

**THE EMOTIONAL AND SOCIAL EFFECTS OF HAVING A SIBLING WITH A  
DISABILITY**

by

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CERTIFICATION OF THESIS/PROJECT CAPSTONE WORK

We, the undersigned, certify that this project entitled THE EMOTIONAL AND SOCIAL EFFECTS OF HAVING A SIBLING WITH A DISABILITY by LINDSEY COX, Candidate for the Degree of Master of Science in Education, Curriculum and Instruction in 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 that is being asked in this study is: What are the emotional and social effects of having a sibling with a disability? There are 4 participants who completed three different questionnaire's that assessed the participants' self esteem, their relationship with their parent(s) or guardian(s) as well as their relationship with their sibling who has a disability. The participants varied in ages from 18-30 years old and the disabilities that their siblings have consisted of Down syndrome and varying intellectual disabilities. Though there has been research done on this topic before, results of those studies have revealed many inconsistencies in regards to whether or not siblings of people who have a disability are affected emotionally and socially. This study aims to potentially recognize consistencies among siblings of people who have Down syndrome and varying intellectual disabilities. If the specific needs are pinpointed, educators could provide appropriate services to help the typically developing student. If a child is not receiving the services that he/she needs, this could potentially affect his or her emotional and social health.

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## Chapter 1: Introduction

The birth of a child with a disability, or the discovery of a disability that a child has, has a significant effect on a family. Children will suddenly have to adjust to having a sibling who may need more time, attention, money and support. It can be extremely difficult for the entire family to make adjustments in order to support the child who has a disability and also provide attention and support for the other children in the family. The sibling(s) of the child who has a disability may be affected socially and emotionally because of this.

When one child has a disability, the family dynamic may shift and the attention and focus may be on the child who has the disability. The other children in the family may feel ignored because of this. Adams (2013) stated that,

But I also believe that the dynamics are quite different when one sibling is disabled. Instead of starting off with perfect equality, there is an immediate imbalance of health and ability. Instead of discovering, years down the road, how life's gifts have not been fairly apportioned, that is where the relationship begins. There is abundant literature on the consequences of growing up with a sibling who is disabled, much of it negative. Books with titles like, "What About Me?," "Being The Other One" and "The Normal One: Life With A Difficult or Damaged Sibling" report that the able bodied child is often neglected as his or her needs are subordinated to the more pressing demands of the disabled sibling (p. 1).

The author of this article was a mother with two children: one who has a disability and one who is a typically functioning child. Even she, as a mother, was able to see how siblings of a child who has a disability can feel as though they do not receive the attention and support that

their sibling receives. She was able to realize that maybe her attention is more focused on the child who has a disability instead of trying to attend to the needs that both of her children have.

Often times, the child with a disability becomes the main focus of everyone in the family. DeLuke, a sibling of a person who has a developmental disability, commented:

Until I left for college, our family operated as one whole unit, with my sister's disability as the controller. It controls my mom, who sacrificed her passion and her work to care for my sister 24/7. It controls my dad, who works hours longer than anyone ever should to provide for us all. And it controls me, in ways I didn't even realize until recently, but mainly it controls me emotionally. When you're 6 years younger than your sibling, and suddenly the older sibling role is thrown at you, you have no choice but to face it. No choice but to mature at a faster pace than your peers around you are. (2014, p.1)

Despite the six-year age gap, DeLuke had to step up and be able to take care of her older sister when necessary. As DeLuke was meeting milestones that her sister was not meeting, she quickly realized that her sister would always be the main focus of their family. This had an effect on DeLuke as she was able to see how the disability affected both her mother and father. DeLuke also commented on how this situation affected her emotionally all throughout her life.

Bowen Family Systems Theory (1966) states that the family is an emotional unit and uses systems thinking to describe the complex interactions in the unit. The theory also states that 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, 1996). When a member of the family is diagnosed with a disability, there are certainly going to be changes in the rest of the family. The priorities of the family change and everyone is affected in one way or another, and often times the siblings are

overlooked due to the disability discovered. The Bowen theory (1966) states that, “The emotional interdependence presumably evolved to promote the cohesiveness and cooperation families require to protect, shelter, and feed their members. Heightened tension, however, can intensify these processes that promote unity and teamwork, and this can lead to problems” (p. 1[RLD2]). If so much of the attention of the family is focused on the child with a disability, the emotional and social health of the sibling(s) may be affected.

Relationships within the family as well as the mental health status of a sibling of a student with a disability can be strongly impacted. Gray (2013) stated that:

Researchers found that compared with siblings of typically developing children, parents said that siblings of children with a disability were less likely to have a very good or excellent mental health status; felt the sibling gets sick more easily; had interpersonal problems with their mother, siblings or adults in general; were more likely to seem unhappy, sad, nervous or afraid; and had more problems with schoolwork or in leisure or sports activities. (p. 1)

A child’s home life and the challenges that may be going on in their household may have a strong impact on their ability to focus and learn in school. Their home life could also have strong impacts on them both socially and emotionally. If siblings of children with disabilities are being affected in some way and are having difficulty socially and emotionally, their mental health status may be at risk. Having a sibling with a disability can also affect the relationships that the student has or that they are trying to create. Some educators believe that the siblings of students with disabilities are not affected but there are studies that show that the siblings do have trouble making adjustments socially and emotionally. Williams (1997) reported:

the negative manifestations of increased risk in siblings, such as feelings of loneliness and isolation, anxiety, depression, vulnerability, anger, worry about the ill child, school problems, poor peer relations, withdrawal or shyness, somatic complaints, low self-esteem, and behavior problems (internalizing and externalizing). (p. 51)

A student who has a sibling with a disability may experience all of these different emotions throughout their lives. As a result of feeling all of these emotions, a person may begin to suffer socially and/or emotionally.

