

PERSONAL PERSPECTIVES:
EXPERIENCES OF PERSONS WITH A SIBLING WITH A DISABILITY

BY

KOREEN SCOTT

A Thesis
Submitted to the Faculty of Graduate Studies
In Partial Fulfillment of the Requirements for the Degree of
MASTER OF EDUCATION

Department of Educational Administration,
Foundations and Psychology
University of Manitoba
Winnipeg, Manitoba

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FACULTY OF GRADUATE STUDIES

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**A Thesis/Practicum submitted to the Faculty of Graduate Studies of The University
of Manitoba in partial fulfillment of the requirements of the degree
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Koreen B. Scott

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Abstract

The purpose of this study is to describe and examine the experiences of persons with a disabled sibling from their personal perspective. Five informants were selected for the study and interviewed in three one-hour sessions. Two of the five informants were female and three were male: their siblings ranged in age from nineteen to mid-forties. Their disabled brothers and sisters were intellectually disabled and diagnosed with either autism or cerebral palsy as well. These diagnoses placed the persons in a group that could be defined as severely disabled with limited or no speech and mobility. Qualitative research methods were used to collect and analyze data in order to gain a subjective perspective into the lives of persons with a disabled sibling. The findings revealed information consistent with that found in the literature as well as some new information. Along with the emotional and social impacts of having a sibling with a disability, there are some indications that positive skills in the area of communication and problem solving may develop as a result of a person's involvement with a disabled sibling. Implications for further study include exploration of best strategies for support for siblings. There is also need for a developmental examination of how emotional and social effects on siblings change over time.

Personal Perspectives: Experiences of Persons with a Sibling with a Disability

Chapter 1: Introduction

The social worker's words remain vivid in my mind, "Your sister is not the only victim here". That December day, six years ago, I was visiting my sister with cerebral palsy in the institution where she had lived for the past twenty years. "Hospitalized" at age eight, this was the fourth such institution in which my sister had lived. It was only the second time in thirty-five years that I had visited her.

The emotional response that boiled to the surface prompted the social worker to take me into her office in an attempt to console me. Until I heard the social worker's words that day, the idea that I may be a victim had never crossed my mind. "How could I, who is strong, healthy, can walk and talk, be a victim?" To me, being a victim in relation to my sister was an unknown and never considered concept. I began speaking to other siblings of persons with a disability. I began with my brother.

My Brother's Story. A talk with my brother about guilt particularly stands out. I was explaining how I had come to the realization that I was not to blame for my sister's disability and that the guilt that I had felt all of these years had been misplaced. I described how a voice had come to me during a time of great stress while contemplating the effects on parents and siblings of having a person with a disability in the family.

To recount, I explained the voice that said, "Koreen, there was nothing you could have done". I told my brother about the thoughts following that comment that made it clear to me that there was nothing that I could have done. The "accident of birth" happened in the hospital and I was, not only at home but six years old at the time. When I explained my thinking to my brother, he seemed shocked that I had even considered any responsibility for my sister's disability. He quite clearly felt that he was to blame.

All of the our lives the family story around my sister's birth and the next six months of her life was retold and circulated amongst family members. The responsibility and concomitant guilt was placed on my brother, that is, according to my brother's interpretation. I had heard the story over and over but until our conversation of that day had never realized my brother's perspective on that incident. The family story as I recall it:

After the difficulties of her birth had passed, my sister appeared to be developing normally until eight months of age. One day, she was in her playpen, pulling herself up and walking around the sides. My brother was playing hide and seek with her, sneaking up and saying "Boo". At one point, she fell down and never got up again.

My brother had always assumed that he had caused our sister's disability by scaring her that day and causing her to fall. During our conversation about guilt my brother was incredulous that I should be assuming guilt. He said, "What do you mean it was your fault? It was my fault because I scared her." With that statement, my brother's view became clear to me. It was one that I had never

considered because I knew that my sister's condition after the fall was merely symptomatic of the problems that started as a result of improper procedures by the nurses during her birth. During most of our lives my brother and I had both lived with misplaced guilt over my sister's disability. This conversation combined with the impact of visiting my sister after thirty-five years helped me to enter into a self-reflective stage in my life.

The ideas that entered my head the day of my first visit changed the course of my life. I began examining my background. My relationships, social skills, behaviours, thought patterns, actions, and philosophical outlook became the subject of self-analysis in relation to the effects of living with a disabled sibling. The visit set me on a journey of discovery and self-discovery that continues today with the development of this thesis in which I will explore the personal perspectives of siblings of a person with a disability. I decided to conduct a study to document and describe the perspectives of other siblings. Specifically, my study focussed on the siblings of people with autism and cerebral palsy.

Autism is a pervasive developmental disorder characterized by three major hallmarks; qualitative impairment in social interaction, qualitative impairment in communication, and restricted, repetitive and stereotypical patterns of behaviour, interests and activities. As defined in the DSM IV onset in delays is prior to three years of age (Definition of Autism, 2003). Cerebral palsy is a term used to describe a group of disorders affecting body movement and muscle coordination.

The medical definition states that cerebral palsy is a non-progressive but not unchanging disorder of movement and/or posture, due to an insult or anomaly of the developing brain (About Cerebral Palsy, 2003). I chose these two disabilities since people with autism or cerebral palsy will generally have limitations in cognition, speech, and/or mobility. Siblings of persons with physical disabilities or learning disabilities may have different experiences to siblings of persons with disabilities that require more care or display unacceptable behaviours. The perceived nature of a sibling's disability may influence how a non-disabled sibling interacts with others. For example, siblings of persons with autism may find their disabled sibling's behaviour embarrassing. Whereas, a sibling of an individual with a physical disability who does not display unacceptable behaviour may not feel embarrassed by their sibling. Many questions arose about the experiences of siblings of persons with a disability.

The Research Question

I developed my research question: *Personal Perspectives: Experiences of Persons with a Sibling with a Disability* with the intent of examining, for myself, the experiences of other persons with a disabled sibling. The purpose of the thesis is to answer questions about the subjective experiences of people with disabled siblings. There is a lack of research dedicated to the experience of siblings: "although many writers have speculated about the special challenges children face when growing up with a disabled sibling, there is a paucity of hard evidence

regarding sibling relationship processes in families with disabled children” (Boer & Dunn, 1992, p. 84). This thesis is an examination of sibling experiences and the manner in which they vary from the experiences of people who do not have disabled siblings.

On examining my own situation I know that I grew up with different experiences than siblings in a family where there is no disability. Things that may have been important to my peers did not hold importance for me to the same degree (Singer & Powers, 1993). For instance, outward appearances such as hairstyles, nail polish, and designer clothes were not as important to me as the life and death issues that my family faced with my disabled sister. I remember clearly when my sister began taking seizures: I recall the fear and concern. At the age of nine years old, nothing else seemed as important as her health and safety and the upset of my parents. There was little acknowledgement of the impact of those challenges on my able-bodied sibling and myself.

For myself, my brother and those that I spoke with in developing this question I came to realize that most people are not aware of the daily struggles of a sibling of a person with a disability. For the most part siblings are expected to function according to society’s norms. This may be a difficult task, however, since the sibling’s upbringing, their family dynamic and their everyday experience deviates from the definition of what is considered “normal” in our culture.

Personal Perspectives: Experiences of Persons with a Sibling with a Disability is a thesis developed to offer insight into the subjective view of persons with a disabled sibling. The work is intended to inform readers of the possible impact, positive and negative, of the experience of growing up with a disabled sibling. Certain features of an able-bodied sibling's development in social, cognitive and emotional domains have similarities. It is important to identify those similarities and to elaborate on them. Professionals working with siblings, such as teachers, doctors, psychologists, social workers and clergy, may benefit from becoming more aware of the effects on individuals of having a disabled sibling. This knowledge can help in their understanding of the individual that they are working with. Other siblings need to be informed that they are not alone and what they are experiencing is not unique. The research question was developed in the hopes that this thesis will add to the body of knowledge about the experiences of persons with disabled siblings and to inform professionals, parents and other siblings about their strengths and needs.

Methods

I used qualitative research methods in this study in order to gain a perspective from the siblings' point of view. By conducting interviews with open-ended questioning I hoped to discover the issues and concerns that siblings deem important. I analyzed those findings by comparing my results with the literature, my personal and professional experience.

In studying the literature I found articles and books that examined a number of issues related to being a sibling of a person with a disability. I found information and concerns that I recognized: I discovered new ideas. I discussed my possible thesis topic with other siblings. In regard to personal experiences, the siblings of individuals with disabilities that I spoke with agreed that it would be beneficial to have more information and support available on the topic. There were a number of themes apparent in the literature.

Themes in the Literature.

The themes in the literature that I examined include emotional responses, family interaction, social interaction, and mediating effects for siblings.

The emotional responses that I highlighted are fear, grief, and denial. In examining family interaction I discovered that communication and allocation for time and resources within the family were important. Without the proper handling of these items siblings may develop behavioral responses that include jealousy, resentment and guilt. Social interaction for siblings may be affected due to their differences and possible stigmatizing. Isolation and loneliness can result from these experiences. Social relationships for siblings may be impaired due to a number of factors including embarrassment about their family situation.

The positive news in the literature is that siblings of disabled individuals seem to develop some common characteristics that include kindness, understanding, tolerance, and acceptance. Effects such as age, gender, and birth

order may mediate their situations. Several authors offer suggestions for activities, programs, and strategies to help support siblings of persons with disabilities and their relationship to the family. These themes will be explored in greater detail in the following chapter.

Chapter 2: Literature Review

Research on the topic of sibling experiences has been done sporadically over the last thirty years. In this chapter I will present a review of the literature and describe the major or dominant themes that I found. I looked at both empirical studies as well as personal accounts from siblings. In the review of the literature I will focus on what the empirical research literature has to say on the experience of siblings. This literature review covers books dating from 1980 and journals that extend back fifteen years. Some of the early research in this area is still heavily referenced in the current literature; therefore, I felt that it was appropriate to refer to authors such as Featherstone (1980), Goffman (1986) and Dunn & Kendrick (1981).

Conducting the literature review

I conducted my research at O.I.S.E. in Toronto and the University of Toronto Robart's Library. In Nova Scotia, I was able to access libraries at Dalhousie University and Mount St. Vincent University. The Novanet Catalogue in Nova Scotia contains the library records for all Nova Scotia University Libraries except Acadia University. I was able to order Helen Featherstone's book, *A Difference in the Family* from St. Francis Xavier University Library in Antigonish, Nova Scotia. I requested a COPPUL (Reciprocal Loan Program, Council of Prairie and Pacific University Libraries) card from the University of Manitoba. It was fortunate that the program had been extended to include Ontario

and Nova Scotia. This card has enabled me to have external borrower privileges. From my home in Peterborough, Ontario the Toronto University Libraries were a considerable distance. In Nova Scotia, however, the universities were an easy distance from my home. The Nova Scotia university libraries extended some ordering privileges to me that were not available in Ontario.

The literature review was conducted over an extended time, approximately two years but the distance from the libraries in Ontario made it difficult to spend very much time there especially since I was working full time. In Ontario, an initial search revealed twenty-two entries from the Cambridge Scientific Abstracts. I chose appropriate books and journals from this search.

I conducted two other searches, which revealed approximately the same amount of entries, but many of them were repeats. I searched the ERIC database and microfilm at O.I.S.E. (Ontario Institute for Studies in Education) for material.

In Nova Scotia, I searched the PsycINFO database. I found several other pertinent books and articles. A recent search of Dalhousie Killam, Dalhousie Kellogg and Mt. St. Vincent University Libraries did not turn up any new material that I found applicable. A search of some of the major journals in this area, such as *Mental Retardation*, *Exceptional Children*, *JASH*, and *Education and Training of the Mentally Handicapped* did not reveal pertinent articles for my research. Several themes emerged in the books and articles that I chose.

Themes

The literature review is organized into four main areas: emotional impact, family interaction, social identity and relationships, and mediating effects on siblings. These themes emerged as I examined the literature. Subheadings in some areas will be used to separate the main themes into smaller segments.

Emotional impact

Several emotional responses to living with a disabled sibling were reported in the literature. These responses include fear, grief, and denial.

