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Dawn L. King
How non-disabled children respond
to a sibling with disability?
The challenges they
may or may not have faced

ABSTRACT

The purpose of this study was to explore how non-disabled siblings respond to their siblings with disabilities. My focus was the ways in which growing up with a sibling with a disability impacts the life of the non-disabled person. This study illuminated this perspective by an examination of the experiences, needs, pressures, advantages, and coping mechanisms of non-disabled siblings in families with disabled children.

In my qualitative study I used (flexible method), open ended questions, to interview adult non-disabled individuals who grew up with a disabled sibling.

The study explored the dynamics between the siblings and between the parents and children. Since this study was qualitative and exploratory in nature, individuals who were interested in participating needed to meet the following criteria: (a) are presently between the ages of 30-60 and (b) a non-disabled sibling who grew up with a physically disabled sibling.

This study found that the physically disabled sibling did impact the family, both positively and negatively; birth order affected sibling relations in that the younger non-disabled siblings reported good relations with their disabled sibling, but the sole older sibling reported a poor sibling relationship; gender played a role in sibling relations and birth order perception, in that non-disabled female siblings were regarded as the

older sibling, even when younger, yet the younger male was regarded as younger; peer relationship and school experiences were problem areas for the participants; and the participants reported their small communities both knew and supported them, their disabled siblings, and families, which seemed to help the sibling relationship.

HOW NON-DISABLED CHILDREN RESPOND TO A SIBLING
WITH A DISABILITY? THE CHALLENGES THEY MAY OR MAY NOT HAVE
FACED

A project based upon an independent investigation,
submitted in partial fulfillment of the requirements
for the degree of Master of Social Work.

Dawn L. King
Summer, 2007

Smith College School for Social Work
Northampton, Massachusetts 01063

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I would like to thank my mom and dad for giving birth to me – even though they never intended to do so. Were it not for their mistake, this one being the first of many, I would not be where I am here today. It has been the unintentional mistakes throughout my life that have been the most monumental milestones.

Were it not for the input and contributions of Tracy Sutton I would never have made it to, or through this program. As a supervisor in a previous job Tracy became my advisor and mentor. Kate Mortiarthy was a source of inspiration when it was needed most.

I relied upon the unending support of Megan Durell whose tireless conversations I could not have done without.

TABLE OF CONTENTS

ACKNOWLEDGEMENTS	ii
TABLE OF CONTENTS.....	iii
CHAPTER	
I. INTRODUCTION.....	1
II. LITERATURE REVIEW.....	4
III. METHADODOLOGY.....	13
IV. FINDINGS.....	20
V. DISCUSSION.....	33
REFERENCES.....	42
APPENDICES	
Appendix A: Informed Consent Form.....	47
Appendix B: Interview Guide.....	49
Appendix C: Recruiting Letter.....	51
Appendix D: Professional Transcriber.....	52
Appendix E: Mental Health Referrals.....	54
Appendix F: Human Subject Approval Letter.....	56

CHAPTER 1

INTRODUCTION

The purpose of this study was to explore how non-disabled siblings respond to their siblings with disabilities. My focus was the ways in which growing up with a sibling with a disability impacts the life of the non-disabled person. In families with disabled children, the emphasis was often on the disabled children and their needs. This can lead to the needs of the non-disabled siblings being secondary or neglected. It also creates a unique perspective of those who are siblings to disabled individuals. This study illuminated this perspective by an examination of the experiences, needs, pressures, advantages, and coping mechanisms of non-disabled siblings in families with disabled children.

The primary exploratory research question was: How did non-disabled children respond to their siblings with a disability? Furthermore, what were the challenges they faced or did not face growing up as adolescent? More specific questions were used to probe into broad answers: What interventions did the non-disabled use to improve their social skills and make their lives better? How did adolescents react if they were neglected or felt pressure from their parents to do better since they did not have a disability? [Additionally, this study explored the role birth order and gender may play in responses and dynamics between the siblings.]

I became interested in this subject while working with adolescents who had a disability and who had siblings that did not have a disability. I often wondered how the non-disabled sibling felt about their sibling with a disability. Through my work in the

school system I had experienced parents treating their disabled and non-disabled children differently. Through this study, I developed a better understanding of how childhood experiences and varied parental responses impact the development of non-disabled sibling in a family with a disabled child.

The needs and feelings of non-disabled siblings are an important and rich area of inquiry, yet have often been ignored or overlooked within outreach, resources and academic study. The findings of this study are meant to assist social workers in the development of interventions used when treating adolescents who have a sibling with a disability. Through my exploratory research, participants offered suggestions in how a social worker or other professionals can work with a non-disabled sibling of a physically disabled person. Opperman and Alant (2002) concluded that adolescents who have a disabled sibling need a stronger professional support network to facilitate coping mechanisms.

My sample was to have included 12-15 individuals but ultimately consisted of 5 interviewees who grew up with a physically disabled sibling and are between the ages of 30 and 60. The participants were recruited through personal or professional contacts, both my own and my willing colleagues. The potential respondents were contacted in person, by phone or through an information sheet distributed by colleagues. They were given information on the research and asked if they met the above mentioned selection criteria and were willing to be interviewed one on one. After contacting 20 potential participants, 5 agreed to the interview; 13 considered participation but never followed through to set up an interview date; and, 2 refused for undisclosed reasons.

This qualitative, exploratory study's purpose was to collect verbal accounts of adult non-disabled siblings' challenges and reactions to growing up with a disabled sibling. It is recognized that having a disabled family members puts an added strain on a family, yet a variety of reactions and outcomes exist. It may be that having a disabled sibling can be both a blessing and a burden. It was the goal of this study to give voice and acknowledgment to the experiences and needs of non-disabled siblings who grew up with a disabled sibling.

CHAPTER II

LITERATURE REVIEW

Background

The New Oxford American Dictionary (2005) defines *disability* as “a physical or mental condition that limits a person’s movements, senses, or activities” (pp. 480). Similarly, the Social Work Dictionary (1997) defines *disability* as “a temporary or permanent reduction in functions; the inability to perform some activities that most others can perform, usually as a result of physical or mental conditions or infirmity” (pp. 121). Therefore, by definition, disability can refer to both physical and mental conditions. For this research study, disability refers to physical disabilities and mental retardation, with the disabled individual being one of at least two children within a family.

Hayden (1993) states “that when one member of the family has a disability, all members of the family have a disability” (pp. 92). Burk and Kingsley (2005) describe this as disabled by association. The sibling without a disability may experience anxiety through being identified as disabled by association (Burk & Kingsley 2005). Each family member has to deal with the disabled sibling and adjust to the disability. Everyone’s perspective is different and needs to be explored.

Dunn, Slomkowski, and Beardsall (1994) stated that studies surrounding the impact of children with disabilities have focused on the influence on the family, not individuals. Research does exist that looks at the non-disabled sibling and parent relationship, but there is little literature about the relationship with the non-disabled sibling and the disabled sibling (Luterman, 1996; Quittner & Opiari, 1994). Not only

are the relationships not explored, the siblings' relations are rarely considered major influences on the family and other children's functioning in the family (Erel, Margoin, & John, 1998). More recently, Williams (2002) also noted the relatively few studies on non-disabled siblings and the challenges they face with having a sibling with a disability as well as the challenges within their families. Ishizaki, Ishizaki, Ozawa, Fukai, Hattori, Taniuchi, and Kobayashi (2005) similarly reported due to the lack of information around psychosocial conditions with having a sibling with disabilities some research may seem limited.