There are not a lot of services for the siblings of students with disabilities. Two of the services that are available for siblings are Sibling Support Project and We The Siblings. The siblings of students with disabilities would benefit from support groups like these and other types of services but there just are not that many available. Cook (2004) reported:

Many suffer embarrassment about their siblings' inappropriate behavior or abnormal appearance and then feel guilty about it. There are difficult emotions for students to struggle with, and Don Meyer, director of the Arcs sibling support project, says the needs of siblings like Mr. Seaton are often overlooked. Most assistance organizations and support groups are intended for disabled children themselves or for their parents. (p.1)

According to Cook, there are a lot of organizations and support groups for the person with the disability, but very few for the sibling who may be affected by this. These students often feel embarrassed of their sibling, and then that embarrassment turns into guilt. These are emotions that take a huge toll on a person and most likely affects this person in an emotional and social manner. If there were services available for these students, it may help their social and emotional health.

I am interested in studying this because as a teacher, I may come across these students in my classes. Some of these students seem completely unaffected by their sibling's disability, while others seem to have difficulties in school. I have had students come up to me and tell me that their sibling gets a lot of attention and that they feel left out of things. I have had students tell me that they feel as though their parents are spending so much time with their sibling with a disability and hardly pay attention to them. I hope to gain knowledge on this topic through a review of related literature and interview siblings of students with disabilities so that I can learn how they are affected. This study hopes to answer the question that is: What are the emotional and social effects of having a sibling with a disability? I plan to conduct this research by giving four participants different questionnaires that will assess their self-esteem, their relationship with their parents and their relationship with their sibling who has the disability. There has been research done on this topic before and results seem to be inconclusive. I hope to narrow the gap and focus on two siblings of students who have Down Syndrome and two siblings of students who have an Intellectual disability. This research will explore the social and emotional effects of siblings of a child with a disability as this is a prevalent issue in education today. In the following chapter, I will review the literature related to siblings of a child with a disability.

## Chapter Two: Literature Review

In the previous chapter, I introduced the problem of whether siblings of students who have a disability are affected socially and emotionally. This chapter is intended to review the literature on this topic and to see what kind of research has already been done.

Many researchers have investigated the effect of children with disabilities on siblings. In a study conducted by Giallo and Gavidia-Payne (2006), 49 families of children with intellectual, sensory, physical or developmental disabilities (aged 7-16 years old) and parents provided information about sibling daily hassles and uplifts, sibling coping, parent stress, parenting and family resilience. The self-report measures that were used were The Sibling Daily Hassles and Uplifts Scale, The Self-Report Coping Scale, The Strengths and Difficulties Questionnaire – Parent Version, The Perceived Stress Scale, The Parent Behavior Questionnaire, The Family Hardiness Index, The Family Problem Solving Communication Index and The Family Time and Routines Index. These surveys were mailed to the families who were willing to participate in the study. The results showed that the family level of risk and resilience factors were better predictors of sibling adjustment than siblings' own experiences of stress and coping resources, which shows the importance of parental contributions to the adjustment process. According to Giallo and Gavidia-Payne, "Professionals working with families need to consider the impact of disability on siblings as well as the identified child and their parents" (p. 946) It is evident that a small percentage of siblings are at risk, despite the majority of siblings who reported to have healthy adjustment outcomes. In a study conducted by Hastings (2006), siblings of children with developmental disabilities were assessed twice, 2 years apart. Behavioral adjustment of the siblings and their brother or sister with developmental disability was assessed. Comparisons of adjustment for siblings of children with autism and Down syndrome took place. The participants

in this study were 75 siblings of children with an intellectual disability and other diagnoses. Four measures were included in this study with data collected using maternal reports about both children. A brief demographic questionnaire was used to record basic information about the child with a disability. Based on maternal reports, there were no significant differences in the behavioral adjustment of siblings of children with disabilities. Siblings of children with Down syndrome were reported as better adjusted than children generally. Hastings reported, “it is reasonable to conclude that the findings from these analyses lend to support to a hypothesis that siblings of children with developmental disabilities are at an increased risk for adjustment problems” (p. 1489). The results of this study did conclude that children with developmental disabilities with more behavior problems themselves may place their siblings at risk of behavior problems. This study also concluded that sibling self-esteem could be affected by the public presentation of unusual behaviors from their sibling and lowered self-esteem could place them at risk for other problems. These studies concluded that there are little to no social and/or emotional effects on people who have siblings with a disability.

There are some investigations that show that there are effects on people who have a sibling with a disability. The next investigation (Dyson 2010) used a focus group interview method. Families were contacted through an advertisement in a newsletter that invited parents to join the discussion regarding learning disability and the family. As a result, thirteen parents representing twelve families were included in the focus group. The focus group discussion was guided around questions that were created for the study. Through the discussions, the researcher concluded that there were some effects of having a sibling with a disability. One effect was “accelerated growth”, meaning some siblings have to grow up very quickly (p. 50). Another effect was one that pertains to sisters. Female siblings tended to take on more responsibilities of

caring for their older sibling with the disability. The third effect that having a sibling with a disability has are “negative” (p. 51<sub>[RLD2]</sub>). Negative effects derive from the additional challenge of having a sibling with a disability. Cox, Marshall, Mandeleco and Olsen (2003) examined the coping responses of siblings of children with disabilities. The sample consisted of 46 children and their siblings ranging in age from six to eighteen years old. Families were contacted via telephone and asked to participate in the study and an appointment was made for a home visit with the families who gave permission for the sibling of the child with a disability to participate in the study. A sentence completion instrument that consisted of 18 open-ended statements was used. This allowed siblings to respond to real or hypothetical stressful situations. A total of 750 individual coping responses were produced from this tool. The responses were put into four categories of modes of coping: proactive, internally reactive, interactive and nonactive. Most siblings in this study were proactive and took responsibility for changing or improving stressful situations. These findings may support research that states that siblings have increased responsibility and decreased access to the attention of their parents. The authors reported: “It could be argued that taking on increased burden in the home makes siblings more personally responsible and more proactive when faced with stressful situations” (p. 409). The results of this study also prompted the discussion that adjustment problems in siblings may be related to the extra burdens they assume when living with a sibling who has a disability. These studies concluded that there can be some effects on siblings of people who have a disability.

