

THE SOCIAL AND EMOTIONAL ADJUSTMENT OF SIBLINGS OF CHILDREN WITH
DISABILITIES

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A Thesis

Submitted in Partial Fulfillment

Of the Requirements for the Degree of

Master of Education

Curriculum and Instruction

At the State University of New York University at Fredonia

Fredonia, New York

May 2014

Project Certification Page

State University of New York at Fredonia
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CERTIFICATION OF PROJECT WORK

We the undersigned, certify that this project entitled THE USE OF CONCRETE MANIPULATIVES IN THIRD GRADE SPECIAL EDUCATION AND STUDENT ACHIEVEMENT by Rhianna Gerfin, Candidate for the Degree of Masters of Science in Education, Curriculum and Instruction Inclusive Education, is acceptable in form and content and demonstrates a satisfactory knowledge of the field covered by this project.


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Abstract

The question addressed in this study is: Are siblings of children with disabilities affected socially and emotionally? This study will take place through interviews with four siblings of children with disabilities, specifically Autism Spectrum Disorder and Down syndrome. The participants vary in age from 16-20, and each of their siblings each fall on a different part of the Autism Spectrum.

The Bowen Family Systems theory states that anything that happens to a specific family member has an impact on the rest of the family. The theory also states that a family is a unit and that all members are interacting parts that cannot be separated from one another as they are dependent on one another and unified (Bowen, 1966). This study will build upon the Family Systems Theory, and will focus on the factors that contribute to the social and emotional adjustments that may affect the siblings of children with Autism Spectrum Disorder and Down syndrome.

Although research has been completed in this area of study, there have been little to no consistencies found. This study will potentially identify consistencies among siblings of children with Autism Spectrum Disorder and Down syndrome and guide future researchers and educators to identifying intervention services, differentiated instruction, and other accommodations that these siblings may need.

Table of Contents

I.	Introduction	1
II.	Review of Literature	3
	a. Family Dynamics and Structure	3
	b. Maternal Depression	5
	c. Differential Maternal Treatment	6
	d. Sibling Interactions	7
	e. Stressors and Coping Strategies	8
	f. Internalizing Behavior Problems	9
III.	Methodology	11
	a. Participants	11
	b. Setting	13
	c. Methods.....	14
	i. Perceived Self Worth	14
	ii. Home Life and Support Systems.....	15
	iii. Relationships with Siblings	16
IV.	Findings.....	16
	i. Perceived Self Worth	16
	ii. Home Life and Support Systems.....	19
	iii. Relationships with Siblings.....	23
V.	Discussion.....	24
	i. Perceived Self Worth.....	24
	ii. Home Life and Support Systems.....	25
	iii. Relationships with Siblings.....	26
	iv. Implications for Future Research.....	27
	v. Limitations.....	28
VI.	References.....	30
VII.	Appendices	
	a. Social Self Efficacy Scale	
	b. Rosenberg's Self Esteem Scale	
	c. Parent Support Subscale	
	d. Hare Self Esteem Scale	
	e. Scale of Perceived Social Support- Family	
	f. Sibling Inventory of Behavior- Adapted	
	g. Consent Form for Participants	
	h. Parental Consent form	

Introduction

Bowen Family systems theory states that anything that happens to a family member has an impact on the rest of the family. The theory also states that a family is a unit and that all members are interacting parts that cannot be separated from one another as they are dependent on one another and are unified (Bowen, 1966). When a family member is diagnosed with a disability, the whole family shifts priorities, and is affected in many ways. The child with the disability becomes the focus of everyday life, and often their siblings are overlooked. The theory states that:

Family members so profoundly affect each other's thoughts, feelings, and actions that it often seems as if people are living under the same "emotional skin." People solicit each other's attention, approval, and support and react to each other's needs, expectations, and distress. The connectedness and reactivity make the functioning of family members interdependent. A change in one person's functioning is predictably followed by reciprocal changes in the functioning of others. Families differ somewhat in the degree of interdependence, but it is always present to some degree (Bowen, 1966 p.1).

Are the siblings of children with disabilities struggling to adjust socially and emotionally? If one member of the family has a disability, then how is the rest of the family reciprocating and changing to allow for this change? The question being raised is what factors influence the degree of change that has to be accounted for? Sibling age, birth order, and gender play an important role in the adjustment of siblings of children with disabilities (Gath, 1974).

This research will delve into the various factors and situations that may have an impact on the

social and emotional adjustment of siblings of children with disabilities, as this is a prevalent issue in the field of education.

A student's home life, and the challenges that they may face have a significant impact on their ability to focus and learn in school. If siblings are being affected and are having difficulty making adjustments socially and/or emotionally, the state of their mental health may raise concern as well. While some specialists and educators believe that siblings are not affected, there are studies that show that siblings are in fact at a greater risk for maladjustment socially, emotionally, and psychologically.

Findings across the previous studies have proved to be inconsistent, thus creating a gap in the research of siblings of children with disabilities. Perhaps previous studies have been too general, and a specific disability category needs to be focused on. This study looks to narrow the sample, and solely look at siblings of children with Autism Spectrum Disorder and Down syndrome. The study hopes to answer the question of are siblings of children with Autism Spectrum Disorder and Down syndrome affected socially and emotionally.

Review of Literature

Family Dynamics and Structure

When a child with a disability is born into a family it can create a lot of stress on the parents. The increase of stress on the parents may significantly affect the non-disabled siblings in the family (Morgan, 1988). Daily life, routines, and relationships may change between siblings and parents, and between parents themselves. Open, and communicative relationships are suggested to yield positive adjustments in typically developing siblings. Dempsey, Llorens, Brewton, Mulchandani, and Goin-Koichel (2012) comment about the importance of communication within the family and state that “the degree to which parents of children with autism are open in their communication about the affected child and the disorder are suggested to be critical factor in the adjustment of the typically developing sibling” (p.1400).

Family dynamics plays an important role in sibling adjustment. Barnett and Hunter (2012) note that “the dynamics of the family milieu is of crucial importance to the child’s adjustment” (p.270). Poor family functioning denotes a potential predictor of behavior problems and maladjustments in the non-disabled siblings. The non-disabled siblings may miss out on extra attention and affection from parents. He or she will then take on some of the challenging behaviors of their disabled sibling in an attempt to regain that affection and redirect the parent’s attention. Shur-Fen Gau, Chou, Chiang, Lee, Wong, Chou, and Wu (2012) propose that mothers of children with autism have difficulty with expressing their affections, thus creating a relationship barrier not only between the typically developing sibling and his or her parents, but between the typically developing sibling and the disabled sibling.

Siblings of children with disabilities often take on more responsibility throughout the household and become somewhat of a caretaker for their sibling as well. Cuskelly and Gunn

(2006) hypothesize that “the greater the contribution from the child’s perspective, the higher the risk of the problem behaviors” (p.918). Benderix and Sivberg (2007) agree and stated that “Many siblings felt an obligation to protect their brother or sister from doing dangerous things and to prevent them from hurting themselves and others. Sometimes they took on the role of parental responsibility to give the parents a break in their day care” (p. 414). This often creates tension among family members, as parents do not always recognize the efforts of the non-disabled child. This can lead to feelings of resentment, aggression, jealousy, and anger, and ultimately result in problem behaviors and maladjustment.

The overall family environment plays a key role in the social and emotional adjustment of siblings of children with disabilities. The Resiliency Model of Family Stress, Adjustment and Adaptation (McCubbin, Thompson, McCubbin, 1996) has been used to show how families adapt and react to various stressful circumstances, including having a child with a disability. A study by Giallo and Gavidia-Payne (2006) used this scale to identify specific characteristics of families that are used as a protective role against stressful life events. The authors looked at family size, coping strategies, and positive associations with the disabled child. The authors found that smaller family size may be a protective mechanism against maladjustment of the children. With a smaller family, more attention can be paid to routines, and a focus on family time, thus resulting in better adjustment and quality of life for all of the children.

Birth order and family size also play a contributing factor in the social and emotional adjustment of these siblings. There may be a different dynamic from smaller families to larger families when there is a child with a disability. Parents may have more time to spend with all of the children in a smaller family, thus creating a more positive and equal environment in the eyes of the child. In a larger family, the parents may not have as much time to spend with each child

individually, and all of their attention is consumed by the child with a disability. A larger family may also impact the parent's ability to model appropriate behavior, social learning, and the explanation of the child's disability to the non-disabled siblings. The lack of modeling can affect the relationships among the siblings, and the non-disabled sibling's future relationships outside the family (Pilowsky, Yirmiya, Doppelt, Gross-Tsur, Shalev, 2004).