Fear. Siblings of persons with disabilities have fears that are connected to their experience and rooted in their particular situation. Brothers and sisters of a person with a disability may fear "catching" the handicap themselves (Powell & Ogle, 1985). Their misunderstanding about the nature of the disability may be a function of their age or the lack of information given to them. Brothers and sisters may fear for the child as well as their own survival in the present and in the future (Gladstone & Montgomery, 1990). Older siblings may fear having to take full responsibility for their disabled brother or sister as their parents get older. Siblings may fear having their own children. They worry about whether or not their children will have disabilities (Featherstone, 1980; Powell & Ogle, 1985).

Coleby (1995) states that the effects of the multitude of fears facing an able-bodied sibling have begun to be acknowledged and studied. Neuroses,

phobias and anxieties can result from the fears generated from having a person with a disability in the family. She suggests:

Possible means of alleviating the adverse effect upon siblings should be explored. Their distress may be underestimated and they should be included in the counselling from an early stage (Coleby, 1995, p. 424).

Dispelling sibling fears can be a difficult process since they are so firmly grounded in reality (Featherstone, 1980).

Grief. Grief occurs because of loss, in the case of disability, it is the loss of the image of the “normally” developing child. It is the loss of the idea of the child or the brother or sister that will “never be” due to the disability. The importance of working through the stages of grief cannot be underestimated. Brearley (1997) discusses fear engendered by the stages of grief in relation to disability. All family members and the person with the disability may need to work through the grieving process. The stages are not necessarily experienced in order nor are they limited to a time frame.

Powers in *Families, Disability and Empowerment*, describes grief as a normal response to loss, she continues:

Loss is typically perceived when the reality of life is changed in such a way as to make it less preferred than wanted or expected. Such is typically the case for families when a member is diagnosed with a disability or health challenge (Singer & Powers, 1993, p. 121).

Brearley describes some processes of grief:

Grief or sorrow is expected of a bereaved person and he will usually be allowed to grieve openly. It is not always possible for sorrow to be

expressed. There may be responsibilities that need to be undertaken or arrangements made. Other people may have to be supported. Social expectations may make weeping unacceptable---for example, the accepted wisdom that 'men don't cry' makes it very difficult for many men to shed tears. Other people may be embarrassed or impatient of tears and 'bravery' held up as an admirable trait (Brearley, 1997, p. 52).

Open communication is very important for the expression of grief. Family members need to talk, cry and laugh together to express the whole gamut of their feelings towards the person with the disability, themselves, and their parents. Often having a person with a disability in the family has the opposite effect and tends to inhibit communication. All members may have difficulty in expressing emotions for fear of divulging painful or (in their view) ugly emotions (Featherstone, 1980).

Brearley talks about grief that is not expressed, "Grief may be suppressed and denied, sometimes diverted to anger, guilt or depression. The grief may be so deep that the mourner is afraid of expressing it, feeling he will go mad or never be able to stop grieving (Brearly, 1997, p. 52). Denial, anger, guilt, grief or sorrow, and depression can all be experienced as part of the grieving process. Regarding fear and the stages of grief, Brearley states:

Any of these stages can engender fear. There may be fear of hearing worse news or having to hear what is being denied. Anger is a common cause of fear, fear of losing control, being seen as a bad person, fear of hurting another person, fear of rejection. Guilt carries the fear of discovery and punishment. Grief, as has already been mentioned carries the fear of being overwhelmed and destroyed. Depression is in itself a very frightening condition when everything seems out of control and hopeless (Brearley, 1997, p.52).

Denial. Gibbs (1993) states that children observe and model their parents' behaviour and emotional responses, therefore, if parents are in denial the siblings will be as well. From a family systems perspective, denial by parents may impact on well siblings. "If parents deny the handicap, feel ashamed and stigmatized, chances are the children will limit their curiosity and restrict the expression of their true feelings," (Jaffe-Ruiz, 1984, p. 69).

In Powell and Ogle, parental denial is discussed:

Parents who have not come to grips with a disability, who have not acknowledged its existence, will provide little support to siblings. Denial is usually clearly communicated and stifles questions and comments from family members. Parental denial typically blocks the flow of information and leaves siblings questions unvoiced and unanswered. Denial results in silence (Powell & Ogle, 1985, p. 59).

To combat denial amongst family members, provision of information to siblings and breaking the silence should benefit non-disabled siblings. These strategies should help siblings move away from denial and unrealistic hopes; towards acceptance of the sibling with the disability (Meyer, Vadasy & Fewell, 1985; Steiner, 1984; Singer & Powers, 1993). In families, it is important to be open and honest when communicating with siblings.

Family Interaction

In this section I will be discussing communication with siblings; allocation of parental time and attention; and behaviour responses such as jealousy, resentment and guilt.

Communication. Open communication amongst family members is reported to be very important to healthy functioning of siblings. Dyson, Edgar, & Crnic (1989) explain that the free expression of feelings and limited interpersonal conflict amongst family members leads to *less* development of problematic behaviours of siblings of persons with disabilities. Gibbs reinforces the need for open communication, "...the extent and openness of parental communication with the siblings is an important factor that contributes to positive adjustment" (Singer & Powers, 1993, p. 346). Marilyn Jaffe-Ruiz confirms the need for open communication in families:

Children also need accurate information and knowledge. An atmosphere needs to be created that encourages children's natural curiosity. Family discussions are necessary in which questions, feelings and worries can be aired. Discussions can best take place in the family, or in groups of other parents and/or siblings in similar situations (Jaffe-Ruiz, 1984, p.67).

Conversely, parents who do not create an atmosphere of open communication may be creating conditions that are detrimental to the well being of siblings. "A lack of information or misinformation about a handicapping condition can lead to unwarranted worries or fears" (Powell and Ogle, 1985, p. 59). Jean Kingsnorth (1975), a parent of a disabled child writes that there is a need to be open with and explain the situation to other children in the family. She said that older children especially need access to professional information; knowledge of plans being made for the future of the disabled child and an understanding of the genetic possibilities (Steiner, 1984, p. 24).

Murphy and Della Corte (1989) offer parents many strategies to help their well siblings work towards understanding, the open expression of feelings and perhaps acceptance of their sibling with a disability. They suggest that open communication may be the single most important factor in positive sibling relationships:

The key to improving sibling and family relationships is honest and open communication. Often the non-disabled child feels embarrassed, jealous and resentful about his disabled sibling but has not been given the opportunity to express his true feelings (Murphy & Della Corte, 1989, p.2).

Several authors offer suggestions to help parents create healthy family relationships. Knott, Lewis & Williams (1995) suggest that scheduling a daily play period between non-disabled and disabled siblings may improve rates of social interaction amongst siblings. Other strategies for parents include being open and honest with all siblings; provide information to siblings about the child's disability and read books about disability with your children. Parents are encouraged not to isolate the family but to join support groups such as sibling networks. Able-bodied siblings should not be expected to take on added responsibilities especially without discussion and explanation. Parents should try to divide their time and attention evenly amongst siblings (Boer & Dunn, 1992; Foot, Morgan & Shute, 1990; Lobato, 1990; Meyer & Vadasy, 1994; Meyer, Vadasy & Fewell, 1985; Murphy & Della Corte, 1989).

Allocation of parental time and attention. In discussing the need for social and emotional support for siblings, Gladstone and Montgomery (1990) suggest that parents dealing with a disabled hospitalized child may have little time and energy left for the able-bodied siblings. Lack of parental time and attention may lead siblings of persons with disabilities to feel that their own needs are being ignored (Sloper & White, 1996). Parents who do not have time to support their non-disabled siblings appropriately may be creating conditions for anxious attachments. Dizon (1984) cites Bowlby in referring to secure attachment as imperative towards the development of healthy, well adjusted individuals who are secure, self-reliant, trusting, cooperative and helpful toward others. The opposite may occur when the parent does not have the time or resources to respond to the child in an appropriate manner.

...many children grow up with parents who do not provide conditions necessary for secure attachments to be accomplished. These children tend to be anxious, insecure individuals, usually described as over dependent or immature. Under stress, these individuals are apt to develop neurotic symptoms, depression or phobia (Dizon, 1984, p. 28).

Time and energy taken up with a child with a disability may make it difficult for a parent, particularly one without supports, to be able to respond to well siblings in a manner that would create secure attachment. Dizon describes Bowlby's explanation of pathogenic parenting as, "Persistent unresponsiveness to the child's care-eliciting behaviour and/or active disparagement and rejection by one or both parents" (Dizon, 1984, p. 28).

Perceived rejection on the part of the parent by the sibling may be a function of parents having limited supports; therefore, their time and their own resources become strained. In the study by Adams, Wilgosh and Sobsey (1990), help for the parent is the number one theme, "...these parents appeared to require significant help...the need is primarily for concrete, practical help, including greater assistance with in-home care, more respite care, and a greater number and variety of future placements as these individuals reach the adult years" (Adams, Wilgosh and Sobsey, 1990, p. 56).

Family environment is discussed in *Psychological Predictors of Adjustment by Siblings of Developmentally Disabled Children*:

It is clear that in an ecological environment containing a disabled sibling, a child's psychological adjustment will be influenced by the dynamic functional and adaptive style of the parents and the family. This conclusion concurs with the proposition that family characteristics and resources will mediate the impact of childhood disease or disability on siblings (Dyson, Edgar, & Cmic, 1989, p. 300).

Behavioural responses. Not all families, however, have the time and energy necessary to create a healthy environment for siblings. Lack of time and attention directed towards siblings may create an array of negative behavioural responses. They include jealousy, resentment, and guilt

Jealousy. Jealousy is an emotion that may be evoked in non-disabled siblings, "Siblings may be jealous of the attention the handicapped child receives.

Jealousy is commonly focussed on the unfairness or unevenness of parental attention” (Powell & Ogle, 1985, p. 83).

Several strategies are suggested to help parents limit jealousy and competition amongst siblings. These strategies apply to all families including those with children with disabilities in them. Strategies include, balancing responsibilities of siblings, recognizing siblings as individuals, recognizing each child’s accomplishments, providing time for each sibling, preparing children for new siblings and talking about positive characteristics (Powell and Ogle, 1985, p. 116). These strategies may help to reduce feelings of resentment in siblings towards their parents and disabled sibling.

Resentment. Many studies report a variation in effects and in intensity of effects on siblings according to age, birth order and gender (Dunn & Plomin, 1990; Jaffe-Ruiz, 1984; Murphy & Della Corte, 1989; Steiner, 1984). Coleby (1995) agrees, “...it is clear that the effect is mediated by the relative birth order of the sibling within the family, sex of the sibling, and the nearness in age to the disabled child” (Coleby, 1995, p. 424).

Older siblings, particularly girls, are often given a large amount of responsibility for their disabled siblings. The amount of care is somewhat dependent on the resources available to the family:

For families of limited financial resources, there is major concern about the “burden of care” that the child will impose on the family. Given the financial constraints, more pressure may be placed on siblings to assist

either with caregiving or with generating family income" (Singer & Powers, 1993, p. 347).

Jaffe-Ruiz refers to the effects on female siblings, "Grossman (1972) also found in her study that female siblings were more involved than male siblings in child-rearing activities, which reflects our cultural sex role expectations. They were, like their mothers, closer to the effects on the family of a handicapped child. However, these same female siblings had a higher incidence of anger and resentment towards their mothers for putting them in a position of mother surrogate" (Jaffe-Ruiz, 1984, p. 69).

Klein & Schleifer (1993) quote from a case study to demonstrate the intensity of feelings of jealousy, resentment and anger female siblings may express:

The battles are about many things. But last week things erupted when she was asked to stay home to 'baby-sit' our eight-year-old son, Eliot, who has Down syndrome. Pam began to scream that she has been sacrificed to care for Eliot. She claims our seventeen-year-old son, George, and her eleven-year-old brother, Michael, were never asked to spend as much time with Eliot, nor were they asked to do as many things as she does. She stormed out and said, 'When I grow up and am living on my own, I'm never coming back here again.' She said she never wanted to have anything to do with Eliot for the rest of her life (Klein & Schleifer, 1993, p. 134).