Pit-Ten Cate and Loots (2000) discussed family characteristics and characteristics of both siblings as important factors to sibling adjustments. This qualitative study focused on the sibling relationship, from the non-disabled sibling's perspective. It also considered family dynamics, birth order, gender, and the public sphere (such as school). It seems reasonable to say that a comprehensive understanding of the experiences and affects of growing up with a disabled sibling has not been done in past research.

Family

Impact of disabled child

Dunn, Slomkowski, & Beardsall (1994) found that disabled siblings can have a significant impact on families and merits further investigation. Having a child with a disability significantly impacts all members of the nuclear family. Pressure on parents and children are high in comparison to that of a family without a physically disabled child (Mchale & Gamble 1989; Dyson 1993). More recently, Harmer, Cox, Marshall,

Mandleco, and Olsen (2003) discussed how a disabled sibling causes stress within the family. Further, the non-disabled sibling is likely to be more affected by living with the disabled sibling.

Nixon, et al. (1999) conducted a quantitative study to examine how disabled and non-disabled siblings impacted families, finding that some families with a disabled sibling have higher levels of family conflict than those without a disabled member. Individual siblings react to this conflict differently. Nonetheless, Nixon, et al. (1999) found that some children with disabled siblings experienced greater emotional distress and more involvement and feelings of responsibility during family conflicts. Williams (2002) similarly reported that non-disabled siblings are at a higher risk of adverse health and psychosocial outcomes.

Harmer, et al. (2003) reported non-disabled siblings take on more household responsibilities, including care taking for the disabled siblings. With an increase in household chores, the non-disabled sibling may experience a decrease in their involvement with school and social life. This may be a factor in the research that suggests non-disabled siblings are more likely to exhibit symptoms of anxiety and depression than those who do not have a sibling with a disability (Healey, 2006; Osman, 2006).

Another potential factor that may relate to the increased anxiety and depression of these siblings is the protective role they take on behalf of the disabled sibling. Nixon, et al. (1999) found that a disabled sibling influenced the non-disabled sibling's reactions to everyday stress. A child will be more protective and hostile when the sibling with a

disability is being teased or bullied in the general public. This protective role seems understandable; however, it could easily be one of the causes of the increase in anxiety and depression in this group.

On the other hand, taking on the protective role may be a positive outcome of having a sibling with a disability. Faux (1993) suggests that non-disabled siblings are more protective and caring for the disabled sibling and have an increase in empathy for others and are less self-centered. Recently, Healey (2006) found that siblings of sick children learn empathy. Non-disabled siblings may change their behavior and feelings as they adjust to their sibling with a disability. The development of empathy not only could be adaptive in relationship to the disabled sibling but also seen as a positive trait in society as a whole. Delouin & Jessee, (1996); Faux, (1993); Mandleco, Olsen, Robinson, Marshall, & McNeilly-Choque: (1997) also identify positive outcomes with non-disabled siblings who have siblings with chronic illness or disabilities, such as self control and positive coping responses.

The different relationships between the disabled and non-disabled sibling is definitely a perspective that needs to be explored more thoroughly in order to better understand the non-disabled sibling's experiences and responses. For example, Pit-Ten Cate and Loots (2000) stated that the non-disabled sibling accepted the disabled sibling, yet the non-disabled sibling would have liked it if the parents paid the same amount of attention to both siblings. Although understanding the family dynamics is critical in positioning the siblings' relationship, the non-disabled sibling's view point needs to be the focal point.

Birth Order

Birth order could be a factor in understanding siblings of physically disabled children. Younger siblings may be more dependent and seek more attention; whereas, older children may be more independent and less attention-seeking. It would seem reasonable that younger and older siblings would be affected differently from having a disabled sibling. Yet, considering the scarce literature on the topic, the findings seem mixed. Howe (1993) reported that sibling gender and birth order characteristically have not been examined together in well controlled studies.

Although an elevated risk group, non-disabled siblings appear to adjust well depending on the birth order and gender makeup of the sibling dyad (Howe, 1993; Williams, 2002). Pit-Ten Cate and Loots (2000) reported, in lieu of some inconsistencies, that siblings adjust better with bigger families, greater age differences, and when the sibling with a disability is younger. Yet, this may depend on the gender of the non-disabled sibling. One finding was that boys who are younger than the disabled sibling are more likely to be at risk of aggression than girls who are younger (Pit-Ten Cate and Loots, 2000).

Even though Pit-Ten Cate and Loots (2000) reported inconsistencies with birth order and gender, Stawski, Auerbach, Barasch, Lerner, Zimin, (1997) reported the older non-disabled sibling has a greater risk of internalizing problems than that of the younger non-disabled sibling who experienced negative affects by their disabled sibling. Additionally, older non-disabled siblings, especially girls, take on more responsibility in household chores and caretaking which decreases their social life (Harmer Cox, Marshall,

Mandleco & Olsen; 2003). Sometimes these responsibilities come at a very young age and when the sibling becomes older they feel more independent and want to be able to do more things on their own. Johnson Silver, E., Frohlinger-Graham, M., (2000) also suggest that non-disabled girls who are older than the disabled sibling take on more responsibilities and are more likely to experience depression and anxiety.

The body of research on birth order in families with disabled children is limited. Johnson Silver, E., Frohlinger-Graham, M., (2000) stated that there is not enough study on sibling gender and birth order. This present study examined gender and birth order as major variables.

Public Domains

School

Another pressure that non-disabled siblings experience is in the realm of school. The non-disabled adolescent believes that he/she is under more pressure from parents to do well in school, behave appropriately and take care of siblings (Nixon, Cummings, & Mark 1999). However; there is also evidence that some adolescents choose not to become high achievers so as not to surpass a sibling with a disability (Osman, 2006). Others felt that they were neglected by their parents and attempted to gain positive attention through positive performance in school, always striving to be the perfect child in school. Conversely, Pit-Ten Cate and Loots (2000) found that other studies reported non-disabled siblings are more aggressive and have more difficulties in social and peer

relationships, therefore they appear to have more psychosomatic illnesses and problems in school.

General Public

In addition to the family relationships, the non-disabled siblings of disabled individuals also need to relate to the outside world. Parents educate the non-disabled child in their own ways. Some parents do not talk about the disability with the non-disabled siblings, which results in a lack of understanding and limited coping skills for the non-disabled sibling to successfully navigate interactions in the community regarding the disability. Healey (2006) noted that one successful intervention to help non-disabled siblings cope is teaching them about their disabled sibling's condition.

Additionally, teaching empathy seems like a tactic in helping the non-disabled individual in the larger community. Raskin (2006) reports that siblings may be playmates when they are young and as they grow up relate in different ways. This phenomenon could be a positive experience if parents can teach empathy through play. It seems possible that with positive parental interventions, non-disabled children will be able to gain insight and understanding from their experiences.

Healey (2006) noted that the family in the intervention was also able to find other children who were in similar situations which allowed the child to get emotional support from peers. Peer support is important in relating to the public. The non-disabled sibling often struggles in the public realm. This is particularly hard during the stages of development having to do with fitting in with peers. Osman (2006) reported that

adolescents often feel uncomfortable around their sibling with a disability when in a public setting. At the adolescent stage, teens are building peer relationships and are often separating themselves from their family, illustrating the need for peer support.