Birth order may affect how a child is adjusted socially and emotionally. For example, if a child with a disability is born into a family with one (older) sibling, then the sibling may be at more of a risk because of the sudden change in the family dynamics and everyday life (Gath, 1974). The sibling is used to routines, consistent parental attention, and with the introduction of a child with a disability, the sibling becomes at risk for behavioral maladjustment (Rodrigue, Geffken, & Morgan, 1993).

Maternal Depression

Mothers of children with Autism Spectrum Disorder have reported higher rates of depression than the mothers of typically developing children (Meyer et.al. 2011). When a mother is experiencing depressive symptoms, it can affect how she is able to care for her children, both disabled and non-disabled. Meyer et.al. (2011) has said that "It is possible that mothers who are experiencing more depressive symptoms allow the child with ASD to have a greater impact on the sibling's life" (p. 1418). The findings indicated that mothers who are experiencing depressive symptoms do not have the energy to address all of the child with Autism's needs, both social and emotional, and this may result in challenging and negative behaviors towards the non-disabled sibling. The non-disabled sibling becomes burdened by the responsibility of caring for their sibling with Autism, and thus faces feelings of resentment, and

aggression towards not only their mother, but towards the sibling as well. A strain is placed on the relationship, and the sibling is at a risk for internalizing behavior problems.

A lack of respite care for mothers of children with disabilities can create elevated levels of stress, and lack of positive family interactions (Benderix, Sivberg, 2007). It can be difficult for mothers of children with disabilities to find time that is their own, and to find time away from the disabled child. A large portion of the mother's time is spent caring for the child, and dealing with challenging behaviors as a result of their disability. As a result, there is an increase in stress for the mother, and the typically developing sibling feels compelled to take on extra responsibilities to compensate for the familial disconnect.

Differential Maternal Treatment

Lobato, Kao, Plante, Seifer, Grullon, Cheas, and Canino (2011) completed a study that looked at Latino siblings of children with disabilities, and examined their psychological functioning. The authors found that in the Latino culture, non-disabled siblings were receiving less positive attention from their mother. The attention that the children were receiving was of a negative connotation, and often criticized their behavior and ability to help around the home. This creates an insecure relationship between the mother and the child, and places the child at a greater risk for developing depression, anxiety, and other internalizing behavior problems. Benderix and Sivberg (2007) comment that typically developing siblings express feelings of bitterness and resentment as a result of the disabled sibling receiving more attention from mothers, and that there is no time left to allocate to the sibling's accomplishments and emotional needs.

Similarly, Hastings (2007) found that mother's may offer differential treatment among siblings. Hastings speculated that mother's may be less likely to report problem behavior in the

non-disabled child because she is accustomed to the extreme behaviors of the disabled child. The problem behaviors in the non-disabled child may go unreported and untreated because “they are perceived as unproblematic relative to more extreme behavior” (Hastings, 2007, p. 1490).

Typically developing siblings have reported a high level of criticism from their mothers that may be directed toward the typically developing sibling, or the disabled sibling. The results of a study by Petalas, Hastings, Nash, Hall, Joannidi, and Dowey (2012) confirmed that siblings rated their mothers as being critical, and thus creating more conflict and behavior problems between the siblings. This critical behavior has also led to an increase in internalizing behavior problems for the typically developing sibling.

Sibling Interactions

“Positive and frequent sibling interactions provide important sources of emotional support (Dunn & Kendrick, 1982), whereas negative and infrequent sibling interactions may disrupt the psychological adaptation process” (Bryant, 1982, p. 90). Given these findings, Rodrigue, Geffken, and Morgan (1993) looked to examine how having a child with a disability can affect sibling relationships and interactions. The authors discovered that if the non-disabled sibling was older than the disabled child then there was an increase in negative interactions, and the sibling was at a risk for maladjustment. The authors also found that negative sibling interactions disrupt the psychological adaptation process. Adversely, if the disabled child was the older of the siblings then there were more positive interactions, and less of a risk for maladjustment.

Hadjikakou, Nicolaou, Antonopoulou, and Stampoltzis (2010) investigated the psychosocial adjustment, and the relationships of siblings of children who are deaf and hard of hearing. The authors found that children make adjustments socially for their disabled sibling.

Siblings with both positive and negative interactions with their sibling showed concern for the future of their disabled brother or sister. The siblings also mentioned increased anxiety when having friends over and having to tell friends about their sibling's disability.

Stressors and Coping Strategies

Rodrigue, Geffken, and Morgan (1993) conducted a study where they compared siblings of severely autistic children, Down syndrome, and developmentally normal children in order to identify internalizing and externalizing behavior problems. Through this study it was revealed that there are many stressors that non-disabled children are facing. "Non-handicapped siblings may experience numerous stressors, including loss of parental attention, changes in family roles, structure, and activities, identification with the handicapped child, feelings of guilt and shame, and the negative reactions of others outside the family" (Rodrigue et.al. 1993, p. 666).

Similar findings were revealed in a study by Giallo & Gavidia- Payne (2006) where parents and siblings of a disabled child provided information regarding daily life, stressors, and coping strategies. The study concluded that sibling to sibling relationships were a stressor, but that the most common and prevalent stressor was the family environment as a unit. Within the family environment communication difficulties, conflicts, and management of daily routines proved to be the leading factor in adjustment of the non-disabled sibling.

Coping strategies of siblings of children with disability has not been widely researched. However, a study by Ross and Cuskelly (2006) revealed four general categories of coping strategies that are utilized by these siblings. The categories included environment directed cognition, self-directed cognition, environment directed behavior, and self-directed behavior. A trend for using "other directed cognitions," such as blaming other persons was revealed from these siblings. This coping style and strategy led to poor adjustment socially and emotionally.

Another trend that was identified included the use of the “self-directed cognitions,” such as using calm down strategies to cope. The siblings who frequently used this strategy were more likely to experience higher depression and anxiety rates, and were at a greater risk for maladjustment (Gamble & McHale, 1989.)

Internalizing Behavior Problems

The results vary on whether or not siblings of children with disabilities are at a higher risk for, or are experiencing an increase in internalizing behaviors. Lobato et al. (2011) argue that siblings are experiencing more internalizing behavior problems, specifically anxiety and depression. The authors look to a different culture to explore their hypothesis. It was found that Latino siblings of children with intellectual disabilities are struggling with personal adjustment and relationships, separation anxiety, depressive disorders, and insecure relationships.

Latino siblings are not the only culture to experience internalizing behavior problems. A study by Ross and Cuskelly (2006) concluded that although the contributing factors are unclear, Latino siblings of children with Autism Spectrum Disorder are at a significant risk for developing internalizing behavior problems.

Pilowsky et al. (2004) explored the social and emotional adjustment of siblings of children with autism and found opposing results. Pilowsky et al. (2004) argue that siblings of children with autism are well adjusted, and are not at an increased risk for developing internalizing behavior problems. Cuskelly & Gunn (2006) had similar results from their study of siblings of children with Down syndrome. The authors concluded that having a sibling with Down syndrome does not have an impact on the likelihood of developing internalizing behavior problems. However, both sets of authors argue that there are other outside factors that determine

a child's disposition and ability to adjust which in turn, could lead to internalizing behavior problems.

A study by Rodrigue et al. (1993) uncovered some of the outside factors that are believed to affect internalizing behaviors. Such factors included sibling age, household responsibilities, and parental marital satisfaction. Rodrigue et al. (1993) sought to prove that these factors do have a bearing on the risk for the development of internalizing behaviors. The authors argue that an increase in stress, household commitment, and changes in family life due to the disabled child are all contributing factors to the increase in internalizing behaviors. Benson and Karlof (2008) uncovered similar factors that can lead to adjustment problems. They argue that parental involvement in education, and stressful life events have a significant bearing on the adjustment of the typically developing sibling. If the level of parental involvement is high, then there is a higher level of prosocial behavior, and lower levels of psychopathology. If parental involvement is lacking and high levels of stress are experienced by the parent, then they are reflected onto the typically developing child, and there is a lower level of prosocial behavior, and higher levels of psychopathology and internalizing behavior problems.

