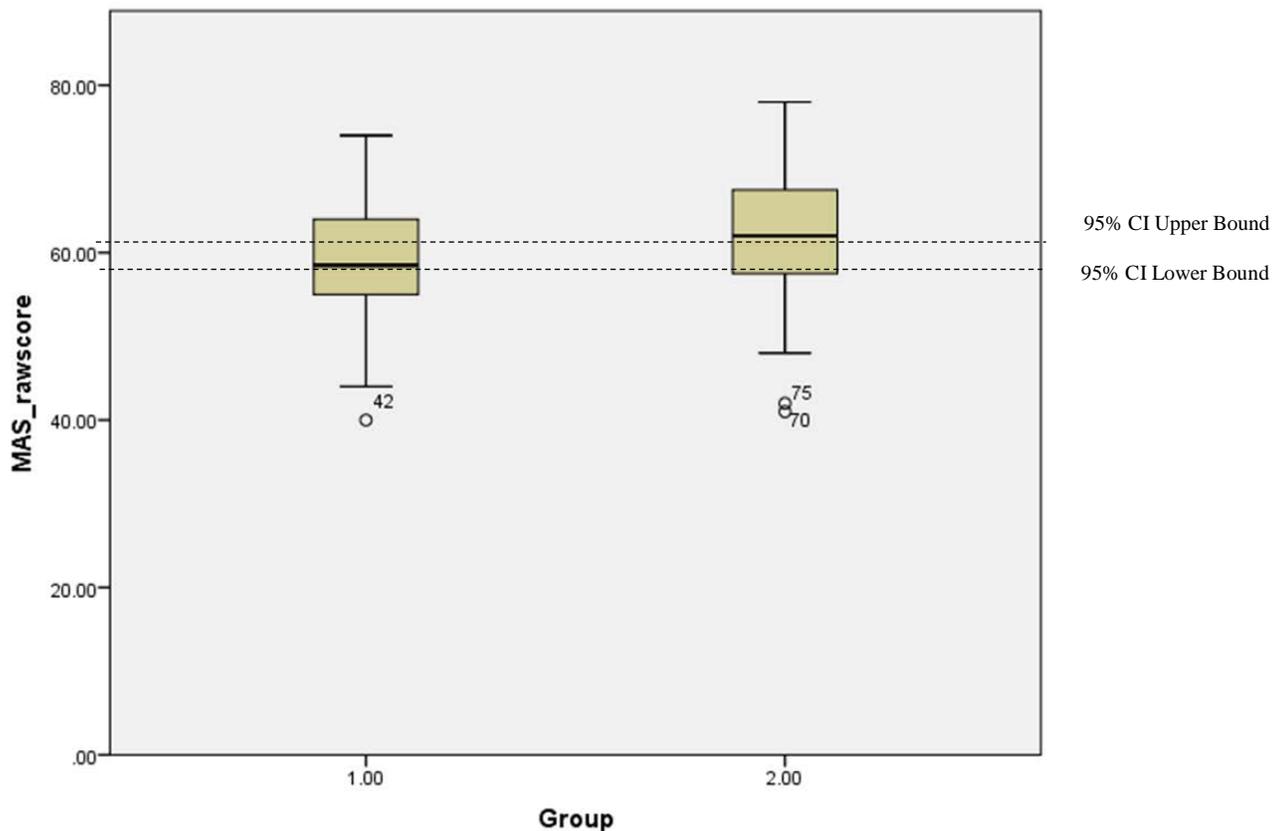


Figure 9. Box plot analysis comparing group 2 mean scores with group 1 95% confidence intervals. Upper boundary (61.91) and lower boundary (57.13). No significant outliers were detected.