Pit-Ten Cate and Loots (2000) reported that there were no implications of complications in peer relationships due to having a sibling with a disability. Non-disabled siblings had normal peer contact, but peers did report feeling nervous when first visiting the non-disabled sibling home because the peers did not know how to interact at first with the physically disabled sibling (Pit-Ten Cate 1998). Burke and Kingsley (2005) echo this experienced nervousness when noting that non-disabled siblings become disabled by association, meaning peers may not want to go over to the non-disabled sibling's home because they are afraid of the sibling with a disability. This study focused on peer relations; both inside the home as well as out in the community.

Summary

The current research (Osman, 2006; Raskin, 2006; Nixon, et al. 1999) focused primarily on the family's response to the disabled sibling and the emotional consequences for the non-disabled child. Harmer Cox, Marshall, Mandelco, and Olsen (2003) reported that children already have to cope with stressors in their daily life and having a sibling with a disability causes more stressors for them. Therefore, understanding the non-disabled siblings' responses to these stressors will give some knowledge about what is related to positive and negative adjustments in non-disabled siblings. Understanding

these adjustments could be used by health care professional, parents, and teachers so they can address the positive adjustments.

Through my research, I explored how the disabled child impacts the family and what factors influence the reactions of the non-disabled sibling. Roger and Tooth (2004) noted that much research has been focused on the challenges and emotions that parents face on a day to day basis with both having a child with a disability with less focus on the sibling without the disability.

This goal of this study was to explore the non-disabled sibling's perspective and responses in relation to the disabled sibling, the family, as well as, the larger community. Through face to face interviewing I captured how the individual managed their emotional responses to situations when their needs were not being met. If their needs were being met, what were the effective interventions that allowed this to occur? I hope to further contribute to the literature surrounding non-disabled children and how they respond to their disabled sibling.

CHAPTER III

METHODOLOGY

In my qualitative study I used (flexible method), open ended questions, to interview adult non-disabled individuals who grew up with a disabled sibling. Through talking with these individuals I determined how they responded to their sibling and the disability. This type of interview structure allowed me to follow up on the interviewee's answers and gain greater insight into their unique experiences.

I explored the dynamics between the siblings and between the parents and children. Because of past research, I expected that the sibling with a physical disability would have an impact on the family which may both positively and negatively affect the sibling without a disability. Birth order is an important variable to consider, as it may play a role in the non-disabled siblings challenges and responses to the disabled sibling. The gender of both siblings is also important to consider and may mitigate the impact of birth order.

Parental relationship is an important aspect of adaptation. I explored if and how the parents set the tone for how the disability is dealt with in the home. The way that the non-disabled child responds to the family may depend on the attitude mirrored by the parents. If the parent neglects this child, his/her response to the family may be different than if the parent makes an effort to include the non-disabled child. Additionally, do the ways in which parents respond to the needs of their disabled and non-disabled children greatly influence later adolescent and adult functioning?

Other factors that are present within any individual's growing up experiences are school, peers, and the outside world. How the non-disabled sibling managed these aspects of life was also explored within the interview. These environments and non-familial relationships may assist in illustrating what the non-disabled sibling faced and how they coped with their disabled sibling and the disability.

Sample

Since this study was qualitative and exploratory in nature, individuals who were interested in participating needed to meet the following criteria: (a) are presently between the ages of 30-60 and (b) a non-disabled sibling who grew up with a physically disabled sibling. Ideally, I wanted to find participants who varied in race and gender.

Utilizing the convenient sampling method, participants were recruited by personal and professional contacts. The pool of potential participants were individuals whom I have known personally or a colleague referred to me. I contacted a total of 50 people. The pool included people who may have known a non-disabled sibling; were themselves a non-disabled sibling; or, were a disabled sibling. I distributed a recruitment letter (Appendix C) to all 50 potential participants. Of the 50 possible participants 20 responded to the recruitment letter by sending an email of interest in participating. I then followed up with that 20 by personal telephone contact.

For all 20 potential participants that I spoke to over the phone, I briefly shared my study with them. I then did a two question screening by asking them their age and if they are a non-disabled sibling who grew up in a household with a physically disabled sibling.

All 20 individuals met that criteria. In the telephone conversation I informed each potential participant that they would have to read and sign the consent form before the interview could be completed. (At the meeting time I handed the two copies of the consent form to the participant in person. I then had the participant sign one copy, which I kept. The other copy I urged the respondent to keep for their records.) Lastly, the interested interviewee and I set up a mutually agreeable meeting day, time and place, such as a private study at Smith College library, to conduct the interview. After contacting 20 potential participants, 5 agreed to the interview; 13 considered participation but failed to return my emails to set up the interview date; and, 2 refused for undisclosed reasons.

Ethics and Safeguards

I used Appendix D, Volunteer or Professional Transcriber's Assurance of Research Confidentiality form and explained to the participants that names would not be used in my research. Strict confidentiality was maintained, consistent with Federal regulations and the mandates of the social work profession. Confidentiality was protected by numerically coding the information and storing the data in a locked file for a minimum of three years according to federal regulations.

The individual's identity was protected, as names were changed in the analysis of the data. The individual's name was never associated with the information he/she provide in the questionnaire or the interview. The data may be used in other education activities as well as in the preparation for my Master's thesis.

This study was completely voluntary. The individuals were free to refuse to answer specific questions, end the interview at anytime and to withdraw from this study no later than March 28, 2007. If an individual decided to withdraw all data describing him/her would have been immediately destroyed. No individuals decided to withdraw.

The participants received no financial benefit for their participation in this study. However, individuals may have benefited from knowing they contributed to the knowledge of how non-disabled children respond to a sibling with a physical disability. It is my hope that this study will help social workers have a better understanding of what interventions are helpful in working with families who have a child with a physical disability. The participants may also have benefited from being able to tell their story and having their individual perspective(s) heard.

The major foreseeable risk of participating in this study was the possibility that an individual may feel strong or uncomfortable emotions as a result of talking about their experiences. In case the individual felt the need for additional support after participating in this study, I gave each participant a list of resources for mental health services in their area.

If my participants had negative interventions and wanted to explore positive ones, I gave them a list of contacts/referrals either in the Western Massachusetts/Boston area so they may do some personal healing.

Data Collection

I began data collection after I received the approval letter from the Smith College School for Social Work Human Subject Review Committee. For those participants that agreed to be in my study, I informed them over the phone at the meeting time, I handed the two copies of the consent form to the participant in person. I had the participant sign one copy, which I kept. Strict confidentiality was maintained, consistent with Federal regulations and the mandates of the social work profession.

Before each interview it was made clear to my participants verbally and through a written form that this study was confidential and I informed them that their names would not be on tapes or journal entries or any other data. Numbers would be used instead of names to ensure confidentiality. I placed numbers on the tapes to maintain confidentiality of the interviewee and continued to use coding numbers instead of names through out the study.

The confidentiality forms were placed separately from completed instruments or tapes. Anyone that transcribed tapes or analyzing data signed a Transcriber's Confidentiality Form prior to transcribing. Prior to the advisor having access to the data all identifying information was removed. Confidentiality was protected by coding the information and storing the data in a locked file for a minimum of three years as required by Federal regulation

I conducted a face to face, semi-structured interviewed, open ended questionnaire that lasted for 30-60 minutes and was audio-taped. I chose interviewing because it is a flexible methods research design "generally used because the research question springs

from a desire to explore and learn more about some phenomenon that has not been previously studied or has been poorly understood” (Anastas, 1999, p. 353).