There have been investigations done by researchers that studied relationships within the family and the overall health of the family. Barnett and Hunter (2011) conducted an empirical study in which they studied 75 siblings and their caregivers. “The Child Behavior Checklist” was completed and it consists of 118 items rating the behavior and competencies of children and

adolescents between the ages of six and eighteen years old. Self-concept was measured in the 8-13 year old participants by using the Self-Perception Profile for Children and in the 14-16 year old participants the Self-Perception Profile for Adolescents was used. The sibling of each person with a disability completed The Family Assessment Device-General Functioning Scale. This measures the overall health of the family. The results of this study conclude that siblings of a person who has a disability are a more vulnerable group to psychological difficulties than would be expected of normally developing children. Aksoy and Bercinyildirim (2008) investigated the relationships of healthy children with their siblings who have a disability and analyzed their acceptance of their siblings. 228 children between the ages of 10-17 participated in the investigation. All participating children had siblings who were diagnosed with a disability. There were three forms of data collection in this study. The siblings of the student with a disability completed the Attitudes Toward Disabled Siblings Questionnaire. The Attitudes towards Disabled Person Questionnaire was also completed by the sibling of the child with a disability. The Persona Data Form was used to obtain more information about all participants. Results showed that the participants viewed their sibling who has a disability in a positive way but had less positive views toward other people who have disabilities.

Studies have been conducted in which the subjects of the study were people who have Down syndrome and their effects that they may have on their sibling. In a study conducted by Cuskelly and Gunn (2006), siblings of children with Down syndrome were examined and compared their findings with the adjustment of children who did not have a brother or sister with a disability. The questionnaires that were used in this study were The Child Behavior Checklist, The Self-Perception Profile for Children and The Sibling Inventory of Behavior. All of the families who were participating were visited at home. Parents completed the Child Behavior

Checklist and children completed the Self-Perception Profile for Children during individual interviews. The authors concluded that being the sibling of a child with Down syndrome does not appear to have a negative impact on either problem behaviors or self-perceptions of competence and these brothers and sisters of a child with Down syndrome do not seem to struggle in their daily lives and have the opportunity to participate in a normal childhood. Gath (1972) conducted a study in which 36 school age siblings of 22 children with Down syndrome and 35 school age siblings of 21 children with facial deformities were studied. The main research instruments that were used were the behavioral scales that were completed by parents and teachers. The researchers also administered a parent interview to explain the research and to ask the parent to complete the behavioral questionnaire. The authors concluded that families who have the student with Down syndrome were experiencing more problems of management of their families. Gath also found that affected siblings were able to develop ways of adapting to the problems that may arise from having a sibling with a disability. These studies focused on siblings of people who have Down syndrome. The results of these studies concluded that siblings did not have adjustment issues and siblings were able to cope and deal with problems that may arise from having a sibling with a disability.

Harvey and Greenway (1982) also explored these issues. There were three groups in this study: two experimental groups and one control group. Each group was made up of pairs of participants, a child and the sibling of the child who has a disability. The Piers-Harris Self Concept Scale for Children titled, "The Way I Feel About Myself" was used as the measure of self-concept. This scale consists of 80 statements such as, "I am a happy person" or "I behave badly at home," and participants must respond using "yes" or "no" to each. The authors of this empirical study concluded that, "the mean scores for siblings of handicapped children were

generally lower than those of the controls” (p. 282). Therefore, siblings of children with a disability had a lower self-esteem than siblings of typically developing people<sup>[RLD4]</sup>.

In conclusion, this literature suggests that there are mixed results coming from studies of siblings of students who have a disability are able to adjust and how these siblings view themselves. Research indicates that a percentage of siblings may be affected in a negative way because of the added responsibility that it puts on them to care for their sibling who has a disability. Research also shows that siblings may be affected negatively because of the way their sibling who has a disability may act outside of the home. Their behaviors could make people view the person with the disability, as well as their sibling, in a negative way, therefore affecting the sibling’s self esteem. Research also shows that siblings of students who have a disability are completely unaffected and that their self-esteem is not affected.

I plan to narrow the sample and study siblings who have either Down syndrome or an intellectual disability. Other research studies have not studied only these two disabilities and the relationship that these people have with their sibling, thus filling a gap in the research.

Therefore, the purpose of this study is to examine four siblings in the Western New York area of people who have a disability. This study is going to narrow the sample, therefore filling a research gap based off of research done in other studies and only study siblings of students who have Down syndrome and varying intellectual disabilities in a setting that is different than where other studies have taken place. The primary research question is: What are the emotional and social effects of having a sibling with a disability? The next chapter will describe how the study was conducted, the participants, setting and a description of the data collection and analysis procedures.

## **Chapter 3: Methodology**

### **Introduction**

In the previous chapter, I reviewed the literature concerning the siblings of students who have a disability. I based my review of the literature on finding studies that focused on siblings of students who have a disability to see if they are affected socially and/or emotionally. Overall, the research findings seemed to be inconclusive. The research concluded that some siblings do not have any type of adjustment issues because they have a sibling with a disability, while other siblings do have negative social and emotional outcomes.

The following chapter will detail the procedures taken for my study. During this research, four people who have a sibling with a disability were given three different questionnaires. They were asked to fill out the questionnaires and return them back to me, the researcher. The questionnaires examined the participants' overall self-esteem, the relationship that they have with their sibling who has a disability and the relationship they have with their parent(s).

### **Research Frameworks**

The research that I conducted called for a design that used both quantitative and qualitative research, known as mixed methods. Bulsara (2012) defines mixed methods as “a methodology for conducting research that involves collecting, analyzing, and integrating (or mixing) quantitative and qualitative research (and data) in a single study or a longitudinal program of inquiry. The purpose of this form of research is that both qualitative and quantitative research, in combination, provide a better understanding of a research problem or issue than either research approach alone” (p. 6 ). Because of this, a mixed methods study was the most beneficial for this type of study.