There are inconsistencies in the research as to whether or not siblings of children with disabilities are affected socially and emotionally. Some children are experiencing an increase in internalizing behaviors, while some children are relatively well adjusted according to their mothers. There is a significant gap in determining the factors that influence the degree of adjustment that these siblings are faced with. I hypothesize that there are multiple contributing factors that lead to a positive or negative social and emotional adjustment of siblings of children with disabilities.

The Typically Developing Sibling's Understanding of the Disability

The level of understanding that the typically developing sibling has of their sibling's disability has a large bearing on the social and emotional development of the typically developing sibling (Tanaka, Uchiyama, Endo, 2011.) When the disability is not defined, and explained in terms that are conducive to the typically developing sibling's cognitive level, it can lead to feelings of resentment and embarrassment of the disabled sibling. Benderix and Sivberg (2007) explain that indifference, social embarrassment, the feeling of being burdened are commonly when the typically developing sibling does not have an understanding of the type, complexity, and severity of their sibling's disability.

Methodology

Overview

The purpose of this study is to answer the question of whether siblings of children with Autism Spectrum Disorder and Down syndrome are affected socially and emotionally. To answer the question, I have used the inquiry methods of surveys in order to examine specific categories of adjustment for each of the siblings. I have collected data for four siblings of children with either Autism Spectrum Disorder or Down syndrome, and asked them a set of questions that described, and explored their social and emotional adjustments while growing up, and also that detailed their current experiences as well. The goal of this study was to focus on and identify the factors that may contribute to the social and emotional adjustments that may affect the siblings of children with Autism Spectrum Disorder and Down syndrome.

Participants

The sample for this study includes three siblings of children with varying degrees of Autism Spectrum Disorder, and one sibling of a child with Down syndrome. The particular

participants were recruited due to the fact that their siblings have varying degrees of severity of their disability. I recruited participants that are family members, and close family friends. In order to recruit these specific participants, I sent a detailed letter that identified the question that I am trying to answer, the expectations of the participants, and the means through which I planned to collect the data. The potential participants were then able to decide if they wanted to continue, and participate in the study. The study is comprised of a 16 year old female, two 18 year old females, and a 20 year old female. Three of the participants have a sibling that is diagnosed with, and falls on the Autism Spectrum, and one participant has a sibling that is diagnosed with Down syndrome. One of the participants is a family member, and the other three participants are close family friends. Confidentiality of the participants will be protected throughout the duration of the study.

Statement of Significance

The question of adjustment is important to address within the field because there has been a previous research with regards to the topic of the adjustment of siblings of children with disabilities, however the consistencies across studies are lacking. This research has a narrow spectrum in which it explores stressors, coping strategies, and the importance of the non-disabled child understanding of their sibling's disability. Researchers and educators are trying to find ways that they can help absolve some of the difficulties that siblings of children with disabilities face, and by studying specific stressors, and coping strategies of these children, it allows them to further strategies for differentiated instruction, and find and allocate appropriate services for these children. (Gamble, W.C., & McHale, S.M., 1989)

The question of the relation between the non-disabled child's understandings of their sibling's disability is extremely prevalent and important in the field. The understanding of the

child's disability can adversely or positively affect sibling relationships and adjustment. If a strong correlation is found between a lack of understanding of the child's disability and an increase in internalizing and externalizing behaviors, and adjustment problems, or vice versa, then researchers and educators can work together to educate families, and work with the appropriate organizations in order to facilitate better living environments for all family members. (Benson, P.R., Karlof, K.L. 2008)

Family dynamics is heavily focused on in the research of siblings of children with disabilities. Previous research has looked at how birth order, family composition, and socioeconomic status affect the adjustment of siblings. However, interactions among siblings has been overlooked and under researched. Positive and negative interactions at a young age shape how siblings will get along with, and care for each other throughout life. If sibling interactions is studied, and positive interactions are facilitated from a young age, then this may be an indicator as to how typically developing siblings adjust as they are growing up alongside their disabled sibling. (Shur-Fen Gau, S. et al. 2012).

Setting

The data was collected via mail from every participant. In order to maintain confidentiality for the participants, all participants submitted their responses to a third party via mail who has obtained Human Subjects Certification. The questions for each of the participants did not vary. The participants' personal data was removed from their responses before being returned to me, the researcher. After the data was collected, the third party contacted the participants if follow up questions were deemed necessary.

Design and Data Collection

The general strategies employed in the collection of information included coding of the responses into graphs and charts to either show either a positive or negative correlation of social and emotional maladjustment with respect to the interviewees having a sibling that has a disability, and comparison of the similarities and differences of the adjustment qualities of each participant based on the disability that his or her sibling has been diagnosed with. This served to confirm or disconfirm my hypothesis that specific disabilities, and/or varying degrees of that disability have a bearing on the social and emotional adjustment of the non-disabled sibling.

Perceived Self Worth

The first step in the methodology was to determine the participant's perceived self-worth, and self-esteem. Participants were provided with the Social Self-Efficacy Scale (Muris, 2001) to determine their perceived self-worth, and to examine their interactions with others. This explored social interactions, how the participants deal with conflict, and also touched on their communication skills in potentially uncomfortable situations. The data was graphed based on the responses of 1-5, where one indicates handling things very well, and five indicated not handling things well.

Rosenberg's self-esteem scale (Rosenberg, 1965) was completed by the participants in order to examine their self-esteem, self-respect, self-worth, and ability to complete tasks. The survey is scored on a four point Likert scale, that can range from strongly agree, to strongly disagree. The data was then graphed and analyzed according to the severity of the disability of their sibling.

Home Life and Support Systems

The second area explored was the participants' home lives, and parental support systems. The participants were asked to complete the Parent Support Subscale (Harter, 1985). The purpose of this scale is to determine how the respondents feel that their parents understand, or try to understand their feelings. The scale also measures whether or not the participants feel as though their parents make time to make them feel special, and acknowledge them. Data was collected using this scale, and the answers were coded based on the responses from either the left or the right side. "Starting at the left, scores are coded as follows: Really True for Me= 1, Sort of True for Me= 2. Sort of True for Me= 3, and Really True for Me= 4. Items 3, 4 and 5 are reverse coded. Responses are summed to create a final score. A high score indicates greater parent support (Harter, 1985, p.85-86)."

Participants also completed the Hare Self-Esteem Scale (Hare, 2000). This scale measures how the respondents feel when they are around their family members, including their sibling with a disability. The scale was scored through coding. "Response choices are coded as follows: Strongly Disagree= 1, Disagree= 2, Agree= 3, and Strongly Agree= 4. Items 2,4,6,8 and 10 must be reverse scored. Then the 10 items are summed for a total score and the higher the score, the higher the person's home self-esteem (Hare, 2000, p. 87-88)."

Participants were asked to complete the Scale of Perceived Social Support- Family (Canty-Mitchell, & Zimet, 2000). This scale measures the amount of support that the family offers the respondent based on the respondent's perception. This scale addresses how the family supports the sibling with decision making, emotional support, and whether or not the sibling feels comfortable seeking help from family members. This scale was scored using a five- point Likert Scale. Responses were given a numeral value based the following: rarely or never (1), a

little bit (2), sometimes (3), a good part of the time (4), and always (5). When scoring the scale, higher scores indicate more perceived social support from the family.

Relationships with siblings

The third step in the methodological process was to address each participant's relationship with their sibling. The participants were asked questions that were based off of the Sibling Inventory of Behavior (Schaefer & Edgerton, 1979.) The participants were asked to answer on a number based scale from 1-5, with 1 indicating never, and 5 indicating always. The participants had the opportunity to elaborate on the answers, and were able to provide examples if they chose to do so.

The data was then broken down into categories of empathy and concern, kindness, leadership and involvement, acceptance, anger, unkindness and teasing, avoiding, and embarrassment. The data was scored and coded based on the participant's responses. The data was graphed for each participant. Data was analyzed according to the participant's age, and their sibling's severity of their disability.

Findings

The data were collected from four typically-developing siblings of children with disabilities, specifically Autism Spectrum Disorder and Down syndrome. The typically developing siblings varied in age, and were all female. The participants were asked to complete surveys which focused on examining their perceived self-worth and self-esteem, family dynamics and interactions, and their relationships with their disabled siblings. The results for each of the surveys are summarized and graphed for each participant.