The previous research has focused on how the disabled siblings impact the family. I hope my study will clarify and provide more research how non-disabled siblings respond to a physically disabled sibling. Therefore, the interview guide is an appropriate form of data collection method for this study. The interview was semi-structured so that I could ask certain questions to obtain information about the topic while keeping the questions open ended enough so that respondents can describe their own individual experiences, reactions, and responses to whatever extent they choose.

My interview guide began with a few questions that collected demographic data such as the participant’s race and gender. The next part of the interview guide consisted of questions that were grouped into the following themes: (1) family stress and conflict (Can you tell me about a typical day for you with the family?), (What is your role as a sibling having a sibling with a disability?); (2) birth order/gender, (Are you younger or older?) (If you have other siblings, is there a difference with the other sibling?); (3) school (What kind of pressure do you feel when it came to school?); (4) public realm (What behaviors did you have in the public around your sibling with a disability? Are you over protective more in public, than in your household?).

Based on the information that my literature review produced, these themes enabled me to answer the research question: How do siblings respond to physically disabled siblings? Additionally, I the organization of the open ended questions allowed

the participants to ease into the material and provide a sense of closure at the end. For the complete interview guide, please refer to Appendix B.

Data Analysis

During each interview, I recorded the narrative data via a cassette-recording device. I took notes during the interviews in order to capture nonverbal expression and movement. After each interview I recorded my reflections into a notebook. Once all the interviews were conducted I had the interviews from the cassette professionally transcribed verbatim into a written format.

I created a coding system for the common themes that my research uncovered such as family impact, birth order, gender, school, peers, community and words of wisdom. I created a document by cutting and pasting responses for each theme. These documents allowed me to keep all the data in one place which made it easier to recognize sub-themes as I analyzed the data. The document allowed me to reorganize the data in order to recognize themes that were not be obvious. In order to enhance the accountability of this study, I created an audit trail by keeping complete records of the research, the data, and the coding process (Anastas, 1999). After each interview, numbers were used in place of participants' names on tapes and journal entries and all other data to ensure confidentiality. For example, each respondent had a number 01-05.

CHAPTER IV

FINDINGS

The purpose of this study was to investigate how non-disabled siblings respond to siblings with a physical disability. The projected number of participants was 10-12, yet a sample of 5 was obtained. After contacting 20 potential participants, 5 agreed to the interview; 13 considered participation but failed to return my emails to set up the interview date; and, 2 refused for undisclosed reasons. Though based on a small pool of participants, this study will aid in the better understanding of non-disabled siblings of disabled individuals. After a brief demographic portrait of the sample, the areas of interest are (1) the impact on the family, (2) gender and birth order; (3) school; (4) peers; and, (5) the community.

The demographic breakdown of the participants illustrates the likeness and differences of the participants. All five participants grew up in small communities. Two respondents come from families of 9 children, two from families with 3 children, and the fifth has 4 siblings. Of the five participants, one was male and four were female. Additionally, four of the five were younger than their physically disabled sibling. The one older sibling was a female. The ages of the participants ranged from 35 to 58. The siblings' disabilities included (1) cerebral palsy; (3) mental retardation; and, (1) deafness.

Family Impact

It is expected that having a child with a disability affects a family and its dynamics. This is clearly illustrated by a couple of the respondents talking about less tension in the house when the disabled sibling would go away on the weekends or during the week for some sort of schooling or respite care. One participant reported that when the sibling did go away, she saw what it was like to have a “normal life” without a sibling with a physical disability.

Many families with physically disabled children face unique trials and experiences. Some participants expressed many challenges while the other participants saw very few challenges. These non-disabled siblings faced a wide variety of challenges connected to the disability and its impact on the family. For example, the participants reported having “to tolerate the violence in the home,” the “constant disruption at dinner”, “learning a new language and trying to teach my sister from right from wrong”, and “understanding what your sister wanted because she could not express herself.” Another example; one participant reported “when my brother would have a seizure it took hours for my father to come him down so he would not hurt himself.” These accounts of the non-disabled siblings, illustrate the extra time and energy a disabled sibling can take from the rest of the family.

Not only was time and energy taken, but tension was added. Two of the participants reported the physically disabled sibling would have tempers that also took up time and energy from their parents. Additionally, their disabled siblings would become “violent”, which would cause them a lot of “tension” in their homes.

The disabled and non-disabled siblings' conflicting needs were, at times, stressors for the non-disabled sibling or for the family. For example, one participant reported "her brother always wanted to hang out with her and she did not want him around all the time. This would cause tension within the home." While, another participant reported "if my brother wanted something and I wanted something, he would get it first, even though I was the youngest he would be babied more than I was."

Not only does it seem that conflicting needs caused stress, but caring for the disabled sibling was sometimes a difficult task for the non-disabled sibling. For example, one participant reported "trying to teach my sister from right and wrong. That was difficult because she just did not get it." Another participant reported "that her sister was not potty trained until she was seven, and that was hard for her because she would have to carry her to the bathroom." She proceeds to tell of "having to take care of the physically disabled sibling all the time because both parents worked and my father was not always around."

Negative affects such as high stress levels and more responsibility are an aspect of growing up with a disabled sibling, yet only one respondent seemed almost entirely negative. It seemed as though she could only recall negative experiences. When asked about highlights, this participant responded that "all the highlights that stand out are nightmares. I remember one Christmas my sister, unwrapped all the presents and ate the light bulbs on the tree." Though, this one participant did not have many positive experiences, she was the exception.

The other four participants spoke of challenges and negative impacts on the family, they also reported having positive memories growing up with their physically disabled sibling. For example, most of the participants reported having a good relationship with their sibling, treated them like any other sibling, and fought with them like any other sibling. Other positive outcome the siblings reported are learning or gaining “empathy, tolerance, sign language, compassionate, understanding of those with a disability, or those who have a relative with a disability.”

An interesting point to note is that the participants reported that the physically disabled sibling did not impact the family when it came to family outings. For example, one participant reported “if my brother was acting out at home, one of my parents would stay behind with him.” Another participant’s account differed in that the family would not go out, but she did not experience it as a negative outcome. “If my sister was having a melt down because she did not want to get dress then we would not go out, this really only happen when we would go to church, so it did not bother me.”

Parents

Parental relationships are obvious an important aspect to family dynamics, along with having a child with a disability. All respondents reported to have a close relationship with their mothers. Four out of the five participants reported having a good relationship with both parents but felt closer to the mother because the father worked more. One participant reported saying “I learned nurture from my mother and responsibility from my father.”

Three participants reported their father was not around much to help take care of their non-disabled sibling. These same participants reported this is when they would have to step in as the other parent. The respondent who did not report a good relationship with her father actually described it as “terrible because he felt embarrassed about my sister’s disability so he was never around.”

Three out of the five reported that the parents were able to sit and explain to them about the disability (cerebral-palsy, mentally retarded, and deaf). The other two reported that they were not educated about the disability (mentally retarded), they were just told that their sibling was different and to treat them like they were “normal”. All five participants reported that most of the peers did not ask about the disabled sibling, they just knew they were different “both physically and cognitive impaired”.