Lobato and Tlaker comment on the negative effects on older, female siblings. "Older sisters have been seen as being particularly vulnerable to feelings of rejection and resentment of the handicapped child due to, among other things, excessive parental expectation that they participate regularly in child-care

responsibilities” (Lobato & Tlaker, 1985, p. 227). The experience of these negative emotions towards either parents or siblings with disabilities can leave the able-bodied sibling with feelings of guilt.

Guilt. A quote from a case study, “Life with my Sister: Guilty No More” demonstrates the complexity of emotions and how guilt can precipitate out:

My biggest problem in dealing with Bonnie has been guilt. I had not been able to forgive myself for the things I had done. I know that God has forgiven me. In fact, He is probably tired of me asking for His forgiveness. Maybe I would have felt better if Bonnie could have fought back---she never said anything bad to me, she never hit me. What is worse, when I would do something to her, she would stand there crying saying, “I love you anyway.” She was defenceless and I abused her. Now, years later, I cannot go to her and ask for her forgiveness---she would not know what I was talking about---so I have to live with my guilt (Klein & Schleifer, 1993, P. 97).

Brearley defines guilt in relation to the stages of grief involving death.

The same can be applied to the experience of a sibling of a person with a disability.

Guilt is a very painful emotion. The bereaved person may feel guilty because he expressed anger towards the dead person or he forgot or omitted some action and this might have hurt the one whom he has lost. He may feel guilt because he imagines he has in some way caused the death, either by action, omission or wish. If he can find no obvious cause he may search for obscure sins on his part” (Brearley, 1997, p. 52).

Older siblings, particularly female, are often delegated responsibility for their disabled sibling and other family members when the mother’s time and energy is stretched to the limited.

Many older siblings report that, "their earliest memories of their disabled brother's or sister's infancy were so filled with anger, worry or jealous feelings, that they felt guilty about having been born normal" (Murphy & Della Corte, 1989, p. 2). Gibbs (1993) explains that lack of information, leading to misunderstanding may account for guilt assumed by siblings.

With little direct information, siblings do their best to understand the situation and in doing so may come up with questions or misconceptions about the situation. They may feel responsible for causing the disability. Children have a remarkable tendency to blame themselves for negative or unpleasant things that they do not understand. They may feel guilty for not having a disability themselves. They may over identify with the child with a disability and wonder if they also have a disability or whether their sibling's disability is contagious. Some siblings may even feign the symptoms of the child with a disability in order to gain attention (Singer & Powers, 1993, p. 350).

Powell & Ogle (1985) suggest that, "siblings may feel guilty about their emotions of anger, jealousy, and hostility. Guilt feelings may be repressed when negative thoughts and feelings have been punished. Excessive guilt may be manifest in overly helpful acts directed toward the handicapped child" (Powell and Ogle, 1985, p. 83).

In order to deal with their guilt, Featherstone suggests that brothers and sisters may have a need to overcompensate, "brothers and sisters struggle with self-doubt. Some feel apologetic about their own good health, wondering whether they ought to have been stricken instead" (Featherstone, 1980, p. 82). Siblings

often feel that need to “conquer the world” in order to make up for the lack of ability and opportunity afforded to their disabled sibling.

A myriad of other emotions play into the guilt about their own “good health” scenario:

Others worry about jealousy: They resent the extra attention paid to the disabled child, but regard their feelings as disloyal and unfair. After all, they are lucky enough to enjoy good health and unimpaired faculties. How could they begrudge their sister the help she so obviously needs? And then there is the issue of behaviour. If the disabled child seems more vulnerable than others his age, brothers and sisters may feel guilty about normal teasing and fighting. Guilt does not obey the laws of reason: although not one child in ten thousand has done anything to cause a brother or sister’s handicap, many feel obscurely responsible (Featherstone, 1980, p. 82).

Featherstone suggests that guilt, anger, and self-doubt are interrelated. In typical family relationships sibs may become annoyed with their brother and/or sister’s behaviour. In the case of a disabled sibling inappropriate behaviour may be “explained”. Special attention afforded the disabled sibling may be rationalized. These activities do not preclude feelings of anger developing in the able-bodied sibling. The feelings of anger and the possible venting of those feelings can leave the non-disabled sibling feeling guilty about his/her actions and intentions against their disabled kin. Feelings of failure and self-doubt may develop as the well sibling feels that they do not measure up to the expectations placed on them (Featherstone, 1980). Guilt and the variety of emotions either causing or resulting from guilt need to be addressed to work through the stages of

bereavement (Brearley, 1997). Grieving or sadness is another stage of the bereavement model that demands attention. When all of these negative emotions of grief, sadness, and perhaps depression are combined, siblings of persons with disabilities may perceive themselves as different from others. Peers and friends may also consider them and their families as dissimilar.

In social relationships, it is a “difference” from others that siblings of persons with disabilities may face that perpetuates loneliness and isolation, whether real or perceived, whether imposed or created.

Social Identity; Social Relationships

In this section I will be discussing difference and stigma, embarrassment, and loneliness and isolation as factors that influence the sibling’s social identity and relationships.

Difference and stigma. Social identity and relationships are somewhat dependent on friends and peer’s interpretation of how we fit into the scheme of society. Goffman (1986) articulates the process of stigmatizing. In “Stigma and Social Identity”, Goffman discusses being different:

Society establishes the means of categorizing persons and the complement of attributes felt to be ordinary and natural for members of each of these categories. Social settings establish the categories of persons likely to be encountered there. The routines of social intercourse in established settings allow us to deal with anticipated others without special attention or thought (Goffman, 1986, p.2).

Siblings of persons with disabilities can feel stigmatized and “different” in the same manner as the person themselves. If the disability is known within the well sibling’s social group the sibling may be stigmatized.

...evidence can arise of his possessing an attribute that makes him different from others in the category of persons available for him to be, and of a less desirable kind---in the extreme, a person who is quite thoroughly bad, or dangerous, or weak. He is thus reduced in our minds from a whole and usual person to a tainted, discounted one. Such an attribute is a stigma, especially when its discrediting effect is very extensive; sometimes it is also called a failing, a shortcoming, a handicap. It constitutes a special discrepancy between virtual and actual social identity (Goffman, 1986, p.3).

Siblings may be embarrassed by their brother or sister with a disability and the difference in their family.

Embarrassment. Being “different” as a sibling and as a family makes it difficult to develop normal social relationships with peers and others. Open communication with social contacts is jeopardized when the sibling of the person with a disability feels shame or embarrassment about their difference. In Steiner (1984) sibling reluctance to talk with peers was noted:

Forty-two percent said it was difficult to discuss their sibling’s disability with friends. There was embarrassment involved but the discomfort also related to lack of knowledge (Steiner, 1984, p. 26).

Not speaking about or hiding the fact that one has a sibling with a disability may be the result. These behaviours lead to increased isolation, abnormal social relationships and functioning. In a study by Coleby (1995), the author’s findings support previous research in confirming that there is an effect

upon the psychological health and social contact of normally developing sibs. In her research, she observed...”increased anxiety and...observed the restriction upon siblings’ social lives and contact with friends. Concerns about the future and loneliness have also been highlighted” (Coleby, 1995, p.424).

Loneliness and Isolation. Several articles and books mention the social effects on the individual and family members of having a person with a disability in the family (Coleby, 1995; Dyson, Edgar, & Crnic, 1989; Featherstone, 1980; Klein & Schleifer, 1993; Singer & Powers, 1993). Ordinary outings, that most people take for granted, become difficult, more time consuming and require more preparation when there is a person with a disability in the family. To withdraw from outings can lead to loneliness and isolation:

Disability may isolate families in a variety of ways. Most concretely, it often interferes with ordinary social activities. Young children always complicate their parents’ efforts to get out of the house whether to a Laundromat, a park or a movie. A disability adds to the difficulty of organizing expeditions and recreation. It also creates invisible social barriers. Many people feel awkward with pain and difference. They avoid a disabled person and sometimes his or her family as well (Featherstone, 1980, p. 51).

In Helen Featherstone’s book, “A Difference in the Family”, the word difference has a double meaning. Featherstone is referring to the difference within the family as well as the difference in the family as a whole within the entire social environment. The author describes how that difference, that setting off, for the family can begin at birth:

The birth of a handicapped child set his parents off from others. If the diagnosis of disability is made in the delivery room or the hospital nursery, a mother, for example, finds herself cut off from the other mothers on the obstetrical ward. She cannot share the happy inconsequential chatter about birth weights, labour, and nursing woes without a sense of heaviness and hypocrisy (Featherstone, 1980, p. 51).

Avoidance of the group may result as the mother seeks to protect herself from the pain and hurt involved in realizing that she cannot share in the happiness of having a healthy, "normal" baby. Regarding loneliness, Featherstone states, "Pain of any sort isolates" (Featherstone, 1980, p. 50).

Loneliness is perpetuated from within the individual as well as from without. Not only are persons with disabilities and their families out of the mainstream of society naturally because of their difference, but persons and family members may experience isolation because of their personal consciousness of their difference. Able-bodied siblings find themselves in the position of not being able to fit into the stereotype of the "normal" family. They remain on the outside of a society that is comprised mainly of families that *do not* have persons with disabilities in them (Featherstone, 1980). They are deprived of opportunities for typical relationships.

Social relationships. Sibling relationships and peer relationships are important for healthy emotional development (Bank & Kahn, 1982). Impaired relationships have an effect on the normally developing personality of the sibling of the person with a disability:

Emotional processes in friendships and sibling relationships play a significant role in social and emotional development because siblings, peers and friends seem to play a more important part in children's growing up than has been assumed so far (J.R. Harris, 1995). Many of the regulatory processes which have been described between parents and children are likely to take place between siblings as well (Mills & Duck, 2000, p. 50).

More investigation and follow up on the effects on siblings of having a person with a disability in the family is in order. Coleby's results confirm this need, "...one must conclude that there is an effect upon the psychological health and social contacts of the normally developing siblings" (Coleby, 1995, p. 424).

Mediating Factors for Sibling Adjustment

There are some factors that can mediate the negative effects of having a sibling with a disability. In this section I will discuss positive sibling characteristics, mediating effects on experiences, and suggestions for support.

Characteristics and mediating effects. Siblings of persons with disabilities may develop many positive attributes. Gibbs (1993) reports some of the benefits:

For example, Grossman (1972) found that almost half (45%) of the siblings of children with disabilities reported that they had benefited from the experience in some way, such as having a 'greater understanding of people and handicaps in particular, more compassion, more sensitivity of prejudice, and more appreciation of their own good health and intelligence than peers' (p.92). Dunn (1988) described siblings of children with disabilities as more considerate and kind. Simeonsson and McHale (1981) cite a study in which three fourths of siblings of children with Down syndrome were reported to be happy and well-adjusted and makes note of the finding that older sisters of children with disabilities are the most likely to pursue careers in the helping professions (Singer & Powers, 1993, p.345).

The good news in the literature is that siblings of people with disabilities seem to be kind, understanding, and tolerant people with a desire to help others. Several variables affect the adjustment of siblings of persons with disabilities. "The presence of mediators for siblings of disabled children was confirmed by investigators reporting the buffering effects of such personal characteristics as age, sex and birth order" (Dyson, Edgar & Crnic, 1989, p. 293). The authors go on to state that other research has revealed that social adjustment in siblings of disabled individuals can be related to parental attitudes and parental acceptance (Dyson, Edgar & Crnic, 1989). Lobato & Tlaker (1985) suggest that sibling intervention in teaching skills to their disabled sibling may be beneficial to both the sibling and the disabled child. Sib networks and workshops are available in some areas to help siblings adjust to their roles (Meyer & Vadasy, 1994).

Support. The literature includes many suggestions that parents and children can incorporate into their lives to facilitate family harmony. As has been previously stated parents can allow equal time for all siblings, provide opportunities for open communication by organizing regular family meetings, join support organizations that include siblings and not delegate large amounts of responsibility based on age and gender of siblings. Several works suggest the importance of programs that include activities and exercises for siblings of persons with disabilities in order to maintain or improve psychological and

emotional health. (Brearley, 1997; Coleby, 1995; Dyson, Edgar & Crnic, 1989; Featherstone, 1980; Meyer & Vadasy, 1994; Meyer, Vadasy & Fewell, 1985).