The data showed that the siblings were overall well-adjusted socially and emotionally. High mean scores on each of the scales indicate that the majority of the siblings are not struggling with social and emotional adjustment, or having difficulties within their families. One sibling stood out as having difficulties with familial support and self-esteem.

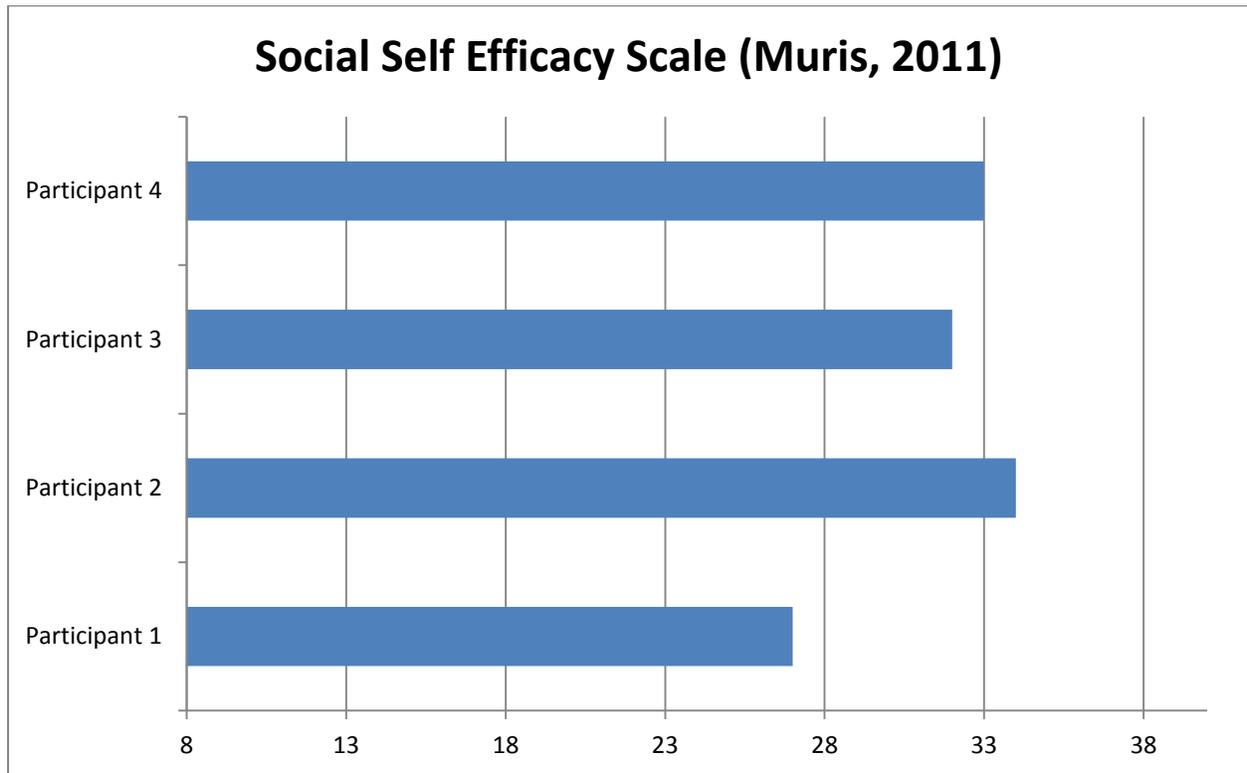
Analysis of Data

Data was analyzed for each scale based on the scoring procedures that accompany the specific scale. The scales have been broken down and organized according to their category in adjustment, and were scored based on the Likert scale that was provided.

Perceived Self Worth

The Social Self-Efficacy Scale (Muris, 2011) asked the participants to self-evaluate their ability to interact in social situations, and their ability to engage in positive social interactions. This data served the purpose of identifying how confident the participants feel when confronting others, or standing up for themselves in a variety of social situations. The data also sought to demonstrate how the participants can compromise with others to create social interactions with others.

The data showed a mean score of 31.5 out of a possible 40 points. The data was scored according to the Likert scale that was provided, with the notion that a higher score indicated higher levels of self-efficacy and self-confidence. Participants two, three, and four scored very similarly, indicating a positive adjustment. However, participant one scored 4.5 points lower than the mean score. This analysis reflects a potential detriment in participant one's conscious thoughts regarding her ability to complete tasks, meet goals, and participate in social interactions with her peers.

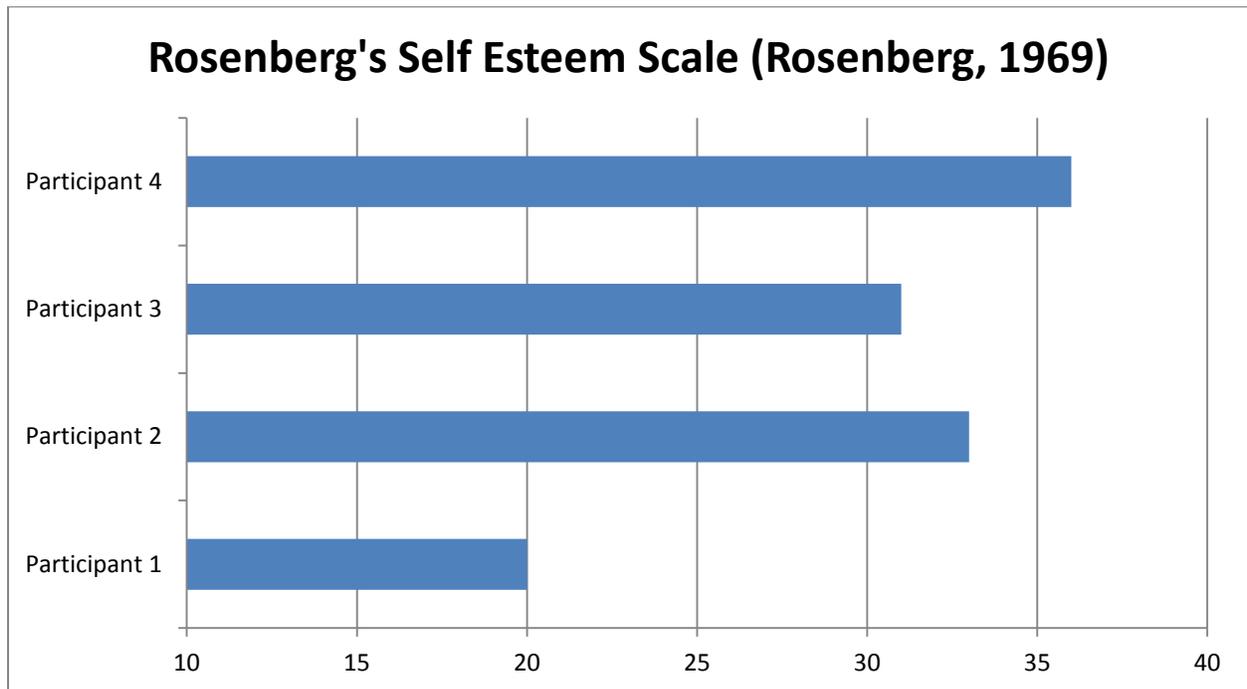
Figure 1

Rosenberg's self-esteem scale (Rosenberg, 1969) examined the self-esteem, self-worth, self-respect, and perceived ability of the participants. The data from this scale was used to explore how the participants view themselves, and to identify their level of satisfaction with themselves as well. The participants were asked questions regarding their successes and failures in order to determine how well-adjusted they are in the area of self-esteem.

The data was scored according to a Likert scale in which the questions were scored with a specific point value, and then summed for a total score. The higher score received indicates a higher level of self-esteem among the participants. A mean score of 30 out of 40 possible points was revealed through the data analysis. According to this data, the majority of the participants

are well adjusted with regards to self-esteem. Participant one stands out as having a lower level of self-esteem with her score being ten points below the mean score.