It is important that, for this study, a mixed methods research design was used. The research integrated different questionnaires in order to learn new information about siblings of students who have a disability and the ways that they are affected in their daily lives. According to Creswell (2016), “Mixed methods research has come of age. To include only quantitative and qualitative methods falls short of the major approaches being used today in the social and human sciences” (p. 4). According to Johnson, Onwuegbuzie, and Turner (2007), “This type of research best suits the type of methodology that will be used. It recognizes the importance of both quantitative and qualitative research methods but also offers a powerful third mixed research methodology that potentially will provide the most informative, complete, balanced, and useful research results” (p. 5). By conducting this type of research, I gained new knowledge about the ways in which siblings of students who have disabilities are affected.

### **Research Setting and Sampling Procedures**

The setting of this research study was in Hamburg, New York, which is just outside of Buffalo, New York. Three of the participants are from Hamburg and one participant lives in Orchard Park, New York. All of the data was collected via email and/or regular mail. Four people were given a variety of questionnaires. After receiving approval from the Human Subjects Review committee at my institution, the participants were recruited based on their having a sibling with a disability(see Appendix F). To recruit these participants, I sent a detailed email stating the question that drives my study, the expectations of the participants and the procedure I am using to collect data(see Appendix E). The data was collected via email and/or regular mail. In order to protect the confidentiality of the participants throughout the study, the questionnaires were collected through a third party. The questionnaires were the same for each participant.

Confidentiality was protected throughout the entirety of the study. The criteria that each of the participants met for this study are:

- 1.) Subjects include both female and male participants.
- 2.) Subjects have a sibling with a disability.

I used purposeful sampling methods when deciding who to recruit for this study. I wanted to focus on people who have a sibling with either Down syndrome or a type of intellectual disability. I also wanted to make sure that I included both male and female participants in this study. I was able to recruit four participants for this study: 3 females and one male. The participants are all close family friends.. One of the participants decided not to participate after reviewing the questionnaires, but I was able to recruit another person to participate in this research study. Two of the participants' siblings have Down syndrome and the other two participants' siblings have an intellectual disability. Each participant signed an informed consent which explained the research project in depth (see Appendix A).

### **Data Collection Procedures**

I used different questionnaires to collect my data (see Appendices B, C and D). The first step in the methodology was to explore the participants' home lives and the parent support systems. This is important because in order to see if the participants are affected socially and emotionally, their home lives need to be taken into consideration. In order to do this, the participants were asked to complete the Perceptions of Parents scale (Robbins, 1994). This instrument measures the way the participant feels about their relationship with their parents. The second step was to have the participants determine their self-worth and self-esteem. This is important because having the participants determine their self-worth and self-esteem will help me to determine if they are affected socially and emotionally because they have a sibling with a

disability. To do this, participants were asked to complete the Rosenberg Self-Esteem scale (Rosenberg 1965). The last step in the methodology was to examine the relationship between the participants and their siblings. To do this, I used the Sibling Inventory of Behavior (Schaefer & Edgerton, 1981). This is the most important questionnaire of the methodology because demonstrates the manner with which the participant feels about their sibling who has a disability.

### **Data Analysis Procedures**

Once I had all of the results from the questionnaires, I analyzed the data that I received and coded the results into graphs and/or charts. The graphs and/or charts that I created showed how the participants feel toward their parents, about themselves and about their sibling who have a disability. 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. I figured out the mean scores for each of the categories for each of the participants so I was able to compare the results. Once the graphs were complete, I was able to decipher the ways in which the participant is affected socially and emotionally based off their results obtained from the questionnaires.

### **Conclusions**

Overall, the methods used during this research helped me to conduct my study in a way that allowed me to find out if people who have a sibling with a disability are affected socially and emotionally. The questionnaires that were collected from each participant gave me a true indication of how they feel about having a sibling with a disability. Because all of this information was confidential, I feel as though the participants were honest and it gave me a true indication about their feelings about their relationship that they have with their sibling who has a disability.

In the next chapter, I will discuss the results of this research study. The results that I obtained from the questionnaires given to the participants were graphed in order to show whether the participants are affected socially and/or emotionally based off of their having a sibling with a disability.

## **Chapter 4: Results**

The study described in Chapter 3 focused on the siblings of people who have Down Syndrome and varying intellectual disabilities. The data was collected from four typically developing siblings of people who have disabilities. Of the participants, three were female and one was male and their ages varied. The participants were asked to complete three questionnaires that examined their relationships with their parents, their self esteem and their relationships with their siblings that have disabilities. The data was taken from these questionnaires, was analyzed and was graphed for each participant.

Overall, the results of the questionnaires showed that each of the siblings are well adjusted and do not seem to be affected socially or emotionally by their relationships with their siblings who have a disability. The mean scores for each of the questionnaires were high, which shows that the participants do not have any difficulties with their lives and are well adjusted people. One of the participants stood out as having a significantly lower self esteem score than the rest of the participants. In the following chapter, I will discuss the major themes that have emerged from the data that was collected in this study.