Summary

From the literature one becomes aware of the need to resolve these effects and work through the stages of grief since resolution of the complexes created in childhood, as a result of our experiences, is important for healthy emotional and psychological functioning. The extent to which human beings are well “balanced” emotionally and psychologically determines the impact that persons have on their family, friends and associates.

It becomes obvious then that more optimum functioning of the individual and society rests on the undoing of these emotional tangles that have developed. For example, a person that has lived with an inordinate amount of fear will behave in a fearful manner and project some of those fears on others. It has been explained, in the literature, that growing up with a sibling with a severe disability can lead to the development of fears for many different reasons, i.e., fear of “catching” the disability, fear of others in the family being in peril, fear of removal from the family (in the case of institutionalization).

Unresolved fears affect the manner in which a person behaves socially and interacts with others. If that interaction is dysfunctional, everyone suffers. The perpetrator is unhappy as well as those that the fearful person associates with. It becomes obvious that this is not the best state for the person or for those around

that person. Therefore, consciousness of unresolved fears and some resolution of them is the only possible path for healthy interactions and the well being of persons.

Since all associates, family, friends, coworkers, etc. can be affected by negative pent up emotions, there is a necessity to work towards releasing the person from this undesirable emotional and psychological state. Many emotions are mentioned in the literature: fear, grief, denial, jealousy, resentment, guilt, and embarrassment. Stigmatization, isolation, and loneliness are consequences that siblings can experience depending on their social relationships and mental and emotional adjustment.

Much of the literature to date has focussed on parents and the effects on parents of having a child with a disability. No one can refute the importance of this research and the need for help for parents. Siblings are no different. Sibling literature is scant. It is my opinion that this situation needs to be improved. Help, guidance and support for siblings will benefit people, in general, and must be improved. Professionals in all areas need to be informed about the effects on individuals of having a disabled sibling. The need for the study that I am proposing to undertake cannot be denied. Information about the personal perspectives of siblings of persons with disabilities can inform and enlighten persons, families and professionals. Providing support and understanding for

siblings can help to relieve some of the negative emotional effect to the persons who, in the social worker's words, "are victims too".

Chapter 3: Research Methods

I used qualitative research methods in this study. Five informants were selected based on two factors: their age, that is, they had to be over nineteen years of age, and the nature of their sibling's disability, i.e., autism or cerebral palsy. I conducted in-depth interviews with open-ended questions in order to gain the subjective perspective of the informant. I transcribed and analyzed the data using a Microsoft Word Processing program. The information was written up in six chapters plus an appendix. The content of the chapters was organized with advice from my thesis advisors. Qualitative research methods were appropriate for this study because they allowed me to collect the perspective of siblings of persons with a disability.

Theoretical framework. I used qualitative methods to document and analyze the perspectives of five individuals about their siblings with disabilities. Qualitative methods "are concerned with intersubjective truth, that is, the way humans construct meaning as a guide to action in particular social contexts" (Skrtic, 1995, p. 89). I chose a qualitative approach as I wanted to collect *personal* perspectives as opposed to a "systematically stated and tested set of propositions about the empirical world" (Bogdan & Biklen, 1992, p. 33). The participant's subjective view and interpretation of reality is of importance in

qualitative research. Smelser (1994) describes the symbolic interactionist approach and its background in relation to phenomenological theory:

An illustration of this approach is symbolic interactionism, rooted in the pragmatic philosophies of John Dewey, Charles Cooley, and George Herbert Mead and given later expression in the work of Blumer (1969). In one respect Blumer's starting point was a negative polemic: that human behaviour cannot be characterized as the product of internal or external forces such as instincts, drives, social roles, social structures, or culture. Instead, the notions of subjective meaning and the self are center. Meaning is found, moreover---as the name of the perspective implies---in the interactive process. Individuals communicate with one another, create and derive meanings, and act on them accordingly (Smelser, N. 1994, p. 32).

Bogdan and Biklen agree that meaning and interpretation of their world is the essence of this subjective approach, "the meaning people give to their experience and their process of interpretation are essential and constitutive, not accidental or secondary to what the experience is. To understand behaviour, we must understand definitions and the process by which they are manufactured. Humans are actively engaged in creating their world" (Bodgan & Biklen, 1992, p. 36).

MacLellan and Norris refer to a concept by Smith to describe this split: "The 'line of fault' is a geological metaphor (Smith, 1987) depicting a point of rupture between prevailing ideologies and the everyday worlds that those deemed to be subordinated through the social relations of race, class, gender, age, ability or sexual orientation experience directly" (MacLellan & Norris, 2002, p. 23). In their study, MacLellan and Norris used qualitative research methods. Their

subjects consisted of aging parents caring for their children with disabilities.

There are some similarities in parental and sibling views; they share the experience of living with a disabled person. The rupture, as described by Smith (Smith, 1987), is between society's determination of what objective reality is and the sibling's subjective view. MacLellan and Norris elaborate further on this rupture:

The experience of a bifurcated consciousness means that perspectives of everyday life may contain two separate, dichotomous, sometimes conflicting themes. One of these is framed in the discursive concepts and categories which embody ideological relevancies and the other is informed by the more immediate reality of everyday life. When experience does not fit within the concepts and categories, alternate concepts may not be readily available. As a consequence, individuals in this position may, sometimes subconsciously, mute *their own* thoughts and feelings when they perceive a "lack of fit" between what *they* know about their everyday lives and what ideology and discourse dictates they *should* know and think and do (MacLellan & Norris, 2002, p. 23).

It is, therefore, important for a researcher to be able to perceive, understand and interpret reality according to the personal perspective of the informant. Rosalie Wax talks about the importance of, "taking an insider's view as a precondition of research" (Wax, 1971, p. 3). "Obtaining something of the understanding of an insider is, for most researchers, only a first step. They expect, in time, to become capable of thinking and acting within the perspective of two quite different groups, the one in which they were reared and---to some degree---the one they are studying" (Wax, 1971, p. 3).

I am in the unique position of having spent time in both worlds. I have lived with a sibling with a disability and I have experienced the reality of having that sibling become non-existent on a day-to-day basis: my sibling was moved to an institution early in life. According to anthropological fieldwork theory, this dichotomous view should be an advantage for the researcher in this study (Wax, 1971).

In fact, during the interview process, it was very easy to establish rapport with the informants. All of the participants appreciated the fact that they were able to talk to someone who really understood their subjective point of view since both themselves and the researcher had lived with similar day-to-day experiences.

Role of the researcher. I was able to relate to many of my informant's experiences. As the oldest sibling I was given added responsibilities to help my mother cope with my sister with a disability. My sister was born in 1954 and lived at home until 1962. At that time there were few supports for families, in fact, I do not remember our family having any outside help except for extended family that lived nearby. I was six years old when my sister was born but I clearly remember the trauma that my father experienced at the time of her birth. She was born "blue" due to being held in the birth canal by the nurses attending my mother; they were apparently waiting for the doctor to arrive. My family suspected that their actions caused my sister's disability. My sister appeared to be developing normally for a few months but then signs of delay started to emerge.

While walking around her playpen, she fell down and never got up again at around six months of age. Seizures started one sunny, summer afternoon while she was in her carriage; my mother was feeding her ice cream. I remember the panic and upset that my mother experienced. The time of diagnosis was painful; my mother left Sick Children's Hospital in Toronto before talking to the doctors because she was afraid of what they were going to say. My sister cried often. She rocked in her chair: she grinded her teeth. She slept with me and seemed to cry all night.

My mother tried to normalize our lives and we took my sister tobogganing, swimming and for walks. We took her to a cottage in the summers and I remember my mother walking her on the dock and taking her in the water. I also remember my mother's upset because the doctors had told her that my sister would not live past five years of age. My sister grew bigger and taller and soon my mother could not carry her up our very narrow staircase. She developed bedsores and finally at the age of eight my mother and father gave in to doctors' suggestions and put her in an institution; the doctors told us that she would receive better care there. My sister is now fifty years old and has been moved to three different facilities in her life. She currently lives in a hospital where she has been a resident for the last twenty years.

This research is of personal interest to me. Over the course of my life I have had periods of increased knowledge and awareness about my sister's

disability. In the past ten years, since the death of my mother, I have given my family's situation much thought and explored my past life with my sister. I have come to realize some of the ways in which growing up with a disabled sibling has affected my family and me. After deciding on the research question, I began the literature review. I was very surprised to discover that many of effects that I have experienced were common to other siblings. A desire to spread this information to try to inform and help other siblings led me to pursue the research.

As a result of my self-exploration I have arrived at many ideas about certain behaviours, thought patterns and characteristics that I have. I was anxious to ask the questions that I prepared to discover directly if other siblings shared my views and experiences. Talking about, discussing, thinking about this subject and writing this paper has been a cathartic experience for me. The support of other siblings has been a most beneficial experience since, for the most part, I have felt alone in my situation. The siblings that I interviewed expressed the same sentiment, i.e., that they have felt isolated in their position as a sibling of a person with a disability. Connecting with other siblings of disabled persons was not an easy task.

Sibling networks are not well established; at least in the area where the research was conducted, therefore searching for siblings was a process that required a lot of investigation and conversation.

Identifying informants. In this study, it was decided that informants who match two criteria would be sought: they had to be over nineteen years of age and the sibling of a person with autism or cerebral palsy. The geographical location where the research took place was not home territory for this researcher; therefore, I was faced with difficulties in attempting to find my informants. I began making contact with the school board in order to find participants. To begin with, the school board threw up some obstacles to the process of gaining access.

I received different information from the various people that I contacted as to what the appropriate channels were for making contact with families of disabled persons within the school system. It was fortunate that a high-ranking person at the board understood the nature of the need; she helped me to circumvent what was beginning to look like volumes of paperwork with no guarantee of approval at the end.

I informed the person at the board that all that I required was permission to talk to special education resources teachers at various schools to determine whether any of their students had siblings that matched the criteria. If the teachers did have connections to people that could serve as informants I merely needed to forward the paperwork to them and allow the families to decide whether or not they wanted to contact me. In my opinion, and fortunately in the opinion of the person at the board, this did not constitute a breach of

confidentiality. In fact, my contact person decided that there was very little school board involvement at all and it may be possible to bypass the otherwise required paperwork. The board person decided that we would do a verbal confirmation and if either the principal or resource teacher had any doubts about authorization they could contact her. Her endorsement allowed me to begin contacting principals and resource teachers.

In view of the fact that I worked as a supply teacher during this time, I spoke to all persons that I met who were involved in special education with regard to my search for informants. I found many people interested and willing to help. My first informant was found as a result of a conversation with an EPA (Educational Program Assistant) at a school. The woman also worked at a group home and knew of a sibling that she thought would be an ideal informant. As it turned out, she was right.

My first informant was twenty years old; he had a sister with autism who was two years older. Noah was very cooperative and interested in the study. Noah was a university student doing a coop work placement in the field of communications. His immediate family consisted of only Noah, his sister and his mother and father. His mother worked at a university and his father was an engineer. His sister was in a group home where she has lived for several years. The family visited her often and Noah took his sister on outings regularly.

My second and third informants were both employed as EPA's with the school board but had disabled siblings. I found them through contact with the special education teacher at the school. Charles was a man in his thirties who was married with two children. His sister with autism was in her twenties and was attending her final year of school. She lived at home with Charles' mother and father who were aging. They were currently looking for a group home situation but their geographically isolated location made that difficult. Charles had several other siblings. Charles worked as an EPA (Educational Program Assistant) and had two other jobs that involve caring for people with disabilities. My third informant also worked as an EPA.

Irene was a woman in her forties with a thirty-year-old sister with cerebral palsy who lived in a group home. Irene had several other siblings and her mother and father lived out of town. They were also aging parents. Irene was separated but had two teenage children of her own that she cared for. At this point the school board contacts were proving to be very helpful. I found a fourth informant through another special education teacher. The informant, however, was still away at university: his mother signed him up for the study. This informant, unfortunately, did not work out for a number of reasons.

We had difficulty setting up dates to meet and I found myself waiting more than once due to a miscommunication about times and dates. I conducted one interview but I did not get the sense that this informant was particularly

comfortable with the topic. In attempting to arrange a second meeting communication broke down and after a few weeks of waiting I concluded that he did not want to participate. The interviewing was nearly completed for three of the five informants but I was still searching for two more people.