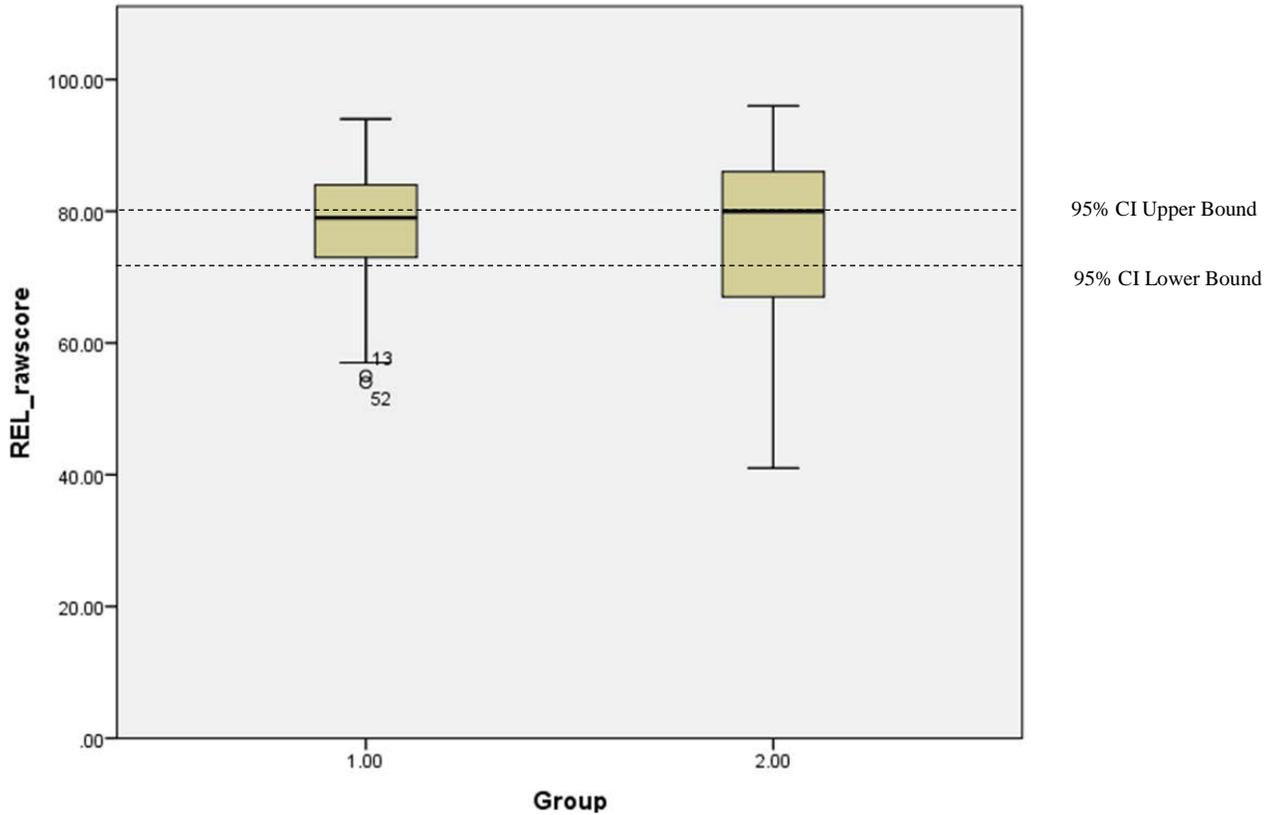


Figure 10 (above). Box plot analysis comparing group 2 mean scores with group 1 95% confidence intervals. Upper boundary (80.54) and lower boundary (74.27). No significant outliers were detected.