Birth Order/ Gender

Within birth order and gender, the sample consisted of one male and three females who were younger than the disabled sibling and one older female sibling. Two major themes emerged within this sample. One point to mention is that while four were younger, only the male who was the younger sibling reported being treated as the youngest. Additionally, all those younger reported a close relationship with the disabled sibling, while the one older sibling did not.

The sole male who was younger than his disabled sibling reported being treated as the younger sibling. He reports “even when we would go to a baseball game together and get lost, we got lost together.” Additionally, he spoke about how he was younger, but

there were nine children in the family, therefore, he did not feel like he was treated as being older than his disabled sibling or had to take on extra responsibilities.

In contrast to the male's experience, the three females, who were younger than their disabled sibling, reported that they were treated as the older sibling, even though there were other siblings in their family. One participant reported "even though I was younger than he was, and there were nine children I understood him more because I was closest to him in age, I was consider the big sister." Another participant reported "that even though I was the middle child and younger than my sister with the physical disability, I was treated like the older sibling. And when I went to college, my younger sibling took on the older sibling role." The third participant reported that her sibling with the physical disability, who was older, called her "big sister", therefore she was treated as the older sibling.

Though they were treated as the older sibling, these participants did not report that they had to take on more chores at home because of the physically disabled sibling. Every participant, including the one participant who was the older sibling, reported that chores were equally divided even though they may not have been the same. All the participants reported that just because their sibling was physically disabled didn't mean they did not have chores to do. One participant reported that "she wasn't disabled as far as being able to do anything. We didn't treat her differently." When it came to chores all the participants reported that their parents treated the physically disabled sibling the same as the non-disabled siblings.

It appears that the non-disabled siblings who were closer in age and younger than their physically disabled sibling had a better relationship with their physically disabled sibling than their other siblings did. For example one participant reported “my disabled sibling and I are closer because we are closer in age and we grew up together. My younger sister is nine years younger so therefore I was in college by the time she became somewhat human.” All four of the participants, who are younger than their disabled sibling, reported being close to their physical disabled sibling.

On the other hand, the one participant who was older reported that she was not close to her physically disabled sibling, but was closer to her younger sibling because “we could communicate with each other.” She reports “that I did not like my sister when she was born because I had my mom alone for three years before my sibling was born and my sister took all my mom’s time. That made me jealous and so my relationship with my sister was never good. Then a couple of years later my sister was diagnosed with a disability (mentally retarded with cognitive impairments).” She continues saying about taking on more responsibilities when her father was not home, summing it up with “I became the second parent.” While jealousy of a younger sibling is often noted, this participant indicated she felt her jealousy of her younger disabled sibling was the result of additional time taken away from her as her parents had higher demands from her disabled sibling.

School

All five participants reported that they did not attend school with their physically disabled sibling because they either went to a “special school or the sibling was older” so they did not have any encounters in school. When asked if the participants felt pressure to do better in school, the participants reported that the parents did not pressure them to do well in school and the teachers at the school knew the situation at home but did not favor the participants in anyway.

One participant reported “I did not feel like I had to do better in school to make up for my sibling’s disability”. The same participant also reported that “this was probably the old school way of doing things, which I think there is a lot of merit to- it’s just the fact of life.” The participants reported they had a lot of support in the school and the community but were not treated any different than the other children who did not have a sibling with a physical disability.

Peers

In speaking about peer relations the participants reported that, generally, their peers accepted the sibling with a physical disability. For three participants, peer acceptance was not an issue. The other three participants reported that their sibling was “accepted so it was not a real issue.” These three participants reported that their physically disabled sibling would hangout with them and their peers. One participant reported that their peers “were more amused trying to learn how to do sign language than anything. It was kind of neat. They didn’t treat her any different.”

Two of the participant's reported of feeling "shame and embarrassed" by their sibling with a physical disability around their peers. These two participants did not let their sibling always hangout with them and their peers. One stated that "it was hard sometimes to take their physically disabled sibling with them to hangout with their peers, because you couldn't be included in things with your peers because they (peers) would refer back to your sibling with a disability. Call them names, and call you names. It was hard for me and I felt bad for my sibling with the disabilities." Those peers who picked on the physically disabled sibling made the participant angry and the participant felt over protective in the situation.

The participants did report that those peers, who were not familiar with the sibling's disability, tended to ignore their sibling with a physical disability or picked on the sibling with a physical disability. One participant reported that most of their peers understood their sibling's physical disability and that some of their peers did make fun of the sibling with the physical disability because they were "afraid of the physically disabled sibling."

The only escape mentioned, surprisingly not drugs or alcohol, was going to peers' houses to avoid home. One participant reported (who was older than their sibling and not close to their sibling) "I would go to my friends houses to escape and if I did not have to be home to take care of my sister than I would avoid going home." The other four participants reported they did not have to escape from their physically disabled sibling or their family.

Community

Within the scope of the wider community issues and reactions arise. For instance, level of acceptance and support is an issue, with emotional reaction such as embarrassment or being protective. These were the main ideas that were repeated by most of the respondents. All the respondents grew up in small communities, which may be a different experience from other types of communities. For instance, all five of the participants felt they did not have to explain the disability to adults and it was not an issue. The participants reported that most adults knew their families because everyone in town knew their parents very well.

Participants reported their group support was from the neighbors, family, and/or church. All five participants reported that the physically disabled sibling was well accepted by the community even when the physically disabled sibling would not be on their best behavior. For example; one participant reported that “my brother could not swim too well and if I didn’t watch carefully the my brother would climb the high dive and jump off and the life guard would have to go in after him. The community really accepted my brother and they knew he liked to push himself to be like everybody else and it was great when someone in the community took an interest in my brother and supported him.”

One participant reported “growing up back in the 70’s it was easier with having a sibling with a disability. You had more neighbors who were your neighbors and supported your family.” The participants reported it was easier to be with your sibling

with a physical disability in public because most of the public knew who your physically disabled sibling was and treated them like any other neighborhood kid.

While the majority of the community was supportive, not everyone was. One participant reported “people in the community knew who he was and looked out for him but then you had the ignorant people who treated him badly. They would call him names like stupid or retarded and those people made me angry.” Additionally, another says, “it was difficult to see others take advantage of my brother with a disability, it’s bad enough when you do it but when others do it, it is hard.”

All the participants reported that they would treat their sibling a little better in public than in their house because they were their sibling and you know how to push their buttons as well as needing to protect them. All participants reported being over protective of their sibling with a physical disability in the public because “they (physical disabled sibling) were family so you had to protect them.” Another participant reported that she had to make her sibling with a physical disability feel safe in the public when others picked on him. She reported that the protection of her brother was not forced upon her, she felt she had to protect him.

This protective feeling may be something that evolves over time and age. For instance, one participant reported “before we would go out on a pond skating we would send my brother with the disability out first to make sure it was safe, we knew he would go out on the ice. But as my brothers and I got older we were a lot more protective of him and needing to make him feel safe.”

Another participant felt “sometimes embarrassed” when in the public with her sister, even though they were close. The participant reported “when we would go to a store and she (physically disabled sibling) wanted something, she would not know how to ask for it and would stand and point until we found her, and people would stare and whisper, that was embarrassing.”

Not all participants reported feeling embarrassed when in the public with the physically disabled sibling. Some participants reported living in a small community resulted in everyone knowing about the sibling with a physical disability which made it easy to go out in the community. One participant reported that when they would go out in the community as a family the sibling with a physical disability would not be the center of attention because there were nine children in the family. Only when the participant’s sibling with a disability could not do the same things as their brothers or sisters would he then be the center of attention.