Since I had exhausted my school board contacts, I called an agency. I found the phone number of the Provincial Autism Society in the directory. The woman who answered was extremely obliging and sensed my need and the urgency. She, kindly, put out a very well written email to all members of the society explaining the nature of the research and the time commitment involved for participants. Approximately two weeks later I received a call from my fourth informant who had given the prospect of being interviewed a great deal of thought. She agreed to participate.

Rose was a thirty-two year old woman with a thirty-year-old brother with autism. Her mother and father were separated. Her brother lived in a group home close to his mother's place of residence. His mother visited him but his father did not. Rose and her brother were raised in an extremely isolated location. They attended different schools and her brother went to a residential school during early adolescence. He did not return to the home but went directly to a group home after five years in residence. At the time of interviewing, Rose lived in a different city and did not visit often although she kept in contact with her mother, in

particular. The fifth informant was found as a result of what seemed like endless talking to almost anyone who would listen to me about my research.

A person that I met while taking a business workshop at a local university was acquainted with someone that she thought would be excellent. After a short delay, contact was made and my fifth informant became part of the study.

Olivia was a twenty-eight year old woman with a sixteen-year-old brother with cerebral palsy and autism. He required twenty-four hour care and spent a lot of time in hospital. Olivia had moved out of the family home at eighteen years of age and had worked and travelled extensively. She originally worked in a group home but had differences of opinion with her supervisor. She was about to marry a military person that she met while living overseas. Olivia's brother lived at home with his mother and father. Her father was a police officer and worked a lot. Her mother had just taken a stress leave so that she could stay at home to look after her son.

The informants were told immediately about the time commitment and logistics of meeting; they were informed either by voice or by reading the cover letter that I wrote. I included the cover letter with the participant information forms approved by ENREB (Education/Nursing Research Ethics Board) at the University of Manitoba.

Data Collection. The interviews consisted of three, one-hour meetings. At the first meeting the paperwork was presented. All consent forms were read

and signed: a copy of all of the consent forms was given to the informant. When written consent was received and any questions answered the interviewing began. All of the interviews were recorded with the full permission of the participant. I took some notes as well. The questions, especially in the first set required some fine-tuning that became apparent during the first interview.

Research questions. The questions were open ended and designed to encourage the participant to talk about himself, his sibling, and his family. The first set of interview questions was geared towards establishing the background. Questions were created that would lead the participant to giving details about his or her family life, i.e., number of siblings, birth order, mother's and father's participation and descriptions of daily life within the family with a disabled child. I asked questions that pertained to the early years and to the present to attempt to get an overall picture of the family. I found that I needed to use counseling techniques such as feeding back the participant's last sentence or fragment of it, in order to inspire the person to elaborate on a statement or clarify a thought. It seemed that not as much prompting was necessary during the second set of interviews. This may have been due either to an increase in participant comfort with the researcher or the nature of the questions.

The second set of interview questions led to more intimate queries about feelings, social life, emotional responses, and philosophical and religious frameworks. During this set of interviews we often touched on very sensitive

issues: the participants and I handled the situation well. To cope with rising emotions, I added words of encouragement and information about my personal experiences; at times, I changed directions if it seemed that the conversation was becoming too poignant. It was in this situation that I believe I had an advantage over other interviewers. Since I am a sibling of a person with a disability, I could relate to and empathize with the subjective perspective of my informants. I could identify with their most intimate stories, feelings and emotions, and usually I could offer words that helped to diffuse their anxiety. I was able to empathize with them as someone who understood and has had similar experiences. The last set of interviews was generally a little less emotional.

The third round of interviews was a wrap up and a checking up on previous information. I asked the informants to elaborate on statements already made to compare and contrast past and present feelings and behaviors. I also enquired about their thoughts and feelings towards interview process. At the conclusion of the interviews I gave each participant a small gift to thank them for their contribution. The process of transcribing the data began as soon as interviewing was completed.

Transcription. A transcriber was rented from a local business machine company; the process of transcribing took several weeks since each set of interviews was approximately sixty pages in length. Using Microsoft Word as I transcribed, I made notes in the data and bolded appropriate sections. During the

interview and transcription process I became aware of several themes that arose. I was able to compare and categorize data during the interview and transcription process by making written and mental notes. My familiarity with the subject was a definite asset in this process. At the time of completion of interviewing and transcription I had settled on seven different themes.

Analysis. In order to organize the data, I created a system of management using Microsoft Word. Since I had isolated my themes, I created one file for each theme. In order to move appropriate datum from the informant's file to the theme file, I opened the informant's data file on the desktop: I also opened all seven theme files. In order to do this I needed a computer with adequate processing speed and RAM. As I read and scrolled through each person's data file, I copied individual sections that I determined would apply to the themes. The notes and bolded sections that I had highlighted during transcription aided this process of selection. I copied each suitable paragraph, sentence, or phrase individually. I then opened the appropriate theme file on the desktop and pasted the copied section into the file. I coded the section with the first initial of the participant and the page number so that I would be able to retrieve the section from the data file if necessary. I selected bolded sections, notes and portions of the data that were related to one of the seven themes. Upon completion of this extensive process I had created seven data files with excerpts from the participant's data that pertained to each theme. At the beginning of this process I had coded all

segments of datum that I had moved to the theme file according to a finer coding key but I stopped this procedure very shortly after beginning. I found that it was better not to determine which aspect of the theme that the datum addressed by coding it on the first categorization. It seemed that I might eliminate or ignore data that may be pertinent to another aspect of the theme if I continued this practice. I carried out this finer categorization during the writing process.

Writing it up. At this stage I began writing up the data according to the theme. After reading through the data in each theme file, I drew webs to outline the key points that I would address. I placed the theme in the center of the web and made “satellites” of related materials that surrounded the theme. I prioritized the modules of smaller units of thematic information and wrote each theme section according to the headings that I had developed at the beginning of the section. During this process I described and analyzed the themes using quotes from the data. The findings are discussed in the following chapter.

Chapter 4: Data Analysis

In this section I will address several themes that emerged as I analyzed the data. These themes are sibling values; social life and relationships; emotional development and issues; work, skills development and knowledge acquisition, characteristics.

Sibling Values

The siblings I interviewed indicated that they valued certain characteristics and attributes in people. Their value system helped them to define what they value in other people, daily interactions, and life experiences. The siblings interviewed in this study stated that they did not prioritize according material wealth. In this section I will discuss valued characteristics in friends and peers, valued characteristics in partners and spouses, understanding, empathy, respect, dignity, family relations, and prioritizing.

Valued characteristics in friends and peers. Siblings chose friends and partners according to standards that they developed as a result of living with a person with a disability. Since sibling experience and the experience of their disabled sibling may have involved a lack of acceptance on the part of others, siblings valued acceptance as a favourable quality.

Charles explained about his and his non-disabled sibling's friends in relation to his sister with a disability:

We all make sure that our friends know that this is our sister, you know, accept her or not right and, a lot of us, I think our criteria in choosing friends was how they took to Faith right. If they were uncomfortable and we took them to the house and Faith was there and she was doing her thing, you know, whatever that may be, if they were uncomfortable and they made us uncomfortable by not accepting her then we really didn't hang out with them anymore so that was, we always used Faith as a criteria, I guess of how we accepted friends and stuff like that.

Noah concurred and referred to friends' understanding of the situation and his sister:

Sure, I mean, having birthday parties and Deanna would come out buck naked or having a fit when we were at the bowling alley and having to deal with that. But all of my friends are understanding. They know my sister and they know how much she means to me so I mean she is my sister and she comes first, so...very understanding.

Rose commented that the only friends that she had were those that accepted her and her brother "completely and fully". All participants in the study agreed that they valued acceptance and understanding as favourable attributes in friends. In friendship situations, their comfort level depended on their friend's acceptance of their disabled sibling. Some participants agreed that they became astute at assessing people's reactions to their disabled sibling and then decided whether that person placed similar importance on acceptance and understanding.

Noah explained:

I guess I value the individual, not who someone says they are. You can look at somebody and not know who they are and what they do, but in those first few, if you bring up certain topics like, I'll bring up my sister and you can find out a lot about a person. How they react. What type of questions they will ask you or if they just blow it off their shoulders and

they say well, 'That sucks'. You know like, some people will ask me, oh, well, how old is she? What type of disability does she have? I have somebody that has the same sort of disability is it like this? And other people will say, 'Oh, that really sucks, did you watch the football game last night?' You know, and that's fine and some people just don't like to talk about it, I guess. But um, you can tell a lot about a person by the way they act and the way that they treat others.

Valued characteristics in partners and spouses. Noah indicated that he would search for a mate who is accepting and understanding:

I know that looking for a girlfriend or a companion that does come into play but most people don't have to worry about that but I'm going to be the person or the primary caregiver to my sister when I'm older and that's very important to me to find someone who understands that, that my sister comes first to me, no matter what and is going to accept that and help me out in those types of situations.

Charles, who was already married, spoke about his wife. He described his spouse as someone who accepted his disabled sister with no difficulty. Charles described his wife as understanding and able to accept people with differences because of her personal experiences; she is a woman of colour and her father has a disability. Charles mentioned that his wife willingly shares in the concerns and caring for his sibling.

Two informants in this study directly expressed a lack of desire to associate with people that they termed superficial in favour of those who appeared to hold similar values. Rose described the superficiality in making small talk and added that it was skill that she had to develop. She valued people who do not "put on airs". Charles summarized the qualities that he considered important in other

people and for himself, "So, that's one of my goals...Just to give everybody dignity and respect and have acceptance for everybody so...those are my best friends that I've always kept. The other ones are just superficial". Due to their experience of living with a sibling with a disability, the people interviewed in this study placed value on qualities that they did not consider superficial such as understanding, empathy, respect, and dignity. They valued these qualities in themselves and in those persons with whom they interacted.

Understanding, empathy. Noah described how he practiced understanding and empathy in his life. I asked him a question about exercising empathy in his daily interactions, he replied, "...like you have to be able to put yourself in another person's shoes. I guess I would be empathetic. I try to put myself in another person's shoes." Another informant stated that empathy developed later in life, after adolescence. Charles described his current perspective:

The situation (with his disabled sister) is still the same, you know, but just, the developmental level and understanding of it has changed. You know, when I was a teenager I had a whole different outlook on it, right, as opposed to what I do now. You know I have more understanding and empathy towards her now.

Respect and dignity. Charles valued people who respected others. He attempts to develop this valued quality in his own children. Charles described a situation where he initiated contact between his young child and a disabled student that he works with. He took his student to his wife's work where his son

was at daycare. Charles and the student visited with his family and enjoyed coffee breaks. Charles is teaching his son that he values the person by introducing him to his family and including him in everyday social interactions (Wolfensberger, 1992). He hoped that these values will transfer to his son, "So, that's what one of my goals is, I want my kids to grow up and have respect. Just to give everybody dignity and respect and have acceptance for everybody."

Irene spoke about dignity in regard to her sister who lives in a nursing home. She is concerned that lack of staffing may have an adverse affect on her sister. Irene expressed that privacy and maintaining dignity in personal care is as important as the care itself, "...and plus, for her dignity because she is quite, you know, quite aware of her personal needs but its just a matter of it had to be done because there weren't enough people to, you know, get her in an out and you know, staffing and all that sort of thing". Irene expected people to respect her sister's dignity. Olivia was concerned about an event that took place at her brother's school that may have affected his dignity and caused him to be less respected by his peers:

Somebody called an ambulance, somebody heard that 911 was called and pulled the fire alarm so the school was evacuated when Sam took his seizure. It was just a mess. It was a mess. I was furious when I heard this because you know, kids will associate things you know, so. He's in a special ed class now um, and I'm sure the other kids are, were pretty traumatized by the whole thing. Sam seizures and everybody has to leave the school.

Olivia criticized the school for failing to inform all staff members of the proper procedure when her brother had a seizure. Their first step should have been to call the family, not the ambulance. Olivia's family, although dysfunctional in her opinion, worked together where Sam was concerned and had developed strategies to encourage respect and protect her brother's dignity. Family solidarity towards positive values of understanding, empathy, respect and dignity was important for Olivia.

Family relationships: Cooperation. The informants in this study agreed that cooperation and working as a team is a positive experience that siblings value. According to all of the informants their families cooperated with one another to ensure that the disabled person's quality of life is the best possible.