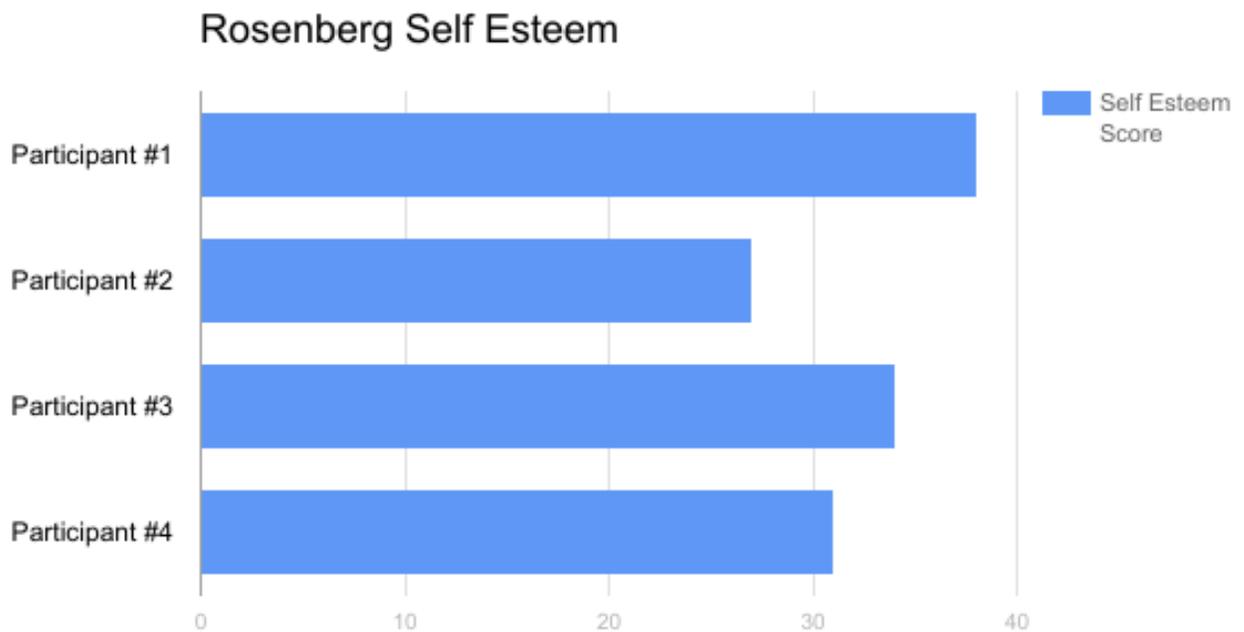
### **Self Esteem**

In order to assess the way each participant feels about him or herself, I used the Rosenberg Self Esteem Scale (Rosenberg, 1969). It is a 10-item scale that measures both positive and negative feelings that people have about themselves. Each of the items are answered using a 4 point Likert scale that ranges from the statement “strongly agree” to the statement “strongly disagree.”

The data was scored according to the Likert scale in which each question had a specific point value and then was summed for a total score. The higher the score that was received, the

higher self esteem of the participant indicated. A mean score of 32.5 out of a possible 40 points was revealed through the analysis of the data. According to this data, each of the participants seem to have a high self esteem, except for Participant #2, who scored 5.5 points below the mean score.

**Figure 1**

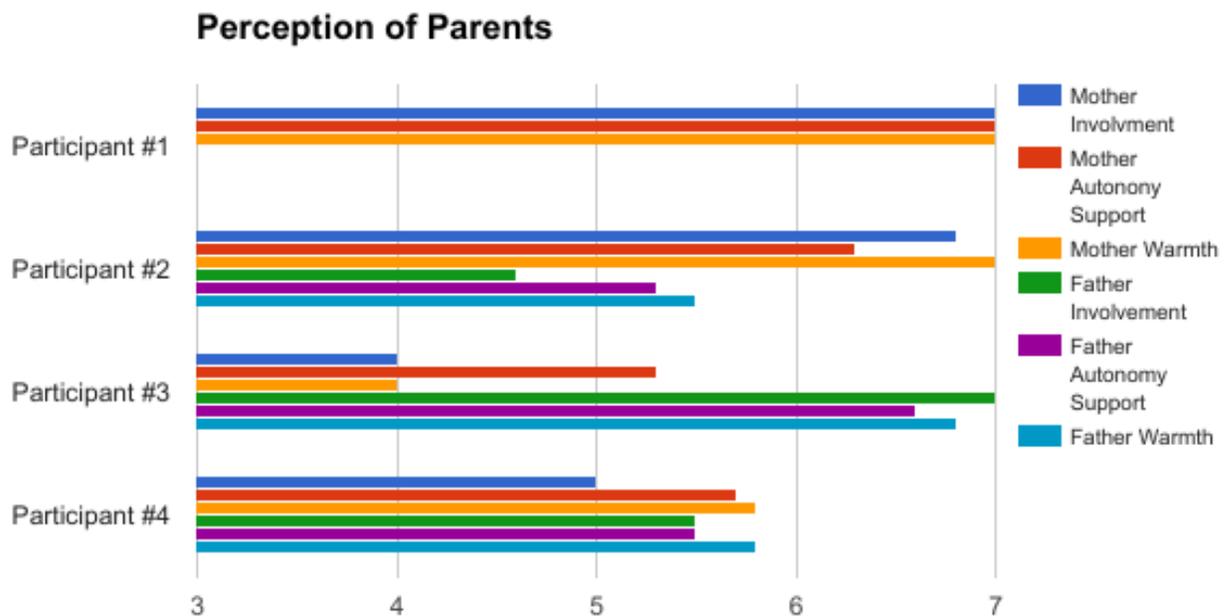


### **Perception of Parents**

It was important to explore the ways that parental support and involvement affected the social and emotional adjustment of each of the participants. In order to do this, I used the Perception of Parents scale (Robbins, 1994.) This scale assessed the participants' perceptions of their parents' support and involvement. The data was scored according to the Likert scale that

was provided and the data was broken up into six different categories, including “mother involvement,” “mother autonomy support,” “mother warmth,” “father involvement,” “father autonomy support” and “father warmth.” The results show that each of the participants seem to have a good relationship with their parents as the mean scores for each category ranged from 5.7-6 out of 7 points. Participant #1’s father is deceased, so the chart below only shows the results for the way he/she feels about his/her mother.

**Figure 2**



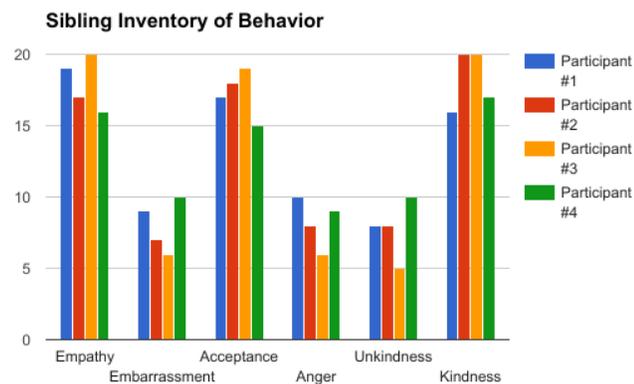
### Relationship with Sibling

The next step in the data collection process was to get information on the relationship between the participants and their siblings who have disabilities. In order to do this, I used the Sibling Inventory of Behavior (Schaefer and Edgerton, 1979). The results of this data gave information on the following categories: “empathy,” “embarrassment,” “acceptance,” “anger,”

“unkindness” and “kindness.” In order to analyze this data, the questions from the questionnaire were grouped into the categories and a score was given for each one.