Figure 2



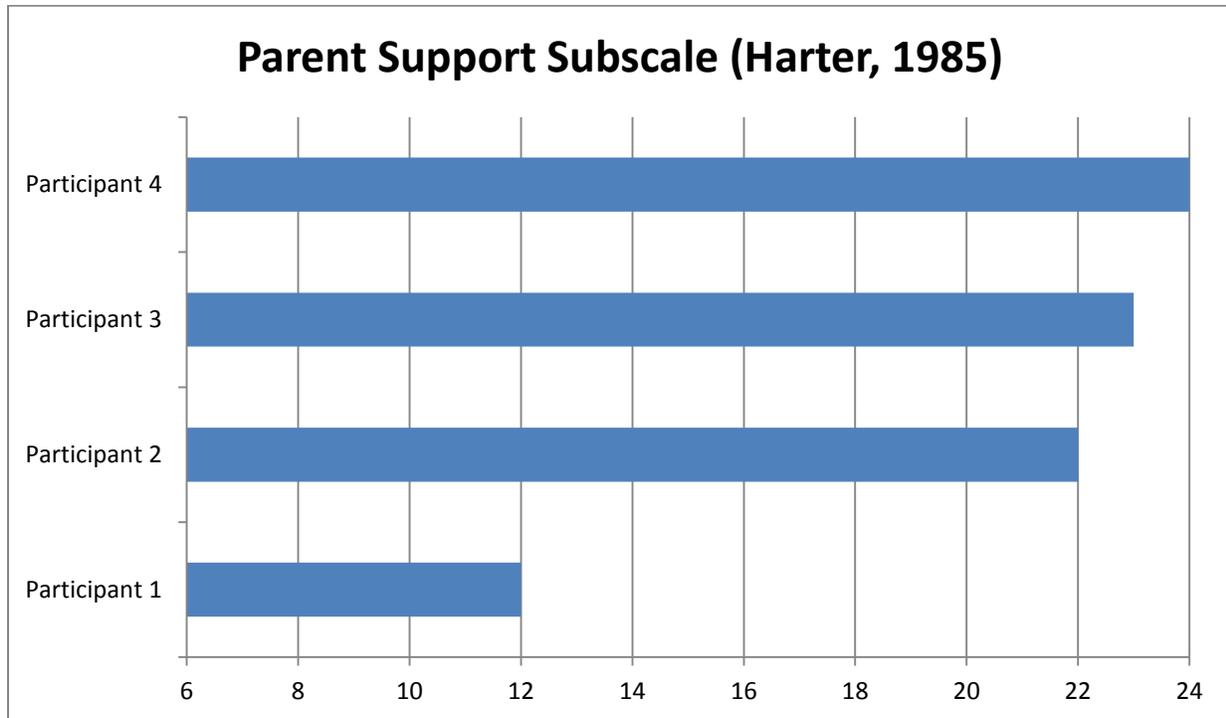
Home Life and Support Systems

In order to explore how parental support affects the social and emotional adjustment of the participants, the Parent Support Subscale (Harter, 1985) was utilized. The scale aided in determining if parental support, involvement, and praise contributed to the adjustment of the participants, and also offered insight on to whether or not having a child with a disability in a family can affect how the typically developing sibling interacts with his or her parents.

A mean score of 20.25 out of 24 points revealed that overall the participants feel that they receive support from their respective parents. The data was scored according to the provided Likert scale, with a higher score indicating a higher level of feeling of support. While

participants two, three, and four scored very high on the scale, participant one scored well below the mean score, as seen in Figure 3. The low score reflects feelings of lack of appreciation, support, and understanding from the parents which in turn can lead to maladjustment.

Figure 3

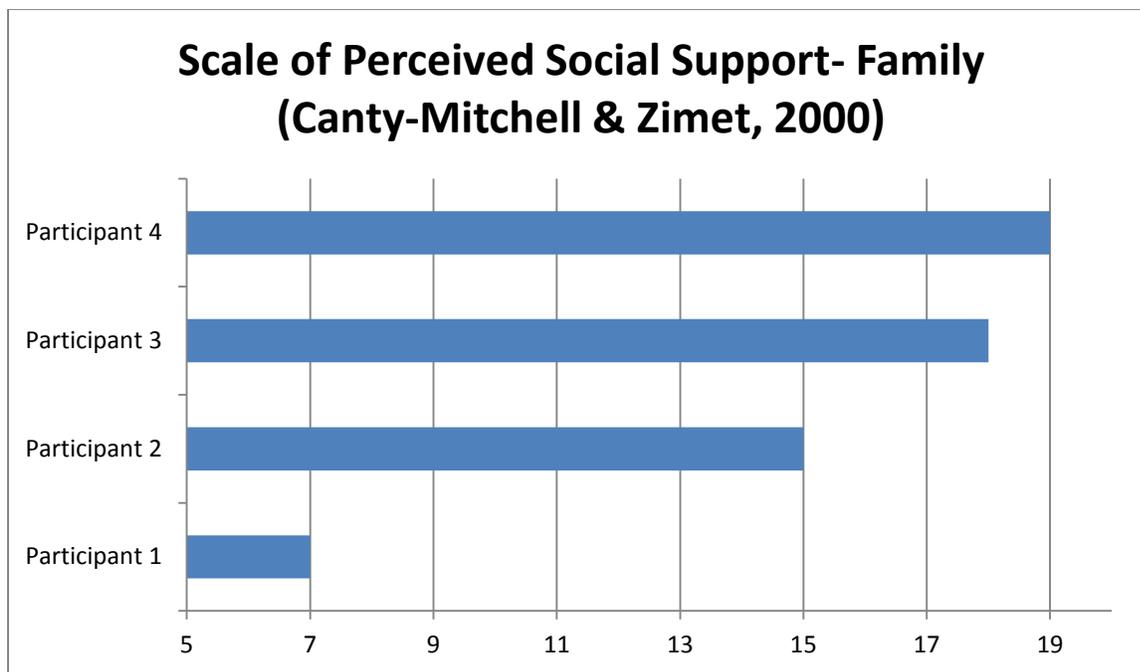


The Scale of Perceived Social Support- Family (Canty-Mitchell & Zimet, 2000) aimed to measure how the participant feels that their family members support them emotionally, with regards to making decisions, and how comfortable he or she is seeking assistance from a family member. The data recorded in this scale helped to understand how siblings feel about their familial relationships, and how they feel that they fit into their own family dynamic.

The data produced from this scale produced a mean score of 14.75 out of a possible 20 points. Participants three and four scored very similarly on this scale, thus showing that they feel a strong sense of support from their family members. Participant two scored slightly above the

mean score, but quite a bit lower than participants three and four, causing the researcher to infer that there may be a struggle with how much support participant three is receiving. Participant one scored significantly lower than the other participants on this scale. Participant one scored well below the mean score, which indicates negative feelings regarding the lack of support from family members.