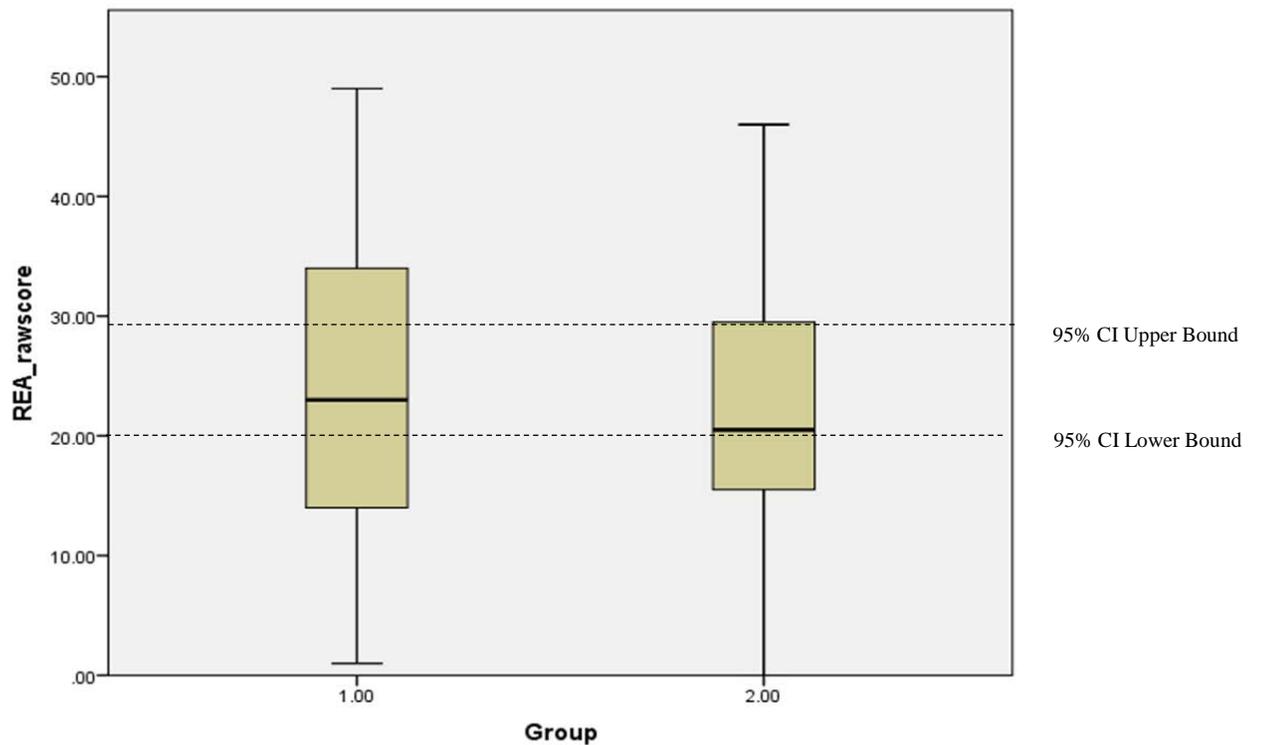


Figure 11. Box plot analysis comparing group 2 mean scores with group 1 95% confidence intervals. Upper boundary (28.01) and lower boundary (20.03). No significant outliers were detected.

Chapter 4: Discussion

The results from this study indicate there to be no statistically significant differences in resilience between siblings of typically developing children and siblings of children with developmental disabilities. This suggests that the experience of being a sibling of a child with developmental disabilities does not appear to have a positive or negative impact on resilience levels, including coping strategies, adaptability, and social competence. These findings are in agreement with previous research showing that resilience is a complex, changing process over time, making it a tool that is difficult to assess and compare between different populations at one point in time. Referencing the McCubbins and McCubbins (1993) model of Family Stress, Adjustment and Adaptation, the theory that resilience is a multifaceted construct with numerous variables that can affect its outcome, support the conclusion that resilience is so variable across participants, despite group association, making it difficult to detect group differences if they exist. Hall et al. (2012) and Bayat (2007) had similar findings when investigating resilience levels and did not identify differences in resilience given an adverse or challenging situation.

The results of this study parallel that of previous studies in that group differences were not found in quantitative analysis, however further inspection of the data through qualitative analysis showed trends toward positive, resilient attitudes. With this research being the first of its kind in this population, many variables could not be explored at large. The methodology of the research design was to compare quantitative scores on the *RSCA* subscales between two groups, and therefore qualitative data were limited. Siblings were asked questions about their experience with a sibling with a disability and thoughts on a sibling support group, yielding some positive developments in their responses. Data analysis and elaboration on these results in the present study were not done at large as much variability across responses was observed, with some

responses definitively positive while others were more ambiguous for interpretation. It is possible that these positive responses may be indicative of resilient trends in this group of individuals, but more specific information would need to be obtained for complete data analysis.

Further, analyses looked at variability about the mean to identify if the mean values were a true representation, or if any outliers existed that may have skewed the results. Scatterplots and boxplots were constructed for each subscale between the two groups and showed that the variability was similar, showing no significantly outlying scores. This implies that the mean values were true representations of average scores and further, that these two groups were more similar across variables than different. This variability in scores across participants, regardless of group assignment, is consistent with the heterogeneity observed in participants. Participants were highly varied on some inclusionary criteria, such as age and qualifying disability, which could have impacted the ability to detect group differences. Further, demographic data analysis was limited because individual responses were subjective in nature. It also appeared that some children understood the questions better than others, and that some children appeared to be in a hurry to complete the assessment and therefore were less focused.