Looking at the mean scores for each of the categories of the data, it appears that each of the participants has a good relationship with their sibling who has a disability. The mean score for “empathy” was 18 out of 20 points, which could imply that the participants understand their siblings’ disability and feel empathy for them. The mean score for “embarrassment” was 8 out of 20 points. Participant #4 scored a 10 out of 20 points for “embarrassment,” 2 points above the mean, and this could mean that there have been some times where his/her sibling who has a disability has embarrassed him/her. All participants scored high in the category of “acceptance,” where the mean score was 17.25 out of 20 points. The mean score for “anger” was an 8.25 out of 20 points. Participant #3 scored a 6 for the category of anger, which is almost 2 full points below the mean. This indicates that this participant shows little resentment or anger toward his/her sibling with a disability. The mean score for “unkindness” participants’ siblings who have disabilities was 7.75 out of 20 points. The mean score for kindness toward their sibling who has a disability was 18.25 out of 20 points, which shows that the participants are kind to their siblings who have disabilities. The results of this questionnaire are represented in Figure 3.

**Figure 3**



**Conclusions**

The results that emerged from the data collection showed that each of the participants seem to be well adjusted and they do not seem to be affected socially and/or emotionally. The final chapter will discuss the results that emerged from this study in depth. The final chapter will also draw conclusions from these results and will discuss the similarities and differences between this study and other studies that have been done on this topic as well as the limitations of this study.

## **Chapter 5: Discussion**

The results of this study show that siblings of students with disabilities seem to be well adjusted and have very little, if any, social and emotional effects. The data that was collected shows the adjustment of a typically developing individual across many different categories. For the most part, all of the participants scored high indicating that they are well adjusted people. The following chapter will detail the significance and limitations of the data that emerged from the study of the social and emotional effects of having a sibling with a disability.

### **Self Esteem**

The results that emerged from the Rosenberg Self Esteem Scale (Rosenberg, 1969) indicated that the participants do not seem to have a low self esteem. The mean score for this questionnaire was a 32.5 out of a possible 40 points. Two of the participants scored above the mean score, one participant scored only 1 point below the mean score, and 1 participant scored 5.5 points below the mean score. A high score indicates a higher self esteem that the person feels and that they think positively about themselves. Participant #2 scored relatively lower than the other 3 participants, which indicates the potential for this person to have adjustment problems. Given that the other 3 participants had relatively high scores, this indicates that they are well adjusted people and that they think highly of themselves. These findings go against the research that was studied in the literature in Chapter 2, which showed that siblings of children with disabilities had a lower self esteem than siblings of typically developing people (Harvey & Greenway, 1982).

### **Perception of Parents**

The Perception of Parents scale assessed the participants' perceptions of their parents' support and involvement in their lives. The results obtained from this questionnaire indicated

that the participants seem to have good relationships with their parents. All of the categories were scored out of a possible 7 points. The mean score for Mother Involvement was a 5.7. The mean score for Mother Autonomy support was a 6. The mean score for Mother warmth was a 5.9. The mean score for Father Involvement was a 5.7. The mean score for Father Autonomy Support was a 5.8 and the mean score for Father Warmth was a 6. With all of the participants scoring relatively high in each category, it can be concluded that they have the support from their parents and that their parents are a part of their lives, aiding in their overall social and emotional well being. The findings from this questionnaire were similar to results that emerged from a study that was explored in the literature review. The results showed that the family level of risk and resilience factors were better predictors of sibling adjustment than siblings' own experiences of stress and coping resources, which shows the importance of parental contributions to the adjustment process (Giallo & Gavidia-Payne, 2006). Therefore, the participants in this study have feelings of support and guidance from their parents/guardians, which is a crucial part of the adjustment process.

### **Relationship with Sibling**

Hastings (2006) revealed that sibling self-esteem could be affected by the public presentation of unusual behaviors from their sibling and lowered self-esteem could place them at risk for other problems. After analyzing the results from the Sibling Inventory of Behavior (Schaefer & Edgerton, 1979), it was shown that this was not the case and the participants all had a good relationship with their sibling who has a disability. Sibling relationships, especially if the sibling has a disability, are so important to the welfare of the siblings. It is important for the typically developing sibling to have an understanding of their sibling's disability, so that they can be accepting of their sibling.

The categories that were analyzed for this questionnaire were empathy, embarrassment, acceptance, anger, unkindness and kindness. Each category was scored out of a possible 20 points. All participants scored high for the categories of empathy, anger and kindness. The mean scores for these categories were 18, 17.25 and 18.25 respectively. These high mean scores show that the participants have an understanding of their sibling's disability. The high mean scores could also indicate that the siblings have positive relationships with each other and do not seem to suffer socially or emotionally.

The participants all scored low in the categories of embarrassment, anger and unkindness. Out of a possible 20 points, the mean scores for these categories were 8, 8.25 and 7.75 respectively. These scores could indicate that the participants are not embarrassed of their sibling who has a disability and that they are accepting of them. This data reveals that the relationship between the typically developing sibling and the sibling who has a disability is not perfect and that they may struggle with certain things, but the data is not strong enough to show any type of maladjustment because of it.

The findings that emerged from this questionnaire go against a study that was looked at in the literature review. Cox, Marshall, Mandeleco and Olsen (2003) reported that that adjustment problems in siblings may be related to the extra burdens they assume when living with a sibling who has a disability. The data that emerged from this questionnaire does not support this research claim and siblings do not see their siblings with disabilities as a burden on their lives.

### **Limitations**

There are some important limitations to take into consideration when analyzing these findings. First, the sample size was very small and only included four participants. All of the

participants were from the same geographic area and the disabilities that were studied were limited to Down Syndrome and varying intellectual disabilities. Another major limitation of this study was the fact that only three questionnaires were used to collect data and it was collected over a short period of time which was about 3-4 weeks. If more questionnaires had been used, different data results could have emerged finding different correlations between typically developing people and their siblings who have a disability.