Charles had this to say about family members supporting each other:

Having to look after Faith, I think that's what brought us closer together anyways right. Because we all had an understanding that Faith needed a lot of assistance, mom and dad need a lot of help but at the same time we learned that we also knew that we each needed help and we all kind of helped each other right and so we learned to pick up after each other, not only in terms of school issues, because many times I've had to do their homework right, but also like with family chores it was tight in the family where we all had to help out and pitch in right? And even today still we still help each other out and we pitch in wherever we can and our lives are changed obviously and we've grown up and we have families of our own but we still, whenever we can we try to help out right.

The individuals who participated indicated that, in their experience, helping out promoted cooperative attitudes. Noah seemed to share the responsibility for his sister's care with his parents and fully realized his care

giving role in the future. It was interesting to note that he constantly used the word, “we” when referring to his parents and himself and their participation in Deanna’s life. For example, Noah was explaining some strategies that the family used in the home for communication, “We actually didn’t put many signs up because we wanted her to try to understand what they were instead of us telling her all of the time”.

Noah’s use of the word “we” demonstrated the extent to which he considered himself part of the team of caregivers. He spoke glowingly about his mother and father and their childrearing strategies towards both siblings. He valued the role that all members of his family contributed towards his sibling’s care and their collaborative efforts. In sharing in the day-to-day care of their disabled member, the informants in this study indicated that family members learned to place importance on things and experiences differently than families who do not deal with disability.

Prioritizing. The siblings in this study did not consider material goods and possessions as things that they valued. Rose made this statement about outward appearances, “And I have very little time for people that put on or value, you know put more value on clothes and how they look or outward appearances.” She pointed out that values of acceptance held more importance for her. For Noah, material goods and wealth are the things that he does not value in friends; he

places importance on qualities that were previously discussed in this section.

Noah states, "I've got friends that are extremely rich, and I have friends that are poor and live in trailers. Just, it's the person that makes, it's the individual that makes the person, not what they are wearing, or what they have or what they don't have". One informant placed value and importance on experiences and feelings as well.

For those who experience the pain and suffering that disability can cause, distress and worry can become relative. Irene mentioned that when it comes to illness or injury she has a higher tolerance than most people due to her experiences with her sibling. She related how she prioritizes in terms of illness or injury in regard to her own children stating that small injuries do not upset her the way in which they may upset other mothers. The siblings that participated here have witnessed and experienced medical situations and behaviours that are extreme by society's definitions, i.e., being rushed to the hospital for seizures or putting one's head voluntarily through a glass window. There is a relative importance to things and events; some incidents that may upset people who have not experienced these extreme events may not upset people who have experienced more serious medical conditions and events. The seriousness of conditions and events can be prioritized. In this example, Olivia laments her inability to totally sympathize with her friend's distress over her child's disability. Olivia's friend's baby was born with a clubfoot. Olivia's own brother has suffered from cerebral

palsy and autism for his entire sixteen years. He has spent large amounts of time in the hospital and he requires twenty-four hour care even when at home. The woman described her response to her friend's upset over her baby's deformity:

It's NOTHING. Because when she's a baby, yeah, she's going to be in pain but she will never remember any of this. It's the hardest on you guys because it's the unknown. I said this is nothing don't worry about it, because it could be so much worse and it was still really just her feet but at the same time, I guess that in a way it seems cold of me but at the same time, like I said, Holly sweetie, she is going to be fine. It's just her feet. That's what this is all over. It's just going to be a small hairline scar and by the time she is 10 years old you are not even going to see the scar so she is going to be fine.

The informant explained the difference in their views and how suffering can be relative to how you prioritize, "it's a trip along the way, you know, you are going to stub your toe instead of breaking your leg, you will be fine." This description of relative values is also demonstrated in the same informant's recollection of an incident that happened while in high school. Her teacher, as an educator, saw only his priorities and assumed that what was important to him was equally important to his student. His student, however, was dealing with life and death issues while the teacher was concerned with marks. Here is her recollection of the events of many nights during adolescence,

When you give your brother AR and make trips in the early morning to the emergency room at 15, 16, 17, you know, you meet your parents there and give them the update and you are talking to the doctors and you are talking to the nurses and...he's been blue for half an hour and his heart rate is at 220 and it's, you know, you are dealing with things that I guess that you normally wouldn't unless you were living in that situation most kids don't

deal with that until they are adults and they've got sick parents or they've got a sick relative. Most people don't deal with that unless you've got a sick child in your family.

Values are fundamental to our existence whether knowledge of them is conscious or subconscious. What we value and what we prioritize determines the manner in which we order the world. Decisions about friends, family, occupations, and possessions are grounded in our value base. Values are important to the sibling's worldview; therefore, I have opened this section of data analysis with this theme. Values, as has been previously stated, help to determine sibling's criteria for the selection of friends and, therefore, have an impact on their social life. Relationships—family, sibling, friends and peers—are dependent on the sibling's *Weltanschauung*, similarly influenced by what is valued.

Social Life and Relationships

In the interviews, the participants spoke about their social life in regard to having a sibling with a disability. In this section I will present my findings regarding; social interaction with friends and peers; family values in socialization and sibling to sibling relationships. For some siblings having a brother or sister with a disability was a negative factor during childhood and adolescence, preventing "normal" friendship situations because of an inability to invite friends to their homes.

Social interaction with friends and peers. Two of the people that I interviewed seldom or never invited their friends to their home when they were

younger. The reasons for this were varied. In one case, it was something that was not done in the family even prior to the arrival of the sibling with a disability, however, her disabled sibling complicated the issue further. Olivia had this to say in response to a question about whether embarrassment was a factor in not inviting friends to her house:

No, never, it was never about embarrassment I don't think and I don't think for William (her non-disabled brother) either. It's more, um, like I said it probably has more to do with the mood in the house, period and then with Sam. But then you can't really hang out with your friends and throw potato chips at each other when...you know even when my parents were out, Sam was home.

In a medically fragile state, the activity level of adolescents who are not accustomed to a person with a disability may be a hazard to the person's health and safety, therefore, social activity that involved inviting friends to her house was curtailed.

Rose lived in a geographically isolated situation and had limited access to transportation and friends. Her inability to invite friends to her home was limited by these factors as well as a lack of people that she considered would be able to accept her brother's behaviours. Her social life suffered as a result of a lack of friends and social opportunities such as inviting people to her house.

Well, what I do know probably, like one big way that influenced me when I was a kid and it has probably come through in the rest of my life, you talk about having friends and I mentioned in the last interview that we couldn't have a lot of people over and there was only certain people that we could have friendships with and those were the people that accepted the fact that I had a brother and you know there was, I think, only one

person all through elementary that I could actually have over to my house that wouldn't be all like freaked out because my brother was putting his head through windows but totally accepted it. So maybe that's the kind of friendships that I seek out or those ones that accept you totally and fully.

Rose confirmed the value that she placed on friends who can "accept" and described how her social life was affected by a lack of such friends and lack of opportunity to socialize with friends in her own home. Other participants have had opportunities to socialize with friends in their home and felt quite comfortable with inviting friends to their house as children and teenagers as long as those friends conformed to the characteristics that they valued, i.e., they were accepting of their disabled sibling. Family attitudes towards socialization of children and affording time and opportunities to non-disabled siblings have an impact. The relationship amongst family members also affected the sibling's ability to socialize.

Family values in socialization. Noah credited parental attitudes with helping him develop positive attitudes towards his sister's inclusion in his social life. When asked about his social life, he responded:

How has she been part of my social life? Well, because I was brought up, like if I was having a birthday party, my parents would say, 'Let Deanna stay at our house and you can go out with your friends and have fun,' and I was, no, I want my sister to be at my party. I don't care if she starts to act up or comes out naked. Like my friends don't care, it doesn't matter to me, and they are not going to be embarrassed because of it.

Noah's teachers recognized this positive attitude towards inclusion and his sensitivity to people who are different since they would ask him to help include

students that were disabled at school events. Parental values towards socialization were reflected in the attitude and behaviour of their son. They facilitated opportunities for Noah to socialize with friends and peers in and out of the home. As a result of their efforts and strategies, Noah had a very active social life with a wide variety of friends that, of course, accepted his sister. His parents helped him to develop positive attitudes towards inclusion, which benefited his sister, himself and others in his social circle. While pondering why his teachers always approached him to include people with disabilities at social events, he came to this conclusion, "...because they saw in my everyday activities that I would always include people in everything".

Noah recognizes the role that his parents have played. When asked what part his parents played in his positive attitudes toward acceptance, this informant responded:

Huge role, a huge role. When Deanna was born she didn't want to be touched, she didn't want to be hugged. She didn't want to communicate. She just sort of laid there and did her own thing. My mom said there is no way I'm going to have a daughter and not be able to hug her and communicate with her so she just, not forcing it on her, but just slowly said now I'm going to give you a hug before you go to bed and that sort of thing and now Deanna will come up to her and sit on her lap and give her a kiss and that sort of thing. My mom has been absolutely incredible; I don't know how she did it and my dad as well. They brought her along so far for an autistic person like that to be able to communicate and do the things that Deanna does, it's incredible.

Noah's respect for his parent's behaviour needs no explanation. Their attitudes and strategies seemed to have been successful in creating a sibling who appears to be as accepting of his sister's disability as his parents are.

Sibling to sibling relationships. In any family, sibling harmony does not always appear. In fact, the term sibling rivalry seems to be much more commonly used. In one instance, a sibling-to-sibling conflict helped to create family disharmony. As any sibling may do, this informant's sibling with a disability took to teasing her brother. He recounted the game:

She'd open the door, turn on the light, and you could hear her laughing and then she'd run up the stairs and then so I'd turn off the light close the door and you could hear her at the top of the stairs laughing. She'd come down just a couple of steps but she was scared to, right, it was like a game. So she'd stop and then you'd hear her run up the stairs and then run back down again. To the point where I'd be standing in my room, waiting for her to come down so I could scare her and say, get out of here and leave me alone. And, of course, she'd come down and I'd say, F. get out of here and she'd run upstairs crying or whatever and then mom would come down.

This is typical sibling behaviour for stirring up parental wrath towards another sibling but in this case where one sibling had a disability, the informant's response appeared cruel. It was upsetting to the point where the whole family joined in criticizing the able-bodied sibling for "being mean" to his disabled sister. Family relationships were affected by his "normal" sibling response.

Charles stated:

Mom would get upset with me and half of my brothers and sister would all get mad, Charles why are being so mean to Faith and I think that when I

was at that age it was a bad time too, for I think for Faith to be around me because as I say with Faith as a teenager you have little or no patience with anybody, your brothers or your sisters or your parents but Faith seemed to always push the right buttons to get me angry.

The accompanying guilt led to increasing behavioural problems for the non-disabled sibling. Charles explained, "...and you still see the tension today. You know, there is still a lot of bad feelings I think with my older sister and my parents like, a lot of things that just haven't been mended and with me." Two informants indicated that they experienced behavioural problems during their teenage years for issues such as added responsibilities.

When non-disabled siblings were given too much responsibility for their disabled sibling, they experienced resentment for having added responsibilities that often had an impact on their social life:

When I was a teenager I really resented the fact that I was stuck home with William and Sam and I had to take care of them and they (parents) were always late and if I made plans for after when they were supposed to be home. They were late. So I'd have to cancel plans because, of course, my ride would have to leave without me and so I resented my parents a lot when growing up. Um, I don't think that I resented Sam and William, I don't think, I mean I can't. I don't know. Now, I don't think I did but maybe then I did. But I don't recall.

The person's position in the family and gender can play a role in being delegated responsibility. In some cases, the oldest daughter can become like a "second mom". Two respondents reported that this was the case. Olivia did not resent her disabled brother but her anger was directed towards her parents for the

added responsibility that affected her social life. Olivia talked about how her actions translated into a poor relationship with her non-disabled sibling:

...he didn't want to take my authority. I was hard on William when he was younger I think. Just because we were still brother and sister. I was still a kid but at the same time I was older and should have been more mature with William but I wasn't so I think we had a lot of spats and stupid arguments that we shouldn't have had because of that and as a result I think that our relationship is suffering now. He can't stand to be around me, living with me because I take charge too much. And I'm too critical and I'm this and that.