Clinically, the observations made between groups through ANOVA results, scatter and box plots, and confidence interval assessment indicates that there either was not a difference to detect, that there was a difference but there still was not enough power to definitively capture the difference, that the *RSCA* was not sensitive or specific enough to this particular research question, or that siblings of children with developmental disabilities are more resilient than we think due to the adversity experienced. If no difference was to be detected, it is possible that siblings of children with developmental disabilities innately have similar resiliency levels to siblings of typically developing children. Looking at Appendix 1, the McCubbins and

McCubbins (1993) model, the amount of resources and risk factors that take part in promoting bonadaptation or maladaptation are quite complex. Research must focus on the interplay of all of these components to best foster resilience, and it may be that previous literature along with this current research cannot definitively measure one aspect due to the amount of interconnectivity and complexity that is resilience. Research such as that by Van Riper (2000), focusing on one component of resilience (self-concept) in relation to other resources and risk factors may be a better approach to take.

The mastery subscale centers on concepts of being in control, having goals and being capable of achieving them, and being confident in oneself. Low scores on this subscale can be concerning as Sandra Prince-Embury (2011), the author of the *RSCA*, explains that a low sense of mastery can be associated with depression, giving up easily, and struggling to recover from negative experiences. Visual interpretation and mean scores on the sense of mastery subscale indicated that similar scores were obtained between the two groups. This may be indicative that the two groups were more alike than different in their ability to master adverse situations. Both group 1 and group 2 had mean scores greater than the moderate range, indicating a moderately high sense of mastery between the two groups. This may support Ann Masten's (2001) theory that resilience is more an "ordinary phenomenon" than superhuman strength, or it could be indicative that children between the ages of 9-17 do have the resources they need to be self-confident and achieve goals despite adverse situations.

Researchers looked at a correlation matrix for the sense of mastery subscale and found that consistently positive relationships existed between subtests on the sense of mastery subscale. These three subtest scores: self-efficacy, adaptability, and optimism interrelate with one another to help promote positive coping in the face of adversity. For this reason, higher scores on the

subtests in this area correlate to better coping skills and likewise higher resilience. For group 1, many of the subtest areas correlated with one another, however these correlations were found to be weak and not statistically significant. This let investigators know that while one variable (subtest score) increased, participants in group 1 did not necessarily show increases across all other subtest scores as well.

Particularly interesting, group 2 has significantly positive correlations for all subtest areas, indicating that all three subtests had some relation with one another. This indicates that these children can pool resources and skills from all three subtest areas, possibly helping them to achieve more resilient attitudes, similar to that of their peers. For example, if a participant scored highly on self-efficacy, he/she also scored highly on adaptability and optimism. This tells researchers that participants in group 2 were moderately strong in all components of mastery. The same is true for the other subtests: as the child becomes better at adapting to situations, their belief in managing the situation (self-efficacy) and optimism are strengthened as well. Relating to Bandura's (1977) work on self-efficacy, this is a good indication that these children are able to initiate coping strategies and perseverance amidst hardship, a key feature of resilient attitudes.

Highly similar sense of relatedness scores between the two groups could indicate that these children had positive relationships and familial support that helped to foster the resilient themes that were observed, and further support their ability to master situations. The scores for group 2 in this subtest paralleled that of group 1, given mean score and boxplot interpretation, indicating that both groups feel they have the necessary supports and relationships to foster resilient attitudes. Research by Greef et al. (2012), Hall et al. (2012), McCubbins and McCubbins (1993), and Walsh (2011) explained the importance of the views of the family

creating a positive atmosphere to foster resilience, and these results support those overall conclusions.

Emotional Reactivity was found to have the most variability across group scores both on the scatterplots and seen with the larger boxplot with longer whiskers and a greater confidence interval gap. While this subscale has higher scores representing a higher frequency of emotional reactivity experienced in one's life, greater variability makes it difficult to discern the necessity of need in this area. Sandra Prince-Embury (2011) explained the impact emotional reactivity can have on these children's lives, identifying a positive correlation between scores on this subtest and experiences of bullying. However, it appears that if emotional reactivity would be an area of concern, this concern is shared by both groups of children and is not unique to siblings of children with developmental disabilities. This draws on the relationship with bullying, as any children who are likely struggling with emotional regulation could show correlations with experiences of bullying, regardless of the population with which they associate.

Sandra Prince-Embury (2011) states, "Boys have been found to need treatment for managing emotional reactivity while girls need to enhance their sense of mastery and relatedness" (2011, p. 678). The literature shows how interconnected concepts of resilience are, including those of self-efficacy, adaptability, and relatedness and how problematic poor emotional regulation can be to successfully achieving resilience. Researchers instead encourage readers and clinicians alike to interpret these findings in a way that best facilitates strengthening of supports and family variables, while reducing effects of risks and emotionally reactive situations in siblings of children with developmental disabilities.