Originally, I had wanted to focus on people who have a sibling with Down Syndrome. I had to make some changes as I was recruiting my participants and had to introduce another disability to my research. Currently, there are not a lot of studies that solely focus on one disability, and I hoped to only focus on one disability. Adding another disability presented another limitation which was there are already a lot of studies that exist that focus on multiple disabilities. The results may have been different and more concrete if I had only studied one disability.

Another major limitation of this study is the fact that I know all of the participants personally, as they are all family friends. In order to maintain confidentiality throughout the entirety of the research process, a third party removed all identifying information from the questionnaires as they were returned to me in hopes that the participants would answer all questions honestly.

### **Future Research**

The four participants from this study all had siblings who had either Down Syndrome or an intellectual disability. If this study were to be done again, researchers could explore relationships between siblings of typically developing people and their sibling who has a different disability than the ones represented in this study. If researchers were able to find

correlations, specific needs that the students have would be pinpointed and then educators could provide appropriate services to help the typically developing student. If a child is not receiving the services that he/she needs, this could potentially affect his or her social and emotional health. The earlier that these areas of need are pinpointed, the better off that student will be because of the early intervention. If the typically developing sibling does accept the services and use them, this could change the way that they view themselves which could in turn create a healthier family unit overall. On top of providing support for students who may have a disability, it is just as important to make sure that their siblings receive the support from educators as well in order to keep their social and emotional health as best as it can be.

**Conclusions:**

In conclusion, the results of this study shows that siblings of students with disabilities appear to be well adjusted and have very little, if any, emotional and social effects. The research study examined each participant's relationship that they have with their parent(s) or guardian(s), the relationship that they have with their sibling who has a disability and their self esteem in order to determine their overall adjustment. It is extremely important for all educators to be aware of these issues presented so that each student in their care can receive the proper support necessary in order for the student to reach their full potential in the classroom.

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## Appendices

### Appendix A

#### Informed Consent

**Protocol Title:** Emotional and Social Effects of Having a Sibling With a Disability

*Please read this consent document carefully before you decide to participate in this study.*

**Purpose of the research study:**

The purpose of this research is to find out the factors that affect the social and emotional modifications of siblings of students with disabilities.

**What you will be asked to do in the study:**

If you agree to participate in this research, and sign this consent form, I ask that you complete three different scales (questionnaires). Each scale should only take approximately 15 minutes to complete.

**Time Required:**

Time required to complete the questionnaire is individual to each participant, but to complete each one should only take approximately 15 minutes. Questionnaires will be collected two weeks after distribution.

**Compensation:**

There is no compensation for participating in the study.

**Confidentiality:**

Your identity will be kept confidential to the extent provided by the law. 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, information that will make it possible to identify you will not be included. Your name and other identifying information will not be kept with this survey. The data will be kept in a secure and confidential area. All of the data that I receive will be kept in a locked filing cabinet that only I will have access to.

**Voluntary participation:**

Your participation in this study is completely voluntary. There is no penalty for not participating.

**Right to withdraw from the study:**

You have the right to withdraw from the study at any time without consequence. You do not have to answer any questions you do not want to answer.

**Potential Benefits and Risks:**

This investigation will add to the research that has already been done on the topic of whether or not people who have a sibling with a disability are affected socially and emotionally. The benefits of this study include finding consistencies among siblings of people with a disability with regards to their social and emotional needs. One risk that participants may be faced with is that negative feelings may emerge because of their participation in the surveys. I will conduct debriefing sessions with participants in order for them to share any negative feelings that came up during the surveys.

**Whom to contact if you have questions about the study:**

Lindsey Cox  
cox1603@fredonia.edu

**Whom to contact about your rights as a research participant in the study:**

Dr. Judith Horowitz  
Associate Provost for Graduate Studies, Sponsored Research and Faculty Development  
Maytum Hall 805  
Judith.horowitz@fredonia.edu  
(716) 673-4708

**I have read the procedure outlined above. I voluntarily agree to participate in this study and have received a copy of this description.**

---

*Participant's signature*

---

*Date*

---

*Principal investigator's signatures*

---

*Date*

## Appendix B

### Perceptions of Parents scale (Robbins 1994)

Please answer the following questions about your mother and your father. If you do not have any contact with one of your parents (for example, your father), but there is another adult of the same gender living with your house (for example, a stepfather) then please answer the questions about that other adult. If you have no contact with one of your parents, and there is not another adult of that same gender with whom you live, then leave the questions about that parent blank.

Please use the following scale:

1	2	3	4	5	6	7
Not at all true			Somewhat true			Very true

First, questions about your mother.

1. My mother seems to know how I feel about things.
2. My mother tries to tell me how to run my life.
3. My mother finds time to talk with me.
4. My mother accepts me and likes me as I am.
5. My mother, whenever possible, allows me to choose what to do.
6. My mother doesn't seem to think of me often.
7. My mother clearly conveys her love for me.
8. My mother listens to my opinion or perspective when I've got a problem.
9. My mother spends a lot of time with me.
10. My mother makes me feel very special.
11. My mother allows me to decide things for myself.
12. My mother often seems too busy to attend to me.
13. My mother is often disapproving and unaccepting of me.
14. My mother insists upon my doing things her way.
15. My mother is not very involved with my concerns.
16. My mother is typically happy to see me.
17. My mother is usually willing to consider things from my point of view.
18. My mother puts time and energy into helping me.
19. My mother helps me to choose my own direction.
20. My mother seems to be disappointed in me a lot.
21. My mother isn't very sensitive to many of my needs.

Now questions about your father.

22. My father seems to know how I feel about things.
23. My father tries to tell me how to run my life.
24. My father finds time to talk with me.