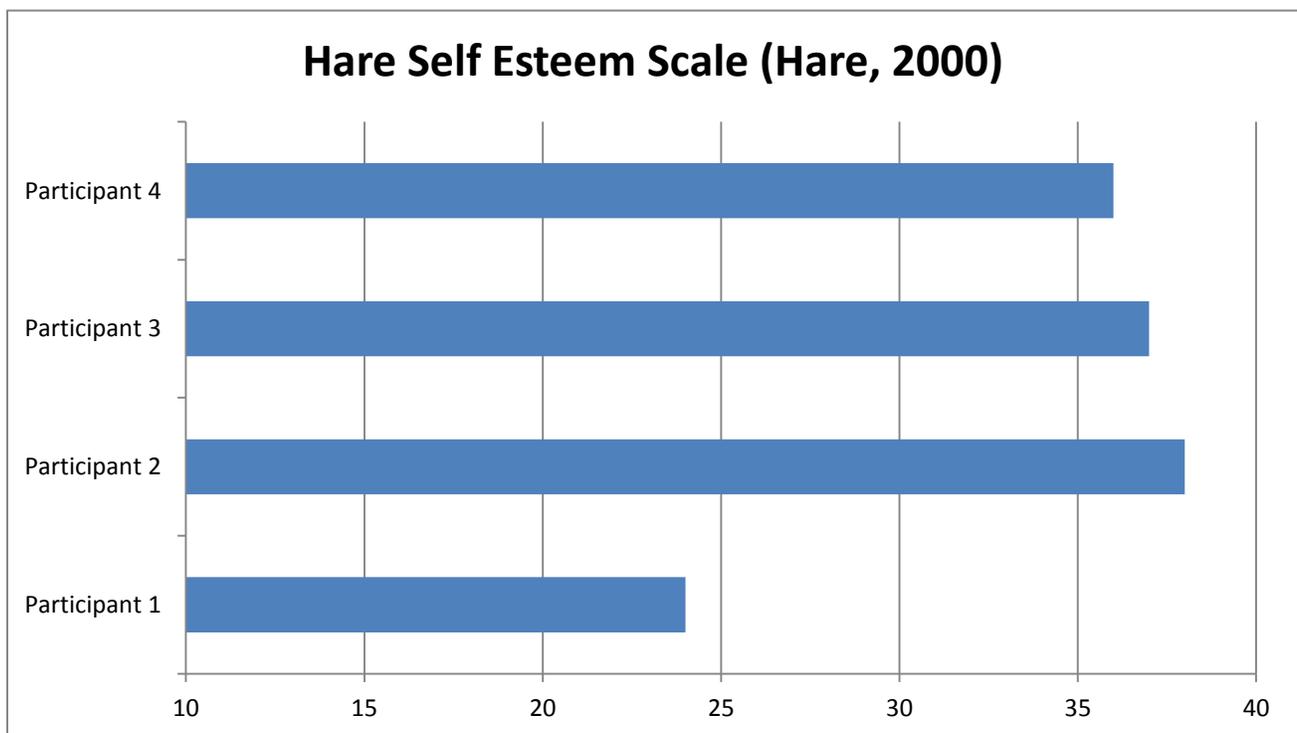
Figure 4



The Hare Self Esteem Scale (Hare, 2000) explored whether or not participants felt as though they could be themselves around their family members. Questions asked the participants how they felt with regards to parental expectations, the amount of attention that they receive, and how well they fit into their family.

The results of this scale produced a mean score of 33.75 out of a possible 40 points. Participants two, three, and four scored consistently high, and again participant one scored very low on the scale. Participant one scored a 24 out of a possible 30 points, 9.75 points below the average. The results imply that participants two, three, and four are well adjusted and feel comfortable around their family members, while participant one is struggling with not only self-esteem, but her self-esteem when it comes to interactions with other family members. The results are further reflected in Figure 5.

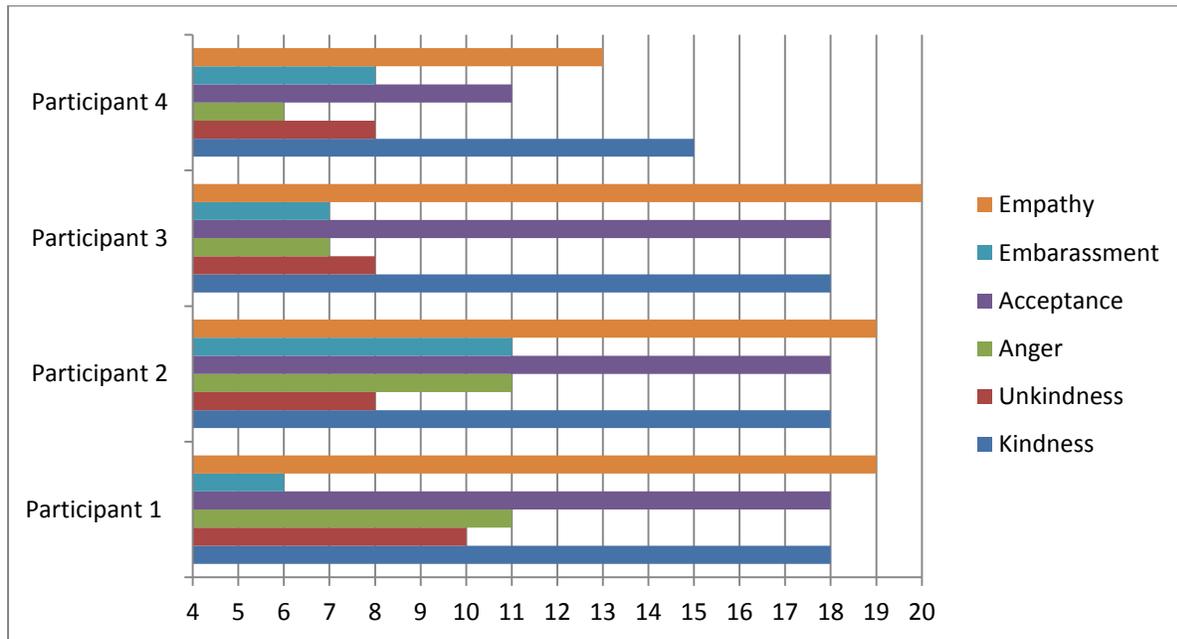
Figure 5



Relationships with Siblings

In order to collect data regarding the relationships between the typically developing siblings and their disabled sibling, the (adapted) Sibling Inventory of Behavior (Schaefer & Edgerton, 1979) was utilized. This scale offered data regarding adjustment in the categories of empathy, embarrassment, acceptance, anger, unkindness, and kindness. Questions were grouped into the categories, and a score was received for each.

The response data were broken down into the various categories and graphed with the results (Figure 6). All participants scored relatively high in the category of empathy, with a mean score of 17.75 out of 20. Participants reported minimal feelings of embarrassment towards their disabled sibling, as the mean score in this category was 8 out of 20. Participants one, two, and three, reported very strong feelings of acceptance towards their sibling, as they all scored an 18 out of 20 possible points. Participant four scored below the mean of 16.25 with a reported 11 out of 20 points. This implies that this participant is potentially struggling with the acceptance of her sibling's disability. The category of anger resulted in a mean score of 8.75 out of 20. Participants three and four scored below the mean, showing that they experience little anger towards their disabled sibling. Participants one and two scored above the mean score, reporting an 11 out of 20 points. This data may reflect feelings of anger and resentment towards the disabled sibling. The mean score for the category of unkindness was 8.5 out of 20, with participants two, three, and four scoring below the average. All participants scored high in the category of kindness, with a mean score of 17.75 out of 20. This data implies that the typically developing siblings are kind to their disabled sibling on a regular basis. The data is displayed in Figure 6.

Figure 6

Discussion

The results of this study indicate that siblings of children with disabilities are normally adjusted socially and emotionally. The data offers a strong overall picture of how the typically developing siblings are adjusted across multiple categories. Although one participant stood out as struggling in multiple areas, the majority of the participants scored high in areas of adjustments.

Perceived Self Worth

According to the data collected from the Social Self-Efficacy Scale (Muris, 2011) there is not a strong indication that siblings of children with disabilities are maladjusted. Three out of the four participants scored very high on the scale, and a mean score of 31.5 out of 40 points was found. A high mean score indicates a high level of self-efficacy and positive thoughts about

one's self. This would indicate that the siblings are well adjusted, and not struggling with negative thoughts or feelings about themselves. This also leads the researcher to believe that the participants are not at a risk for developing internalizing behavior problems. These findings were similar to the research studies that were explored in the literature review, which revealed that siblings of children with disabilities are not significantly maladjusted socially or emotionally (Pilowsky et.al, 2004, Cuskelly & Gunn, 2006), and that they are not at any risk for internalizing behavior problems.

The data from Rosenberg's Self Esteem Scale (Rosenberg, 1969) indicated that the majority of the siblings were well adjusted with regards to their self-esteem, self-worth, self-respect, and their perceived ability to meet their accomplishments. However, one participant scored significantly lower than the other three, thus showing a potential for maladjustment, and an increased struggle with self-esteem. Participant one's results may reflect an increased risk for anxiety and depression, as Lobato et al . (2011) argues in her research study found in the literature review.

Home Life and Support Systems

Petalas et al. (2012) revealed that siblings of children with disabilities feel as though they experience differential maternal treatment, mainly higher levels of criticism and expectation from the mother. The results attained from the Parent Support Subscale (Harter, 1985) offered different results, with three out of four siblings scoring high, thus displaying feelings of support, and positive interactions from their family members. One participant stood out again as having a significantly lower score than the rest. This data could reflect poor familial relationships, whether it be specifically with the mother, or other family members. The data from this scale

does not provide enough evidence to support the hypothesis that siblings of children with disabilities are maladjusted with regards to their family interactions, and support systems.

The Scale of Perceived Social Support- Family (Canty-Mitchell & Zimet, 2000), and the Parent Support Subscale (Harter, 1985) offered varying results in this study. With relation to the mean score, the participants scored high, in the middle, and one participant scored very low. This data demonstrates inconsistent findings in this category. Although the majority of the participants were seemingly well adjusted, further research and exploration may yield more conclusive information. Participant one's score is again, significantly lower than the rest of the participants' scores. Feelings of lack of support may be present, and the sibling may be experiencing some internalizing behavioral problems. However, there is not enough consistent data from this scale to infer that siblings of children with disabilities are maladjusted.