Consider a family as a whole. When part of that whole is affected then the entire family will feel the affects. This is demonstrated in the examples of social interaction amongst family members—parents and siblings—presented in this section. The impairment of social relationships is extended to friends and peers in some cases. Not all of the affects are negative. Parental attitudes and other variables such as age, birth order of the sibling within the family, sex, and the nearness of age to the person with the disability may mediate the affects on siblings. Coleby reports similar findings; “one must conclude that there is an effect upon the psychological health and social contact of the normally developing siblings. The increased acceptance of disabled people is a possible positive effect requiring further evaluation” (Coleby, 1995, p. 424). Acceptance is the final stage of the grieving process (Singer and Powers, 1993). Grieving is a process involving the emotions that most siblings of persons with a disability need to work their way through.

Emotional Development and Issues.

The persons that I interviewed expressed a variety of emotional responses to their experiences of growing up with a disabled sibling. In this section I will discuss the negative responses that take in embarrassment, resentment, anger, guilt and fear: positive emotions include love, kindness, caring, and acceptance. From the data that I collected in this study I will show examples of the range of emotions. The following excerpt indicates the conflicting emotions in Noah's recollection of his childhood. There is positivity and optimism but there is also an admission of stress:

There was no privacy or anything at that sort of time. But uh, my life with my sister was great and I wouldn't trade it for anything, I wouldn't say that, you know that I didn't have a great childhood or a bad childhood. I had a great childhood my parents made sure that all things were equal. You know, that Deanna didn't get all of the attention, I got attention too. But yeah, it was sort of stressful.

Some siblings are on the front lines. They may participate in the lives of their parents and their sibling with a disability. They may have no choice but to experience and watch. Rose described some of her memories of her brother's behaviours:

...(He would) take a temper tantrum or ...and he also was very self destructive and like, ok, we had big window in our living room and I don't know how many times he put his head through it...like at that age it was embarrassing because you couldn't keep anything nice. He would take forks and run them along the walls and write on the walls and everything and my mom tried so hard and now I can kind of relate when you are trying to keep a place nice and you know, she would paint and he would just take a fork and go right through the gyprock and everything, and there

would be holes in the walls, all patched up and the windows were taped trying to cover them over so it's just not something that people who don't live with that can understand. Sometimes I try to explain to (my partner) and I see him trying to understand but I don't think that he will ever truly understand what it was like.

It is interesting to note that this sibling is aware of the difference between herself and those who do not have a disabled sibling. If you do not live with it, it is very difficult to understand. One can understand intellectually but the emotional component is missing. It is the emotion that is difficult; the feelings as you watch your sibling suffer. Olivia questioned her brother's level of understanding and described a seizure:

But yeah, it's like, I just don't know what he's thinking, what he's feeling, what he knows, what he recognizes, what hurts him, what makes him happy. There's a lot of laughing seizures. He takes seizures where he'll laugh, he'll belly laugh, and he can't stop. He gets the hiccups he laughs so hard. We have to give him Valium for that because it's a grand mal seizure. But he laughs, it manifests itself in laughter and he can't stop, like he'll turn purple laughing if you let him go and it's the cutest thing I've ever seen. You hate to stop it but you know it's bad. He has seizures, where he'll; we call them the head drops. He'll be, he sits in a W on his bum. You know with his legs out so his knees are malformed and stuff. But he'll drop like this (Olivia demonstrates her brother's head dropping).

These experiences for Rose and Olivia were common occurrences.

Watching, experiencing, and thinking about situations such as these can do little other than create emotional stress. An individual may experience many emotions as a result of living with a sibling with a disability.

Negative emotions. In this section I will discuss and give examples of the negative emotions of embarrassment, resentment, anger, guilt and fear.

Embarrassment. In the previous section Rose referred to embarrassment to describe how she felt about her brother's constant damage to the house. In the interviews Rose mentioned embarrassment on a few occasions. She described one incident that she remembers from childhood when they went as a family to a fast food restaurant and her brother would walk over and take other people's food, "...he would go over and grab it and start eating it and people would just be like totally shocked. They wouldn't even be able to speak." Rose recalled this incident and the next with feelings of embarrassment:

I remember being at an outside pool and he put his head through a huge plate glass window right at the entrance of the pool in front of everybody, like in front of all the kids and everything and I was just like, yeah.

Rose was aware of her feelings of embarrassment at a younger age and admits that those feelings still surface now when she is out in public with her brother.¹ During the interviews she discovered that she was probably less embarrassed by her brother when he was really young since temper tantrum and some behaviours are common for many children but as her brother grew the inappropriate behaviours became more outstanding when out in public. Rose was aware of other feelings as well as embarrassment, she added that she also "probably resented".

Resentment. Some siblings often resent the attention that is received by their disabled sibling. Memories and recollections of these feelings may extend

into adulthood as is evidenced in this passage from Charles. He is aware of the lack of parental time and attention that was given to him:

I guess maybe when I was young and a teenager, I might have been acting more selfishly, like I wanted mom and dad's attention like a lot more than what they gave me because a lot of attention was focused on Faith. But now, I mean, it's not so much a selfish feeling that I have towards mom and dad but more so wanting them to get on with their own life.

Rose indicated that she too longed for "normal" parental interaction and attention, "Yeah, the resentment was bad when I was living with it but I don't resent anything now". Some of her resentment stemmed from a longing for "normal" family life. Rose described Christmas celebrations that stood out in her mind. When the family attended events at the Autism Society she had reasonably good memories of her brother and felt that the family was as close to "normal" as she ever experienced. She also indicated that the people there understood her brother and if he took a temper tantrum it was not as embarrassing as it was in the other public areas. Rose indicated that the "normal" family feeling often disappeared when the family was in a smaller extended family group. It was in this situation that temper tantrums and her brother's other behaviours usually triggered family arguments. Her recollections of Christmases were that they were, "Bad, bad, bad". Certain events seemed to be outstanding in the minds of the participants as situations that had caused trauma in the past due to the amount of time that needed to be focused on their disabled sibling.

During the interviews, Irene mentioned on three separate occasions how her parents and herself, since transportation was a problem, could stay at her college graduation for only one hour since her sister with a disability was in the hospital. In later years, Charles and Irene looked back on their behaviour and termed it as “selfish”. Four of the five siblings in this study stated that they tend to be hard on themselves and from my research it was apparent in some cases that they expected a lot of themselves then and now. Rose explained:

I tend to be very hard on myself. I don't know if that's a quality that comes up a lot but I probably just, you know a lot of people are hard, I'm probably just a little bit harder and more of a perfectionist and never quite satisfied. And I don't know if some of that kind of translates over but I always had to be top of my class. I always had to be first you know. Um, all through school I had to be smartest. That was a big thing. That was how I kind of identified myself as being the smart one. Um, you know, I couldn't accept less. Like I would spend hours and hours getting things right and making sure that I stayed at the top.

Rose was not the only informant that mentioned a tendency to overwork and achieve. Irene mentioned her inclination towards being a workaholic:

You know it might be too because I use to, looking back, I used to think that I became like a second mother and then, at sixteen, I started working. I worked at the airport doing waitressing and that sort of thing so work became kind of a, like there was home and work and home and work...so maybe that carried on into the workplace, you know, where I became bit of a workaholic because of the responsibility.

Irene looks back now and realizes that anger accompanied the resentment that she felt from lack of parental time and increased responsibility.

Anger. Irene was aware of anger that had been buried and came to the surface at times directed towards her children as of late. She has received counselling to help deal with these feelings. The healing consisted of exploring some the situations in growing up with a disabled sibling and being put in the position of added responsibility due to her situation as the oldest daughter. In later years she learned to speak up to her parents and tell them what she wanted, she related the story:

...at the time my parents wanted me to be a guardian for my sister and they had asked me that without consulting me first but I remember saying, No, sorry I can't do this because I'm having a life and I'm doing this and I'm doing this. I love my sister but I'm not taking the full responsibility.

Guilt. By accepting so much responsibility, Irene had also taken on guilt that she had to deal with, as she got older.

...I got involved with a woman's group and she did a lot of inner healing and a lot of looking at, looking back at where you came from and how come and why this, and different things like my father would say to me like, it's your fault because of blah, blah, and I was sent to this woman's ministry who helped me so tremendously and said you were only a child yourself and you are not to blame and it's not your fault that this happened. So when I released some of that in prayer and in woman's counselling I would feel much better about myself that I did what I could do and it wasn't totally my fault and it was one of those things and I've had a lot of inner healing in the last 5 – 10 years and I've grown tremendously.

Feelings of guilt were common amongst my informants. This concurs with research in this area since guilt is part of the grieving process (Brearley, 1997). Rose expressed guilt over feelings of resentment and embarrassment

during childhood. The informant felt that she had not developed a sibling bond with her autistic brother:

Yeah, yeah, there is no...it seems more like a fact of life than having someone that you think about or wonder how they are doing, you know, like it's like a distant relative that you haven't really, not somebody that you grew up with or...and I guess that a lot of the time, depending on when I figure out when he went away to the training centre maybe it was only 12 years of my life or something that he was really ever a part.

She later stated her feelings of guilt. "You know it was those feelings were there. Um, the guilt maybe because I feel like I should be doing more even though intellectually I know there isn't anything that I could do." The feelings of helplessness and inability to be able to do anything to make things right can lead to fears for siblings: fear of the lack of control, fear of being unable to do anything, fear of having your children in the event that the story will replay itself.

Fear. It is interesting to note the emotional stress that seems to have been created at the time of diagnosis. The impact is notable since the stories stand out in memory. One informant related this devastating story that her mother told her:

Yeah, after many years of going back and forth to Halifax and everything and we ended up going to Toronto, there was someone up there I guess that told them and she said, you know what they told me when they first...they said Ok, your son has autism and they said, your life is going to be miserable and your marriage is going to break up and your daughter is never going to have normal life. That's what they told her. So I guess one of them, one of them came true, but you know, I hope, you turned out pretty normal. Yeah, that was what they told her.

Rose related this story as if she had heard it and thought of it often. All of her experiences combined to make her fearful of having children of her own. She explained:

I'm sure that having a child with autism probably greatly increases chances of them not being able to keep their marriage together. Maybe we shouldn't have children. What happens if we do and that ends up being...so it's hard not to have that kind of shape your outlook.

Rose watched her mother go through difficult times in raising her brother but she did comment that even though it was hard she knew it could be done. She was determined to have her own children regardless of her fears. There were some positive experiences even in Rose's recollection.

Positive emotions; love, kindness, caring and acceptance. In the interviews, the childhood memories of siblings seemed to be clouded with negative experiences but in later life there are some rays of sunshine. This informant spoke of a first indication that her brother recognized her:

So it's just ah, that, it just ends up, those feeling surrounding him that you had before, you haven't had a chance to be around him while he has developed or, he hasn't really developed or there isn't really a whole lot that's changed with him or his behaviour. There are subtleties. When I was home at Christmas time they had taken him off a lot of his medication and for the first time as I mentioned before there was a double take and he was actually looking and making eye contact. And that was really strange. Like even my mom was even amazed at the difference.

For another informant, she describes her feelings towards her brother in nothing less than inspirational words:

When I think about him, I think, it's just like this bright, white light but it doesn't hurt your eyes to look at it, you know, that's how I think of Sam. When I think of his aura, I guess. There is just an aura about Sam. And that's just his aura. It's just pure white, absolutely innocent, absolutely innocent. He is just the most innocent creature. He's never, I don't think he's ever known hate. Anger and frustration definitely. But he's just never known hate. He's never known, ah, I know that he knows fear, he knows contentment and discontentment and frustration, anger but in a way related that we don't know anger. I guess anger at, why don't you, more of a frustration, I guess than anything. But Sam, Yeah, he's just, I love that child, like he's my own. I love him like my own.

The siblings in this study did express feelings of resentment and embarrassment that they remembered from childhood in particular. Those feelings were related to lack of parental time and attention as well as increased expectations for taking responsibilities. At time anger resulted; behaviour problems emerged for three of the five informants. Guilt was a common emotion amongst all participants. The two female informants who did not yet have children had fears that their children would have a disability. However, in the light of all of the negative emotions there appear stories of unconditional love, caring, kindness and acceptance. All of the people that I interviewed for this study seemed to be compassionate, understanding, caring, kind individuals who love their families and their disabled sibling. They had developed some unique skills from growing up with a sibling with a disability. These skills translated both directly and indirectly into their occupations.