Words of Wisdom

When participants were asked what they would tell other families who have children with disabilities they each had a very different response. Two participants reported it was a “privilege”. Another two reported “treat them normal and not exclude them. They have feelings too, even though they may not be able to express them”, and the fifth participant responded “good luck, because it was hard for my family. We did not have the resources that are available now. If there are resources available for you such as social outreach programs, more education, or therapy use them. The parents

should sit down with the non-disabled siblings and explain what the disability is so the non-disabled sibling has a more understanding of their sibling with a disability.” One participant said “it is important to have government resources, whether it is health care or group homes, but none of that can come close to the family, neighborhood and church support.”

CHAPTER V

DISCUSSION

This study explores non-disabled individuals' experiences and responses to having and growing up with a physically disabled sibling. The interviewed, non-disabled siblings are now adults, between the ages of 35 and 58 years old. Through their recollections, these five individuals shared their perspective of growing up with a physically disabled sibling. Overall, they experienced a variety of emotions from joy to frustration and embarrassment. They gained understanding and patience while enduring added stress and tension.

In the journey of growing up with a sibling with a physical disability, the participants faced some challenges that, ultimately, resulted in their ability to cope with and protect their sibling with a physical disability. Even more importantly, the participants came to understand the disability and all but one, stated they learned to accept their disabled sibling. These participants gained valuable life assets through their experiences with a physical disability such as empathy, understanding, and patience.

This study found that:

- 1) the physically disabled sibling did impact the family, both positively and negatively;
- 2) birth order affected sibling relations in that the younger non-disabled siblings reported good relations with their disabled sibling, but the sole older sibling reported a poor sibling relationship;
- 3) gender played a role in sibling relations and birth order perception, in that non-disabled female siblings were regarded as the older sibling, even when younger, yet the younger male was regarded as younger;

- 4) peer relationship and school experiences were problem areas for the participants; and
- 5) the participants reported their small communities both knew and supported them, their disabled siblings, and families, which seemed to help the sibling relationship.

Many of the participant's responses reinforced findings from other studies that report disabled siblings impact the family (Dunn, Slomkowski, & Beardsall, 1994) or that disabled siblings cause stress within the family and non-disabled siblings are affected by living with the disabled sibling (Harmer, Cox, Marshall, Mandleco, and Olsen, 2003). These points are illustrated within the present study by the participants' stories of the physically disabled siblings' impact on the family by adding tension and frustration. As a result of the added stress, the participants did report that family adjustments had to be made (such as seeking alternative education for the physically disabled sibling). These adjustments often lessened the household stress. The participants reported they experienced a normal life and felt less tension at home, when the disabled sibling was away during the week or weekends for school.

Although, extra tension and stress filled the homes of the participants, most did not feel overburdened by the disability. Past studies have suggested that non-disabled siblings of disabled siblings may take on more household responsibilities (Harmer, Cox, Marshall, Mandleco, and Olsen, 2003) becoming less involved in school (Pit-Ten Cate & Loots 2000), or feeling pressure to do better in school (Nixon, Cummings, & Mark 1999) because of their disabled sibling. Yet, the majority of the participants did not experience these affects, the one older non-disabled sibling did.

The sole older sibling in this study reported “being jealous that her sister took all her mother’s time.” Additionally this older sibling, who was a female, did feel some extra burdens of care-taking and negative affects of the disabled sibling, which is in line with Stawski, Auerbach, Barasch, Lerner, Zimin (1997). As a result, she reported as she got older she would avoid going home to feel less anxious.

This study suggests the majority of the participants and their sibling relationships were affected by birth order and gender. The one older non-disabled sibling reported more negative feelings than all those that were younger. One explanation for this is that she knew life without the sibling and the disability, while, the younger non-disabled siblings did not know life without the disabled sibling.

Another aspect of birth order and gender is whether the younger non-disabled sibling takes on the older sibling role. In this study, the younger female siblings took on the older sibling responsibility. This supports Howe (1993) and William (2002) argument that because “they were closer in age, they became closer to their physically disabled sibling therefore they took on the older sibling role.” The one male participant reported birth order and gender did not come into play because “there were nine of us. He [physically disabled sibling] did not become the center of attention.” He reported it was a big family and the sibling adjusted well, which supports Pit-Ten Cate and Loots (2000) idea that siblings can adjust to big families.

It is often the case that the physically disabled sibling does become the center of attention. It is also the case that, especially younger, non-disabled siblings act out (Pit-Ten Cate & Loots 2000) or become model individuals (Raskin 2006). Yet, in this present

study the younger siblings did not seek attention. Additionally, the participants reported not feeling added pressure from their parents to do well in school and found the teachers in school being supportive and not treating them any different. It may be that these participants did not feel neglected by their parents, therefore, did not seek positive attention by trying to become the perfect child as Osman (2006) reported.

Additionally, outside of the home, some of the participants reported feelings of “disabled by association”, as described by Burke and Kingsley (2005). More specifically, some reported not liking to go out with their disabled sibling for fear of others calling either of them names. According to Faux (1993) non-disabled sibling feel over protective in the public and can increase empathy. The participants illustrate this protective feeling and thus an increase in their empathy. Learning empathy is something that happens with time, as one participant spoke of his attitude changing from poking fun to protective and empathetic. This adjusting and changing with age supports Healey’s (2006) findings.

Some participants reported no hesitation or apprehension when going into public with their disabled sibling. These individuals did not feel they were affected when going out with their physically disabled sibling. One reason for this ease may be that the participants reported the community, such as churches and neighbors, were supportive and many of their peers were supportive because they understood the disability.

All participants in this study, regardless of the respective disability, expressed that understanding and being able to explain the respective disability was a key to adapting. Those participants who reported peers feeling nervous or scared to be around the disabled

sibling, as reported in past studies (Pit-ten Cate, 1998; Burke and Kingsley, 2005), were the non-disabled siblings who lacked understanding of the disability. Therefore, they could not explain the disability to their peers. This gave them a disadvantage by not being able to explain the unknown.

Question 19 of the interview guide asked the participants what they would tell other families who have children with disabilities. In their responses participants urged others to educate non-disabled siblings, find resources and therapy for family members. Furthermore, they directed people to social outreach programs, government resources, health care, group homes, and other support groups via local churches and neighbors.

Limitation of the Current Study

An effort had been made to reach as many non-disabled siblings as possible. The recruiting process, discussed in detail in the Methods section, included a visit to a local independent living agency, tapping into my vast personal and professional network of social workers, educators, and public servants (which resulted in a list of 50 potential participants). Yet, the population of non-disabled individuals who grew up with a physically disabled sibling proved to be difficult to locate, not to mention recruit.

Of the potential participants I was able to contact, a majority were not interested or available to participate. 30 contacts never replied to my original request; 13 did not disclose why they chose not to participate but simply failed to return my emails and/or telephone calls; and, the remaining 2 directly refused for undisclosed reasons. As a result, the pool of five actual participants is one limitation of this study. Yet, their

perspectives allow for some interesting comparisons and observations. More aggressive recruiting efforts are encouraged in future study and are discussed in the next section:

Implications for future research.