25. My father accepts me and likes me as I am.
26. My father, whenever possible, allows me to choose what to do.
27. My father doesn't seem to think of me often.
28. My father clearly conveys his love for me.
29. My father listens to my opinion or perspective when I've got a problem.
30. My father spends a lot of time with me.
31. My father makes me feel very special.
32. My father allows me to decide things for myself.
33. My father often seems too busy to attend to me.
34. My father is often disapproving and unaccepting of me.
35. My father insists upon my doing things his way.
36. My father is not very involved with my concerns.
37. My father is typically happy to see me.
38. My father is usually willing to consider things from my point of view.
39. My father puts time and energy into helping me.
40. My father helps me to choose my own direction.
41. My father seems to be disappointed in me a lot.
42. My father isn't very sensitive to many of my needs

**Appendix C****Rosenberg Self-Esteem scale (Rosenberg 1965)**

Directions:

Below is a list of statements dealing with your general feelings about yourself. Please indicate how strongly 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'm a person of worth, at least on an 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 that 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 D****Sibling Inventory of Behavior (Schaefer & Edgerton, 1979)**

I am pleased by the progress he or she makes.	1 (Never)	2 (Seldom)	3 (Sometimes)	4 (Often)	5 (Always)
I show/tell him/her interesting things.	1 (Never)	2 (Seldom)	3 (Sometimes)	4 (Often)	5 (Always)
I tease/annoy him or her.	1 (Never)	2 (Seldom)	3 (Sometimes)	4 (Often)	5 (Always)
I help him/her in any way possible.	1 (Never)	2 (Seldom)	3 (Sometimes)	4 (Often)	5 (Always)
I accept him/her as a playmate.	1 (Never)	2 (Seldom)	3 (Sometimes)	4 (Often)	5 (Always)
I am embarrassed to be seen with him/her in public.	1 (Never)	2 (Seldom)	3 (Sometimes)	4 (Often)	5 (Always)
I want him/her to succeed.	1 (Never)	2 (Seldom)	3 (Sometimes)	4 (Often)	5 (Always)
I stay away from him/her if possible.	1 (Never)	2 (Seldom)	3 (Sometimes)	4 (Often)	5 (Always)
I get ideas for things we can do together.	1 (Never)	2 (Seldom)	3 (Sometimes)	4 (Often)	5 (Always)
I do things to please him/her.	1 (Never)	2 (Seldom)	3 (Sometimes)	4 (Often)	5 (Always)
I fuss/argue with him/her.	1 (Never)	2 (Seldom)	3 (Sometimes)	4 (Often)	5 (Always)
I have fun at home with him/her.	1 (Never)	2 (Seldom)	3 (Sometimes)	4 (Often)	5 (Always)

I act ashamed of him/her.	1 (Never)	2 (Seldom)	3 (Sometimes)	4 (Often)	5 (Always)
I show sympathy when things are hard for him/her.	1 (Never)	2 (Seldom)	3 (Sometimes)	4 (Often)	5 (Always)
I frown/pout when I have to spend time with him/her.	1 (Never)	2 (Seldom)	3 (Sometimes)	4 (Often)	5 (Always)
I teach him/her new skills.	1 (Never)	2 (Seldom)	3 (Sometimes)	4 (Often)	5 (Always)
I say unkind things to him/her.	1 (Never)	2 (Seldom)	3 (Sometimes)	4 (Often)	5 (Always)
I help him/her adjust to new situations.	1 (Never)	2 (Seldom)	3 (Sometimes)	4 (Often)	5 (Always)
I treat him/her as a good friend.	1 (Never)	2 (Seldom)	3 (Sometimes)	4 (Often)	5 (Always)
I try to avoid being seen with him/her.	1 (Never)	2 (Seldom)	3 (Sometimes)	4 (Often)	5 (Always)
I am concerned for his/her welfare.	1 (Never)	2 (Seldom)	3 (Sometimes)	4 (Often)	5 (Always)
I would rather be alone than with him/her.	1 (Never)	2 (Seldom)	3 (Sometimes)	4 (Often)	5 (Always)
I make plans that involve him/her.	1 (Never)	2 (Seldom)	3 (Sometimes)	4 (Often)	5 (Always)
I hurt his/her feelings.	1 (Never)	2 (Seldom)	3 (Sometimes)	4 (Often)	5 (Always)
I try to comfort him/her when he/she is upset.	1 (Never)	2 (Seldom)	3 (Sometimes)	4 (Often)	5 (Always)

I complain about the trouble he/she makes.	1 (Never)	2 (Seldom)	3 (Sometimes)	4 (Often)	5 (Always)
I am glad to have him/her in the family.	1 (Never)	2 (Seldom)	3 (Sometimes)	4 (Often)	5 (Always)

**Appendix E****Email Script**

Dear (Participant's Name),

I am a student in the Curriculum and Instruction Department at SUNY Fredonia. In preparation for my final thesis project, I am gathering data on people who have a sibling with a disability and if they are affected socially and emotionally. I would like to invite you to participate in a series of three questionnaires that will address your relationship with your parents, your self-esteem and your relationship with your sibling. While the questionnaires may be filled out on your own time at your convenience, I ask for them to be completed and returned to me within two weeks. Your participation is strictly voluntary and you can withdraw from the project at any time. Additionally, no form of compensation will be available. Your confidentiality during the project will be ensured. If you have any questions, please feel free to contact me.

Thank you for your time and consideration in this manner.

-Lindsey Cox

**Appendix F**

20 January 2017

Lindsey Cox

c/o Robert Dahlgren, Ph.D.

Curriculum and Instruction

College of Education

Thompson Hall

The State University of New York at Fredonia

Re: Lindsey Cox—Emotional and Social Effects of Having a Sibling with a Disability

Your research project using human subjects has been determined Category 1, Exempt, under the United States Department of Health and Human Services Code of Federal Regulations Title 45 Public Welfare, Part 46 Protection of Human Subjects, 46.101, Subpart A (b) (1) and/or (2). This document is your approval and your study titled “Emotional and Social Effects of Having a Sibling with a Disability” may proceed as described, beginning on **January 23, 2017 and ending on February 6, 2017**.

Thank you for keeping the high standards relating to research and the protection of human subjects under the auspices of the State University of New York at Fredonia.

Sincerely,

A handwritten signature in cursive script that reads 'Judith M. Horowitz'.

Judith M. Horowitz, Ph.D.

Associate Provost, Graduate Studies,

Sponsored Programs and Faculty Development

Human Subjects Administrator