Relationships with Siblings

In order to evaluate sibling relationships and interactions, the (adapted) Sibling Inventory of Behavior (Schaefer & Edgerton, 1979) was used. This scale was broken down into categories of empathy, embarrassment, acceptance, anger, unkindness, and kindness. Sibling relationships and understanding of the disabled sibling's disability can have a significant effect on the adjustment of the typically developing sibling's future relationships and interactions. Tanaka, Uchiyama, and Endo (2011) argue that the typically developing sibling's understanding of their sibling's disability can impact the typically developing sibling's social and emotional development. After the analysis of the scale, it would appear as though all of the participants were knowledgeable about their sibling's disability, as there were minimal categories that stood out as being signs for potential maladjustment.

All of the siblings scored high in the category of empathy, which leads the researcher to believe that the typically developing siblings have experienced positive interactions with their siblings, and that they are aware of their sibling's disabilities. High scores were also reported in the category of acceptance. High scores of acceptance can imply that positive social and emotional interactions are occurring between the siblings. A previous study by Benderix and Sivberg (2007) reported that feelings of indifference and embarrassment are commonly found in typically developing siblings who do not have a clear understanding or representation of the disability of their sibling. Participants scored relatively low in the category of embarrassment, which would support the findings in the previous study, and indicate that the participants have a clear understanding of their sibling's disabilities.

The data in the category of unkindness is consistent and scored relatively low. Siblings go through tumultuous times, and are bound to argue with each other, but the data does not reflect that the participants are outwardly unkind towards their sibling on a regular basis. All participants scored consistently high in the category of kindness. The results indicates that the participants are kind to their siblings, which could relate back to the typically developing sibling's understanding of the disabilities, and prior interactions between the two siblings.

Implications for Future Research

The four participants in the study are siblings of children of varying ages with Autism Spectrum Disorder of varying degrees of severity, and also one sibling of a child with Down syndrome. Future researchers could replicate this study and expand to other disability categories. If future researchers can find a correlation, whether positive or negative between being a sibling of a child with disabilities and social and emotional maladjustment then we will

be able to pinpoint their needs, and find appropriate services to offer them. If a child needs extra services and is not receiving them, then that only adds to the struggles and maladjustment that they may be faced with. If the non-disabled child is able to work through their maladjustment, and utilize the services, then it may be possible that the rest of the family will function better as a unit, thus making it a more cohesive, and positive environment for both the disabled and non-disabled child.

Specific factors that affect the social and emotional adjustment of these siblings can be preliminarily identified through this study, and can lead researchers to explore interventions, and ways to combat negative factors. If these factors can be identified early, the families can work together with researchers and practitioners to collaborate on early intervention and educational services for the siblings, and potentially the whole family. Early intervention strategies and education can also be studied by future researchers, and may implicate a positive impact for typically developing siblings.

Limitations

A limitation of this study is the fact that I, the researcher know all of the participants personally. One participant is my younger sibling, the second participant is a cousin, the third participant is a family friend, and the fourth participant is a coworker. In order to ensure that confidentiality was maintained, a third party removed the identifying information from the participants' surveys. The removal of identifying information helped to ensure that participants felt comfortable answering the questions, and that they answered honestly without feeling as though they would be scrutinized.

Although the removal of personal information allowed for more honest and thorough answers on the surveys, it led to another limitation in the study. The researcher was hoping to analyze whether or not age was a factor in the adjustment of the typically developing siblings, however with the removal of the personal information from the surveys, the researcher was unable to know the age of each specific participant.

When beginning this study the researcher had hoped to work solely with siblings of children with Autism Spectrum Disorder. One of the potential participants was unable to continue with the study, so the researcher reached out to others, and was able to recruit two more participants, one with a sibling with Autism, and one who was a sibling of a child with Down syndrome. There are few studies that exist that focus solely on one disability category, and the researcher's hopes were that the study could become a part of that group. By adding another disability to my study, an additional limitation was introduced; there are already studies that exist with surveying siblings of children with different disabilities. The results may have differed, had the researcher focused solely on one disability.

Conclusion

This research study looked to explore whether or not siblings of children with disabilities are affected socially and emotionally. The findings from the study do not strongly indicate social or emotional maladjustment in siblings of disabled children. The findings show that the majority of the participants were well adjusted, and were not significantly affected in their day to day lives. Future research could benefit from focusing on a larger sample, and one specific disability category for a stronger analysis.

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Appendix A

Social Self Efficacy Scale (Muris, 2001)

Circle the answer that best shows how well you can do each of the following things.

1. How well can you express your opinions when your classmates disagree with you?	Not Very Well 1	2	3	4	Very Well 5
2. How well can you become friends with other youth?	Not Very Well 1	2	3	4	Very Well 5
3. How well can you have a chat with an unfamiliar person?	Not Very Well 1	2	3	4	Very Well 5
4. How well can you work in harmony with your classmates?	Not Very Well 1	2	3	4	Very Well 5
5. How well can you tell other youth that they are doing something that you don't like?	Not Very Well 1	2	3	4	Very Well 5
6. How well can you tell a funny event to a group of youth?	Not Very Well 1	2	3	4	Very Well 5
7. How well do you succeed in staying friends with other youth?	Not Very Well 1	2	3	4	Very Well 5
8. How well do you succeed in preventing quarrels with other youth?	Not Very Well 1	2	3	4	Very Well 5

Appendix B

Rosenberg's Self Esteem Scale (Rosenberg, 1969)

Circle the answer that shows how much you agree or disagree with each statement.

1. On the whole, I am satisfied with myself	Strongly Agree	Agree	Disagree	Strongly Disagree
2. At times I think I am no good at all	Strongly Agree	Agree	Disagree	Strongly Disagree
3. I feel that I have a number of good qualities.	Strongly Agree	Agree	Disagree	Strongly Disagree
4. I am able to do things as well as most other people.	Strongly Agree	Agree	Disagree	Strongly Disagree
5. I feel I do not have much to be proud of	Strongly Agree	Agree	Disagree	Strongly Disagree
6. I certainly feel useless at times.	Strongly Agree	Agree	Disagree	Strongly Disagree
7. I feel that I am a person of worth, at least on equal plane with others.	Strongly Agree	Agree	Disagree	Strongly Disagree
8. I wish I could have more respect for myself	Strongly Agree	Agree	Disagree	Strongly Disagree
9. All in all, I am inclined to feel like I am a failure.	Strongly Agree	Agree	Disagree	Strongly Disagree
10. I take a positive attitude toward myself	Strongly Agree	Agree	Disagree	Strongly Disagree

Appendix C

Parent Support Subscale (Harter, 1985)

Check only ONE box for each question. For each question, decide first which statement is most like you. Then put an X in one of the answer boxes next to that statement. It should look like the sample item below.

	Really True for Me	Sort of True for Me	<u>Only choose one answer for each question</u>		Sort of True for Me	Really True for Me
Sample Item						
S A M P L E	X		Some kids like to do fun things with a lot of other people.	BUT	Other kids like to do fun things with just a few people.	
1.			Some kids have parents who don't really understand them.	BUT	Other kids have parents who do really understand them.	
2.			Some kids have parents who don't seem to want to hear about their children's problems.	BUT	Other kids have parents who do want to listen to their children's problems.	
3.			Some kids have parents who care about their feelings.	BUT	Other kids have parents who don't seem to care very much about their children's feelings.	
4.			Some kids have parents who treat their children like a person who really matters.	BUT	Other kids have parents who don't usually treat their children like a person who matters.	
5.			Some kids have parents that like them the way they are.	BUT	Other kids have parents who wish their children were different.	
6.			Some kids have parents who don't act like what their children do is important.	BUT	Other kids have parents who do act like what their children do is important.	

Appendix D

Hare Self Esteem Scale (Hare, 2000)

Circle the answer that best shows how much you agree or disagree with each of the following statements.