The lack of diversity within the sample is also seen as a limitation. For example, four out of the five participants were female, therefore an insufficient gender balance. All the participants identified themselves as white, so there were no participants of minority. Another factor was the participants were only drawn from one geographic area, western Massachusetts. Additionally, the participants were from smaller communities which give no comparison to larger communities. Yet, it does allow for a closer look at growing up in small communities.

Another potential limitation is that interviews were only done with one member of the family. It is possible that other siblings in the family could have had different interactions as a result of growing up in a household with a disabled sibling. It may be a directive to future study to interview more than one non-disabled sibling from a family with a disabled child. The pool of participants did not include any additional siblings willing to partake in the interview process.

The desired information and the interview questions were focused on the past, sometimes the distance past. Therefore, the accuracy of recollection needs to be considered. Adult perspective allows for life lessons, gained wisdom, and retellings to filter memories. Yet, the participants' accounts seemed to be balanced in that they discussed both negative and positive aspects to their experiences.

Finally, this study was done with open ended questions, a single interview, and different environments. Potential bias, therefore, may be due to the way the questions were asked verbally, how the questions were followed up, or the interviewer's non-verbal responses to the participants' answers.

Implications for Further Studies

This study supports the notion that gender and birth order affect the disabled and non-disabled siblings relationship. Therefore, these should be major variables to consider in researching sibling relationships and family dynamics within families with a disabled child. Family size also appears to be an important attribute to consider in how people adapt to the disabled individual.

As an exploratory study, this research has provided accounts of how non-disabled siblings respond to their sibling with disabilities. Because of the small pool of participants for this study, further studies need to focus on the recruiting process. One method to increase potential participation would be to arrange for a personal meeting with the head of the independent living agency following the hand delivery of the recruiting letter. Personal contact may result in an opportunity to provide additional encouragement and information regarding participation in the study.

Another suggestion for redesigning this study is to have participants fill out an on-line survey. One possibility for an on-line survey is the use of survey monkey. An on-line survey has the ability to reach beyond the scope of personal contact. Therefore, this process could potentially reach participants of differing cultural backgrounds and race not

otherwise easily accessible. It would be important, and potentially impact the results of the study, to include families of differing cultural backgrounds.

Other benefits for the use of an on-line survey is the ability to reach participants from different geographical rather than one concentrated area. Communal support may be impacted by placement in rural and urban setting. In addition, the online survey would expand the pool gender and birth order diversity.

Implications for Counselors

The sample of individuals in this study did not face a lot of negativity and did not resort to negative outlets, such as alcohol or drugs. This was a surprising finding and may not represent the norm. The one girl who did avoid home went to friends to escape. These were individuals that had support networks within small communities. Yet, by looking at the participants' experiences and their coping mechanisms, these recommendations can be made to those who counsel non-disabled siblings of disabled individuals.

- Assess: knowledge of disability / support system / family role / extra burdens / sibling relations and communication.
- Arm client with information about the disability / support networks / reasonable expectations / positive outlets.

Conclusion

Future research may expand upon family dynamics; birth order; gender; and, public sphere to include how different cultural experiences impact the family of a sibling set of disabled and non-disabled children. The focus of this study is how the non-

disabled sibling responds to the sibling with a disability. Overall, most of the siblings interviewed reported positive relationships and positive coping mechanisms with little negative outcomes. The fifth sibling reported negative experiences and had no positive relationship with their physically disabled sibling.

The message the participants really wanted to share was that the disabled sibling should not be treated any different. The special needs of their disabled sibling should not result in special treatment beyond that necessary to address the needs of the disability. Therapists and/or social workers working with families who have a disabled sibling are best advised to treat the disabled sibling the same as the non-disabled sibling to the best extent possible while still meeting the needs that clearly address any limitations presented by the disability. Additionally, inform the family of the importance of understanding the disability so they can identify the differing needs of each child – the disabled and non-disabled sibling. Furthermore, encourage the families that they will learn patience, tolerance and empathy from the disabled sibling as well as better social skills when interacting with others.

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Appendix A

Informed Consent Form

My name is Dawn King. I am conducting a study on how non-disabled children respond to a growing up with a sibling with a physical disability to learn more about how the non-disabled sibling cope. The study is being conducted for the (thesis) Master of Social Work degree at Smith College School for Social Work.

I am interested in how non-disabled children respond to growing up with sibling with a physical disability. You are being asked to participate in this study if (a) you are between the ages of 30-60, and (b) grew up with a sibling with a physical disability. As a subject in this study you will be asked to do a one on one, face to face interview. Open-ended questions will focus on your experience growing up with a sibling with a disability. Demographic questions will also be asked. The interview will take between 30 to 60 minutes. Interviews will be tape recorded with your consent, and tapes will be coded numerically to ensure your confidentiality. Tapes will be destroyed after the interviews have been transcribed by a professional transcriber.

Your participation is voluntary. You will receive no financial benefit for your participation in this study. However, you may benefit from knowing that you have contributed to the knowledge of how non-disabled children respond to growing up with a physically disabled sibling. It is my hope that this study will help social workers have a better understanding of what interventions were helpful in working with families who have a child with a disability. You may also benefit from being able to tell your story and having your perspective heard.

The potential risks of participating in this study are the possibility that you might feel strong or uncomfortable emotions while talking about your experiences. In case you feel the need for additional support after participating in this study, you will be given a list of resources for mental health services in your area.

Strict confidentiality will be maintained, as consistent with Federal regulations and the mandates of the social work profession. Confidentiality will be protected by coding the information and storing the data in a locked file for a minimum of 3 years. Your identity will be protected, as names will be changed in the analysis of the data. Your name will never be associated with the information you provide in the questionnaire or the interview. A professional transcriber will sign a confidentiality pledge. The data may be used for my thesis and possible presentation and publication. All data will be destroyed when no longer needed.

This study is completely voluntary. You are free to refuse to answer specific questions, end interview at anytime and to withdraw from this study no later than March 28, 2007. After this date, my thesis will be too fully developed to remove data from the project. If respondents decide to withdraw, all data describing them will be immediately destroyed.

YOUR SIGNATURE INDICATES THAT YOU HAVE READ AND UNDERSTAND THE ABOVE INFORMATION AND THAT YOU HAVE HAD THE OPPORTUNITY TO ASK QUESTIONS ABOUT THE STUDY, YOUR

PARTICIPATION, AND YOUR RIGHTS AND THAT YOU AGREE TO PARTICIPATE IN THE STUDY.

Please keep a copy for your records.

SIGNATURE OF PARTICIPANT

SIGNATURE OF RESEARCHER

DATE

DATE

If you have any questions or wish to withdraw your consent, please contact:

Dawn King
VAMC Northampton
421 No. Main Street
Leads, MA. 01053

413-582-3053

dking@email.smith.edu

Appendix B

Interview Guide

- A. What is your sibling's disability?
- B. What were the challenges you experienced due to having a sibling with a physical disability?
Example of areas to address, but not limited to, are challenges in peer groups, family (impact), community and school.
- C. What were the advantages you experienced due to having a sibling with a physical disability?
- D. Are you younger or older than the sibling with a disability?
- E. How do you think your place in the birth order affected your experience?

The following questions will act as a probing guide if the participant is short with above answers or s/he needs redirecting.