The design of the *Resiliency Scales for Children and Adolescents* is set up so that one can use this format as a pre-post measure when assessing qualities of resiliency. This tool lends itself

to use as a beginning measure of finding areas of need in regards to promoting resilience for siblings of children with developmental disabilities and siblings of typically developing children. Similar to the box plots designed above, scores can be compared to normative samples to identify outlier scores, and then build upon those corresponding themes. For example, a student who scores low on a self-efficacy component may benefit from treatment focused on Albert Bandura's principles, increasing one's belief in their own ability to achieve. Resilience is a process that changes over time and the lack of differences between groups supports the facts that resilience is an ordinary phenomenon, not a superhuman strength, which needs to be fostered in all individuals regardless of the sibling relationship.

Limitations

Despite attempts to minimize threats to validity, confounding variables inherently existed in the research process creating limitations to the study. Participants were relatively evenly matched on gender, age, and sample size across groups to the best of the investigators' ability. The researchers attempted to control for differences in sample size, limiting the power of the study, by no longer recruiting siblings of typically developing children once a predetermined sample size was reached via a-priori power analysis. This allowed both groups to have relatively equal numbers of participants, and equal weight when running group analyses. Gender and age happened to be controlled for via random selection.

Some variability was introduced via disability type, demographic area, and interpretation of the results. Due to the disability type being a fill in the blank format, the responses were subjective in nature. Responses ranged from one medical diagnosis of Down syndrome, to other impairments including vision problems, cognition issues, and physical impairments. While these were all valid responses based on the screening instrument, it did create difficulty as the types of

disabilities could not be compared. It would have been unfair for researchers to rate the disability types along some continuum, in order to compute statistical analyses, given such little information about the disability itself. Further, having recruitment first in a school district and then at the Minnesota State Fair allowed for participation from a wide range of demographic areas, but unfortunately limited background information was obtained. Finally, interpretation of results was, in some instances, limited by the responses of the children and the interpretation of the researchers. Especially in the first phase of the study, researchers were not present during the administration of the *RSCA* scale, and therefore could not control administration or answer questions in these instances. Despite these limitations, the substantial amount of information gathered with the *RSCA* assessment and parent intake/demographic form allowed for extensive analysis of resilience levels in siblings of children with developmental disabilities. The possibility of researcher error in data collection and analysis does exist, yet the possibility of researchers committing a type II error remains very small.

Future Study

There remains much to be investigated for the future of measuring resilience levels in siblings of children with developmental disabilities. A continuation of the study using an even larger sample size could provide more power, as well as more insight into demographic variables such as socioeconomic status and urban versus rural populations. There also remains the possibility of continued analysis with the data obtained from this research. Some possibilities that remain would be to investigate correlational data with other subtests, within group and within subject differences on resilience levels, and resiliency level scores according to ranges of severity level from mild to severe. Should a researcher want to further this investigation, it would also be important to add more specific information for diagnostic categories, specifically

including a complex communication needs diagnosis that may help to decrease ambiguity in interpretation of results. Finally, much information remains to be investigated in regards to the success of programs set up for siblings of children with developmental disabilities.

Chapter 5: Conclusion

This study was the first of its kind to take a strengths based approach in measuring resilience levels in siblings of children with developmental disabilities. Emphasis was given to three areas that promote resilience if fostered, and results supported the fact that these children did not have a substantially positive nor negative effect to being a sibling of a child with a developmental disability. Researchers were able to discern that based off of scores and correlational data, these children likely had the resources in place and the coping strategies necessary to foster resilient attitudes whether it was an innate strength or developed in response to adverse situations. The results of this study helped to minimize the gap in research between familial representations of family coping and competence with that of the actual attitudes, strengths, and resources of the siblings. While much remains to be investigated, this research is a promising step to help bring a voice to the research realm for siblings of children with developmental disabilities.