1. My parents are proud of the kind of person I am	Strongly Disagree	Disagree	Agree	Strongly Agree
2. No one pays much attention to me at home.	Strongly Disagree	Disagree	Agree	Strongly Agree
3. My parents feel that I can be depended on.	Strongly Disagree	Disagree	Agree	Strongly Agree
4. I often feel that if they could, my parents would trade me in for another child.	Strongly Disagree	Disagree	Agree	Strongly Agree
5. My parents try to understand me.	Strongly Disagree	Disagree	Agree	Strongly Agree
6. My parents expect too much of me.	Strongly Disagree	Disagree	Agree	Strongly Agree
7. I am an important person to my family.	Strongly Disagree	Disagree	Agree	Strongly Agree
8. I often feel unwanted at home.	Strongly Disagree	Disagree	Agree	Strongly Agree
9. My parents believe that I will be a success in the future.	Strongly Disagree	Disagree	Agree	Strongly Agree
10. I often wish that I had been born into another family.	Strongly Disagree	Disagree	Agree	Strongly Agree

Appendix E

Scale of Perceived Social Support – Family (Canty-Mitchell, & Zimet, 2000).

Circle the answer that best reflects how much of the time each of these statements is true for you.

1	My family really tries to help me.	Rarely or Never	A Little Bit	Sometimes	A Good Part of the Time	Always
2	I get the emotional help and support I need from my family.	Rarely or Never	A Little Bit	Sometimes	A Good Part of the Time	Always
3	I can talk about my problems with my family.	Rarely or Never	A Little Bit	Sometimes	A Good Part of the Time	Always
4	My family is willing to help me make decisions.	Rarely or Never	A Little Bit	Sometimes	A Good Part of the Time	Always

Appendix F

Adapted Sibling Inventory of Behavior (Schaefer & Edgerton, 1979)

	Never	Seldom	Sometimes	Often	Always
1. I am pleased by progress he/she makes	1	2	3	4	5
2. I show/tell him/her interesting things	1	2	3	4	5
3. I tease/annoys him/her	1	2	3	4	5
4. I help him/her in any way possible	1	2	3	4	5
5. I gets angry with him/her	1	2	3	4	5
6. I accept him/her as a playmate	1	2	3	4	5
7. I am embarrassed to be with him/her in public	1	2	3	4	5
8. I want him/her to succeed	1	2	3	4	5
9. I stay away from him/her if possible	1	2	3	4	5
10. I get ideas for things we can do together	1	2	3	4	5
11. I do things to please him/her	1	2	3	4	5
12. I fuss/argue with him/her	1	2	3	4	5
13. I have fun at home with him/her	1	2	3	4	5
14. I act ashamed of him/her	1	2	3	4	5
15. I show sympathy when things are hard for him/her	1	2	3	4	5

	Never	Seldom	Sometimes	Often	Always
16. I frown/pout when I have to spend time with him/her	1	2	3	4	5
17. I teach him/her new skills	1	2	3	4	5
18. I say unkind things to him/her	1	2	3	4	5
19. I help him/her adjust to new situations	1	2	3	4	5
20. I treat him/her as a good friend	1	2	3	4	5
21. I try to avoid being seen with him/her	1	2	3	4	5
22. I am concerned for his/her welfare/happiness	1	2	3	4	5
23. I would rather be alone than with him/her	1	2	3	4	5
24. I make plans that include him/her	1	2	3	4	5
25. I hurt his/her feelings	1	2	3	4	5
26. I try to comfort him/her when he/she is upset	1	2	3	4	5
27. I complain about the trouble he/she makes	1	2	3	4	5
28. I am glad to have him/her in the family	1	2	3	4	5

Appendix G**PARTICIPANT CONSENT FORM****Adjustment of Siblings Study**

You are invited to take part in research about the social and emotional adjustment of siblings of children with Autism Spectrum Disorder. You are a potential participant because you are a sibling of a child with Autism. The research is being conducted by Rhianna Gerfin. I ask that you read this form before agreeing to participate in this study.

Purpose

The purpose of the research is to find out the factors that affect the social and emotional adjustment of siblings of children with disabilities.

Procedures

If you agree to be in this research, and sign this consent form, I ask that you complete six different scales. Each scale should only take 10-15 minutes to complete.

Risks and Benefits

You will be asked to answer questions that directly ask about your self-esteem, parental relationships, family dynamics, and relationships with your sibling. Some of the questions may be personal, but the information will not be shared with anyone else. You may refuse to answer any questions on the scales and surveys that will be sent to you. I will not share this information with anyone, and your identity will remain confidential as the results are graphed.

The benefits of this study include finding consistencies among siblings of children with autism with regards to their social and emotional adjustment. If a consistency can be found, then future researchers may be able to replicate this study, and it may allow them to further strategies for differentiated instruction, and find appropriate services for siblings of children with Autism.

Confidentiality

The results of this study will be kept private, and only used for the purpose of completing a Master's Thesis Project. In any sort of report of the study, I will not include any information that will make it possible to identify you. Your name and other identifying information will not be kept with this survey. The surveys and results will be kept in a locked file cabinet, and only the researcher for this study will have access to the records.

Voluntary nature of study

Your decision whether or not to participate in this research will not affect your current or future relations with the researcher. Even if you sign the consent form, you are free to stop your participation in the study at any time. You do not need to complete it if you feel uncomfortable doing it.

Contact

You can ask questions about the study at any time. If you have questions or decide you want to stop participating in this study, please contact Rhianna Gerfin. Additionally, you may also contact the following individuals if you have any questions.

Dr. Carrie Fitzgerald

Cathe Kilpatrick

SUNY Fredonia Faculty Member

Acting Human Subjects Administrator

(716) 673-3702

(716) 673-3528

Carrie.Fitzgerald@fredonia.edu

Catherine.Kilpatrick@fredonia.edu

If you have questions regarding your rights as a research subject, you may contact Cathe Kilpatrick, Acting Human Subjects Administrator. You may also contact her about any problems, complaints, or concerns related to this research study.

I, _____, want to be involved with Rhianna Gerfin's research study described in this form.

Signature: _____

Date: _____

Appendix H

PARENT CONSENT FORM

ADJUSTMENT OF SIBLINGS STUDY

Please print CLEARLY

Name of parent or guardian: _____

Address: _____

Telephone: _____

I am the legal guardian of _____. I consent for her to participate in a research study on the social and emotional adjustment of siblings of children with disabilities. I understand that Rhianna Gerfin, a graduate student in the College of Education at SUNY Fredonia is the principal investigator in this study.

I understand that participation in this study includes the following commitment for my child and me:

- 1) Read and sign this consent form.
- 2.) My child will complete scales related to her self-esteem, parental relationships, family dynamics, and relationships with your sibling. Some of the questions may be personal, but the information will not be shared with anyone else.
- 3.) Your child may refuse to answer any questions on the scales and surveys that will be sent to her. I will not share this information with anyone, and your child's identity will remain confidential as the results are graphed.

Procedures

I understand that my child will complete scales related to her self-esteem, parental relationships, family dynamics, and relationships with your sibling. Some of the questions may be personal, but the information will not be shared with anyone else. I understand that I can contact Rhianna Gerfin at (716) 361-0284 about any concerns I have about this project. I understand that I may also contact Cathe Kilpatrick, Acting Human Subjects Administrator about any problems, complaints, or concerns related to this research study.

Confidentiality

All information obtained in this project will be kept private by the principal investigator of this research study. All information will be stored in a locked file cabinet. I understand that no information about my child will be released and no names will be recorded other than the consent forms.

Risks and Benefits

I understand that the risks of participating in this study are minimal. I understand that participating in this study will help the researchers better understand the factors that affect the social and emotional adjustment of siblings of children with Autism Spectrum Disorder.

Right to Refuse Participation

Participation in this study is voluntary. Your child has the right not to participate at all or to leave the study at any time. Deciding not to participate or choosing to leave the study will not result in any penalty or loss of benefits to which your child is entitled, and it will not harm his/her relationship with the researcher. If you or your child decides to leave the study, your child's data will be removed from any papers or projects published by Rhianna Gerfin. **You are able to remove your child from at any time throughout the study.**

Contact

You can ask questions about the study at any time. If you have questions or decide you want to stop participating in this study, please contact Rhianna Gerfin. Additionally, you may also contact the following individuals if you have any questions.

Dr. Carrie Fitzgerald

Cathe Kilpatrick

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If you have questions regarding your rights as a research subject, you may contact Cathe Kilpatrick, Acting Human Subjects Administrator. You may also contact her about any problems, complaints, or concerns related to this research study.

I, _____, consent for my child to be involved with Rhianna Gerfin's research study described in this form.

Signature: _____

Date: _____