- 1) What was it like for you to grow up with a sibling with a disability?
- 2) What was your role as a sibling of a physically disabled individual?
- 3) Describe your responsibilities growing up?
- 4) If you have other siblings without a disability, is there a difference with that sibling?
- was there a difference between your sibling in how you interact with the disabled sibling?
- 5) How would you describe your relationship with your physically disabled sibling?
- 6) Was it always like that? or did it change?
- 7) What was the relationship between your mother and your brother/sister?
- 8) What was the relationship between your father and your brother/sister?
- 9) What was your relationship with your mother like?
- 10) What was your relationship with your father like?
- 11) How did most people respond to your brother/sister?
- 12) Was your relationship with your brother/sister different in public/school than in your house?
- 13) Describe any highlight growing up with a physically disabled sibling?
- 14) Describe any lowlight growing up with a physically disabled sibling?
- 15) Would you say you gained from your experience?
- If yes, how would you describe those gains?
- 16) When you were growing up, how did you explain the nature of your sibling's physical disability to peers? To adults?
- 17) Did you ever use drugs/alcohol growing up?
If yes, did you do this to cope with having a sibling with a disability?
- 18) Did you ever do any self harming growing up?
If yes, did you do this to cope with having a sibling with a disability?

- 19) Do you have anything you would say to other families with children with a disability?
- 20) Is there anything else you would like to add?

Demographic Questions

How old are you?

How do you identify yourself racially?

How do you identify yourself; male or female?

Appendix C

RECRUITING LETTER

As a requirement of my Master's degree in Social Work from Smith College School for Social Work, I am writing a thesis researching the impact in families of a child with a physical disability. More specifically, I would like to interview adults who are presently between the ages of 30-60 years old who have grown up with a sibling with a physical disability. My study will explore how non-disabled children respond to a sibling with a physical disability to learn more about how the non-disabled siblings cope with having a sibling with physical disabilities. My interest in this research is from my own life experiences, as well as working with adolescents who had a disability, who had siblings that did not have a disability. I often wondered how the non-disable sibling felt about their sibling with a disability.

If you have received this letter, either myself or a mutual friend or colleague thought you fit this description, or you may know someone who does and would be interested in participating. I am currently recruiting participants for this study and would appreciate your support. Please contact me directly at dking@smith.edu. All responses to this request are confidential. If contacted, I will contact the interested individual directly to talk and set up a meeting.

Participation will consist of an interview process that will take between 30-60 minutes. The interview process will take place in a convenient location that both parties agree upon.

Thanks!

Dawn King
Candidate for Master in Social Work
Smith College School for Social Work
dking@smith.edu

Appendix D

Volunteer or Professional Transcriber's Assurance of Research Confidentiality

STATEMENT OF POLICY:

This thesis project is firmly committed to the principle that research confidentiality must be protected. This principle holds whether or not any specific guarantee of confidentiality was given by respondents at the time of the interview. When guarantees have been given, they may impose additional requirements which are to be adhered to strictly.

PROCEDURES FOR MAINTAINING CONFIDENTIALITY:

- All volunteer and professional transcribers for this project shall sign this assurance of confidentiality.
- A volunteer, or professional transcriber should be aware that the identity of participants in research studies is confidential information, as are identifying information about participants and individual responses to questions. Depending on the study, the organizations participating in the study, the geographical location of the study, the method of participant recruitment, the subject matter of the study, and the hypotheses being tested may also be confidential information. Specific research findings and conclusions are also usually confidential until they have been published or presented in public.

It is incumbent on volunteers and professional transcribers to treat information from and about research as privileged information, to be aware of what is confidential in regard to specific studies on which they work or about which they have knowledge, and to preserve the confidentiality of this information. Types of situations where confidentiality can often be compromised include conversations with friends and relatives, conversations with professional colleagues outside the project team, conversations with reporters and the media, and in the use of consultants for computer programs and data analysis.

- Unless specifically instructed otherwise, a volunteer or professional transcriber upon encountering a respondent or information pertaining to a respondent that s/he knows personally, shall not disclose any knowledge of the respondent or any information pertaining to the respondent's testimony or his participation in this thesis project. In other words, volunteer and professional transcribers should not reveal any information or knowledge about or pertaining to a respondent's participation in this project.
- Data containing personal identifiers shall be kept in a locked container or a locked room when not being used each working day in routine activities.

Reasonable caution shall be exercised in limiting access to data to only those persons who are working on this thesis project and who have been instructed in the applicable confidentiality requirements for the project.

- The researcher for this project, Dawn King shall be responsible for ensuring that all volunteer and professional transcribers involved in handling data are instructed in these procedures, have signed this pledge, and comply with these procedures throughout the duration of the project. At the end of the project, Dawn King shall arrange for proper storage or disposition of data, in accordance with federal guidelines and Human Subjects Review Committee policies at the Smith College School for Social Work.
- Dawn King must ensure that procedures are established in this study to inform each respondent of the authority for the study, the purpose and use of the study, the voluntary nature of the study (where applicable), and the effects on the respondents, if any, of not responding.

PLEDGE

I hereby certify that I have carefully read and will cooperate fully with the above procedures. I will maintain the confidentiality of confidential information from all studies with which I have involvement. I will not discuss, disclose, disseminate, or provide access to such information, except directly to the researcher, Dawn King for this project. I understand that violation of this pledge is sufficient grounds for disciplinary action, including termination of professional or volunteer services with the project, and may make me subject to criminal or civil penalties. I give my personal pledge that I shall abide by this assurance of confidentiality.

_____	Signature
_____	Date
_____	Dawn King
_____	Date

Appendix E

MENTAL HEALTH REFERRALS

Massachusetts

Jeffrey Fishman - Psychologist
24 S. Prospect St.
Amherst, MA 01003

(413) 256-0947

Andrea Cousins - Psychologist
155 Main St.
Northampton, MA 01060

(413) 584-8635

Adele S. Oppenheim – Clinical Social Worker
5 Strong Ave., FL 2
Northampton, MA 01060

(413) 584-0072

Amy A. Hirsh, PHD - Psychologist
6 Main St.
Amherst, MA 01002

(413) 256-6679

Jennifer Bryan – Psychologist
155 Main St.
Northampton, MA 01060

(413)- 582-7002

Andrea Cole – Psychologist
16 Center St.
Northampton, MA 01060

Barbara Meyer – Psychologist
264 Elm St.
Northampton, MA 01060

Barry Nigrosh – Psychologist
7 Hadley St.
South Hadley, MA 01075

Department of Mental Health
25 Staniford Street
Boston, MA 02114

Toll-Free: 800-221-0053 (Information and Referrals)

Appendix F

Human Subject Review Board Approval Letter

January 10, 2007

Dawn King
VAMC of Northampton
421 North Main Street
Leeds, MA 01053

Dear Dawn,

Bravo! Your letter is fine and we are now glad to give final approval to your study. It should prove to be very interesting and very useful.

Please note the following requirements:

Consent Forms: All subjects should be given a copy of the consent form.

Maintaining Data: You must retain signed consent documents for at least three (3) years past completion of the research activity.

In addition, these requirements may also be applicable:

Amendments: If you wish to change any aspect of the study (such as design, procedures, consent forms or subject population), please submit these changes to the Committee.

Renewal: You are required to apply for renewal of approval every year for as long as the study is active.

Completion: You are required to notify the Chair of the Human Subjects Review Committee when your study is completed (data collection finished). This requirement is met by completion of the thesis project during the Third Summer.

Best of luck with your project.

Sincerely,

Ann Hartman, D.S.W.
Chair, Human Subjects Review Committee

CC: Joan Lesser, Research Advisor