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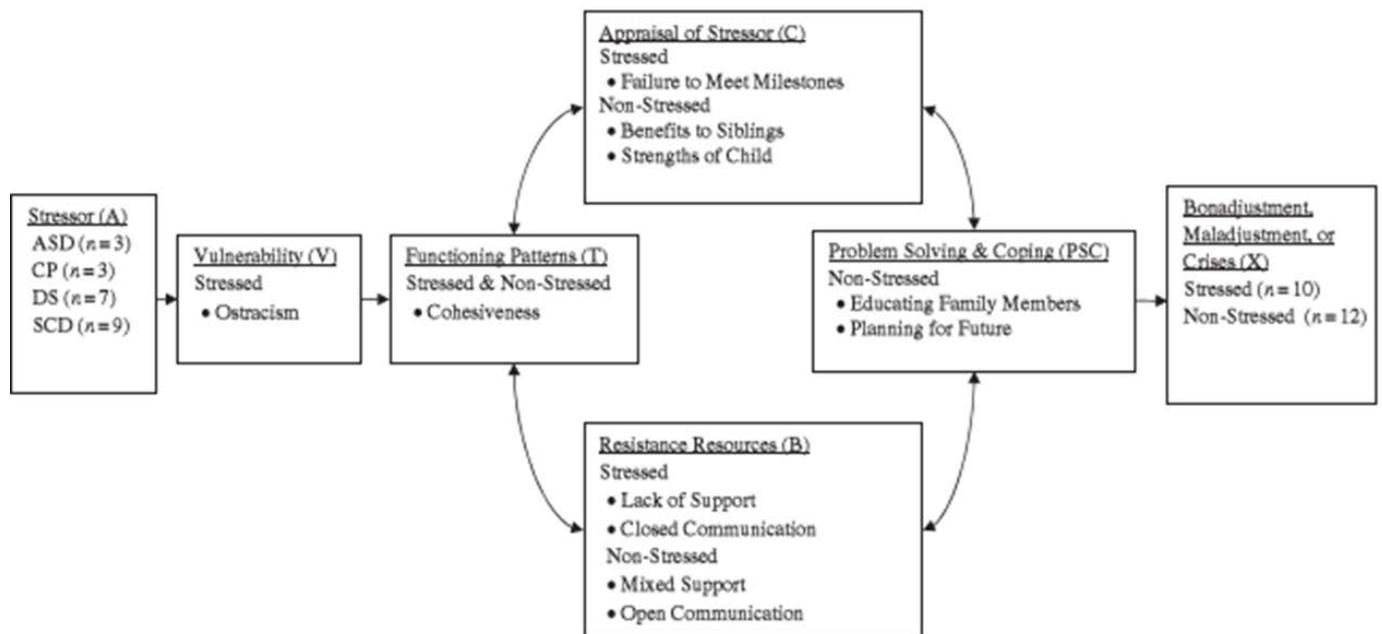
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APPENDIX A: McCubbins and McCubbins (1993) Model of Family Stress, Adjustment and Adaptation



Note: ASD refers to autism spectrum disorder, CP refers to cerebral palsy, DS refers to Down syndrome, and SCD refers to Sickle Cell Disease.

APPENDIX B: Subject Screening Form

Sibling Support Subject Screening Form

Subject Code (child): _____

Chronological age (child): _____ Male Female

- | | | |
|--|-----|----|
| 1. Does the child who is participating currently have an IEP or IFSP through the school or county? | Yes | No |
| 2. Is your child an only child? | Yes | No |
| 3. Does your child's sibling(s) have an IEP through the school district or an IFSP through the school or county? | Yes | No |
| 4. Are you the child's parent or legal guardian? | Yes | No |

Must be between ages 9-17 years

Answering No to questions 1 and 2 = Eligible to participate

Answering Yes to question 3 = assignment to DD group

Answering No to question 3 = assignment to TD group

APPENDIX C: Parent Intake Form

Sibling Support

Parent Survey: DD Group

Chronological age of participating child: _____ Male Female

How many siblings does the participating child have _____

List ages and gender of all siblings:

Gender		Age	Sibling			
Male	Female	_____	Biological	Step	Half	Adopted
Male	Female	_____	Biological	Step	Half	Adopted
Male	Female	_____	Biological	Step	Half	Adopted
Male	Female	_____	Biological	Step	Half	Adopted
Male	Female	_____	Biological	Step	Half	Adopted
Male	Female	_____	Biological	Step	Half	Adopted
Male	Female	_____	Biological	Step	Half	Adopted

Has one of your children been diagnosed with a developmental disability? YES NO

If yes,

- Circle which child has a developmental delay on the above list
- What is their medical diagnosis (if any)? _____
- What is their communication diagnosis (if any)? _____
- What is their developmental diagnosis (if any)? _____
- What is the duration of the disability? Sudden onset Chronic
- What is the type of disability? Acquired Congenital
- What services (if any) does he/she receive? PT OT SLP
- Other _____
- What is the severity of the disability? Mild Moderate Severe Profound

Would you be interested in a sibling support group for the participating child if one was available? YES NO

If yes, what would you like your child to gain from this support group?