Work; Skills Development and Knowledge Acquisition; Characteristics.

Three of the five informants for this study work in the helping professions. The other two participants work in occupations that require skills directly related to those acquired as a result of being a sibling of a person with a disability. In this final section I will present my findings in relation to work; skills development and knowledge acquisition and characteristics of siblings. Many of the siblings that I interviewed and their able-bodied siblings worked in what can be termed as the “helping professions” of medicine, teaching and counselling (Murphy & Della Corte, 1989).

The Helping Professions. Learned skills, personal characteristics, and experience with a disabled brother or sister all contribute to equipping siblings with the abilities and qualities necessary for certain fields of work. For Charles, there was no question as to where his level of comfort rested:

I said that if you would have come to me and asked me a question like, what I wanted to do 15 years ago, I think that I would have said that I wanted to help people but I always wanted to be in this field but I just never knew. Being a program assistant, I think, that to me it's just like a natural job like, I mean, the money isn't that good but it's not even like a job like it's, just, ah, something that I don't have to prepare for at night and I wake up in the morning and I just go and it's just a matter of putting on a happy face and making the kids that I work with happy, you know. Kids in the group home...that's what I try to do you know, because to me it's like if I never had a sister like Faith. I wouldn't be doing this because I think it was an eye opener to me right. Like having a sister like this...

Charles and all of his able-bodied siblings worked in the “helping professions”. They worked in schools as educational assistants, in group homes and some had summer jobs at camps for children with disabilities. Growing up with their disabled sibling taught them how to care for people with disabilities and made them familiar with people who required their care.

Skill development and knowledge acquisition. Some siblings grow up involved in the care of their brother or sister with a disability. They are generally comfortable in the company of persons with disabilities due to their contact with their sibling. They learn at an early age much information and develop the skills necessary to help their sibling and their parents cope with the disability.

Irene spoke of concrete skills that she learned in helping with her sister’s care. In her position as second mother, she would often be left to cook the dinner for her six other siblings as her mother rushed her disabled sister to the hospital. It was a hectic time but she needed to learn those skills quickly and out of necessity. “Yeah, well we learned, and you know like a lot of times my mother would have suggestions like there’s the meat, can you make a hamburger or make macaroni.” It was left to the sibling to take responsibility for dinner in her mother’s absence. Irene originally went into restaurant management. However, some component was missing for job satisfaction and several years ago she changed occupations to find something more in line with all of her skills. She now works as an Educational Program Assistant with disabled students.

Noah and Rose work in occupations that cannot be termed, “helping professions” but rather they are in the field of communications. I will discuss skills that they may have developed that enable them to work in this area. They are both good communicators and have developed observation and listening skills. Noah has to solve various customer related problems in his job; he practiced problem solving and task analysis while learning how to communicate with his sister. Some siblings developed a knowledge base and skills as a result of looking after their disabled sibling. Irene talked about her new employment. She revealed her knowledge in this area and the development of appropriate skills:

As an EPA (Educational Program Assistant) I work with special needs. And over the five years I’ve had different students, some with autism. The student that I work with now has a bit of cerebral palsy but he’s totally non-verbal as was the student before. So you have to rely on body language and being able to read the children. What needs they have, but my experience with my sister has really helped to be able to read the children. And, it’s really rewarding because you see them when they first come in being very shy and not able to do certain things and then you work with them and know the personality and then they become more aware and more able to do more things.

Olivia spoke about the need to learn how to anticipate and to watch for signs of a seizure:

Well because he gets Valium for really bad seizures or if we see that he’s building we’ll give it to him Valium preemptively hoping to stave off a bad seizure with the Valium. Chances are he is still going to seizure but it won’t be as bad if he gets the Valium before. If we see him building for it we’ll just give him the Valium beforehand. If he has three shots of

Valium in twenty-four hours he has to go to the IWK(hospital) if he has another seizure because we can't give him anymore Valium and that's when they get the promaldyhyde. Then we go home and they don't do anything. They just give him the ... promaldyhyde...observe and then send him home.

This quote demonstrates Olivia's level of knowledge about medical procedures connected with seizure activity. Both informants have worked in fields directly connected with care for persons with disabilities. Here is another description of how life and work have blended:

And now when I see in the job that I do, I work with special needs kids, and this Cec Lynes who is the teacher that I work with, when we first came in we had no idea. None of us had really worked with special needs, we had worked in different professions and what she said, you are going to be baptized by fire, we have all these kids with special needs and seizures and whatever and so growing up I learned to do that. OK, she's having a seizure let's deal with that, ok you're cooking supper and take over and whatever (mom would say). So, at work, I find that I almost have like a sixth sense with some of these kids who are non-verbal. I can say oh, they are going to have a seizure now and look, you know, you are working with one child and you can see another child across the room that is flipping out, you know, so you can, you leave this child and run to this, you know what I mean because, and different coworkers have said, you know, how did you know they were going to do that? You just get to read certain situations.

Communications skills: observation and listening. Noah and Rose, however, were not connected directly with the helping professions. Both of these people were working in or headed towards careers that involved communication skills. Noah spoke about his skills in the areas of observing and listening and how they helped him in his job:

Uh huh, in my job, at school. At my job, customers come in and they can be very abrupt and wanting this and wanting that and they actually don't know what they want so you have to sort of ask them questions and deal with them and find their needs before you can help them. And I find that that's sort of what you have to do with my sister, you have to find out what her needs are and what she actually wants rather than her trying to tell you what she wants. Sometimes she doesn't know the correct word or sign language to tell you what she wants but you have to look at the big picture and see, OK, what do you think she is trying to tell me.

The acquisition of skills of relating to observation and listening seems to be positive information that has come out of these interviews. Noah went on to say how these skills translated into his personal life. When asked about life on a daily basis, he responded:

Everyday life. Every action that you do everyday, even with school, just being outgoing and participating in classes is a huge part of my day. My school has a lot of communication, we have to communicate with each other and a lot of people are shy and don't say much but I find that just because of the understanding and the ability to talk to my sister, ask the simple questions, do the simple things, has enabled me to speak well in my class and communicate with others. Um, I'm able to make friends very easily in class just because I'm an outgoing person. Not much bothers me in the fact that you know when you hang out with my sister, like you can be in the mall and she'll strip down naked and you have to learn how to, you know, deal with those type of situations, so when you are in class and talking to a teacher and having a rough time you sort of, it tends to come a lot easier when you are in tough situations just because you've been there before. I was actually, I was elected to be a peer helper just because of that. Some people in my school noticed that I was able to help people with their problems like, they would always come to me, so they elected me to be a peer helper and they didn't even know that I had a handicapped sister at the time, but, ah, when they were asking. 'Why do these people come to you, why can you help them so much?' and I told them, 'Well I have a handicapped sister.' And I'm just used to dealing with problems, well not so much problems, but just different situations.

Problem solving, task analysis. It is interesting to note that there are other areas of skill development in regard to having a sibling with a disability. Noah spoke about problem solving as it related to his sister with autism. Professionals who work in this area are aware of the necessity of breaking down routines into the smallest components in order to teach or train people with autism to perform daily tasks. A sibling may learn this knowledge and skill at an early age. Noah explained:

You are taking something for what it's worth and you are breaking it down into components, as you say, and really you are taking simple tasks that we take for granted everyday and you have to break it down for these people in order for them to understand exactly why they have to do it and it helps them to get through I guess. I don't really know how to explain it too well.

It should be noted that this informant does not know how to explain what he is doing but he is aware that he is doing it. Noah is also aware that it is his sister that is responsible for a lot of learning, "...communication, that's what I'm working with at school. So she's influenced me that way, not so much influenced me, but helped me understand what I'm doing a lot clearer".

Rose also works in the field of communications. Living in an isolated community with a brother with autism, Rose spent a lot of time writing. She developed skills that led to her present employment. Rose was also aware that she had developed certain characteristics from living with her brother. She talked about those characteristics in this passage:

It's definitely made me more tolerant of people's differences. Like I'm more aware of that if I see somebody out in public or if it's another person's sibling or just anything, like something minor, she's stuttering too. I think I'm able to be more accepting of it and ah, not as judgemental maybe...well you had to become so much stronger and kind of tolerant.

Characteristics. Siblings of persons with a disability seem to share certain characteristics. All participants in this study referred to tolerance, patience, understanding, and empathy. Each person considered himself or herself to possess these characteristics. Charles speaks of himself and all of his siblings who are in related fields. He begins by describing his sister:

She is non-verbal, and she has mild seizures. Just a real, she is a handful and because of her we are all in this field obviously it is all attributed to her but, ah, we have grown to deal with her and to have a lot of patience and understanding. Like we have grown up with that.

Some siblings of disabled persons seem to develop skills that may not be developed by all siblings. This information shines a positive light on the experience of living with a disabled sibling. Skills may be developed that can help other people when the person grows and becomes part of the workforce. Some of the skills mentioned are as follows: communications skills – observation and listening skills, problem solving skills, task analysis abilities, and logical deductive skills and ability. The siblings that participated in this study are aware of the source of the development of many of these positive skills. They recognize that life with their sibling has contributed to that development. Certain attributes of personality can also be noted: kindness, understanding, tolerance, patience, and

empathy have been mentioned here as characteristics that can be assigned to the informants that participated in this study. In light of the collection of negative effects that siblings may endure, it is encouraging to note the long list of positive skills and characteristics that may develop as a result of growing up with a disabled brother or sister. The personal perspective of siblings of persons with a disability, as described in this section, will be explored further in the final chapter.

Chapter 5: Summary and Conclusion

The findings in this study were divided into four major themes: sibling values; social life and relationships; emotional development and issues; the helping professions, skills, knowledge and skill development and characteristics. In this chapter I will summarize the key points from the data for each of these themes.

Sibling values

The informants in this study indicated that they had certain standards when it came to choosing friends. Since their family life differed from our society's definition of "normal" they needed to find friends that accepted those differences. The qualities that they valued most in friends were understanding and acceptance. In order to invite their friends to their houses, the friends needed to be comfortable with their disabled sibling. The informants suggested that they had become perceptive when it came to deciding whether a person was able to understand and accept. Noah gave an example of a fictitious conversation with a person that would be an indicator of whether the person would understand and accept his sister's disability. In that conversation it was important that the person appear interested and showed understanding of what was involved in having a disabled sibling. If the person "blew off" Noah's verbal introduction of his sister to go onto another topic, Noah felt the person probably did not

understand the implications of disability. To go along with what I will describe as a “shallowness” of personality or thought, Rose indicated that she had difficulty engaging in “small talk”. It was a skill that she needed to learn since she had not indulged in that superficiality in her upbringing with her disabled brother. All of the siblings agreed on these things that they valued in friends as determinants of whether a friendship would begin and last.

Two of the informants in this study, both of whom were male, suggested that the same standards existed in their choice of a mate. They could not have a wife or girlfriend who did not accept their sisters and who were willing to participate in the care of that sister. Charles who was already married expressed extreme satisfaction with his wife’s attitudes and concern directed towards his sister. He had a companion that he could talk to, who understood and was thoughtful towards the situation. Noah has found a girlfriend who demonstrates the same characteristics and willingly offers to spend time visiting his sister. The siblings in this study value the qualities of compassion, empathy, respect and dignity as well.

Compassion and understanding were qualities that were extremely important to siblings. They exercised these qualities and they expected them in others. Empathy, as described by Noah as the ability to put yourself in another person’s shoes, was actually a method by which he lived while growing up. He needed to attempt to understand what his sister was thinking in order to learn

methods of communication and care. Charles understood empathy and exercised it in his life and work. Respect and dignity were important to all siblings as well. They appreciated people who demonstrated these qualities towards their disabled siblings since there were many experiences where they saw the opposite. An appreciation of these qualities extended to all aspects of their lives and Charles expressed a strong commitment to teaching them to his children.

In family relationships, the siblings in this study valued cooperation and teamwork. All of the siblings described how their family “pulled together” to support their disabled member. They helped each other and supported one another throughout their lives. Some conflicts did emerge, however, that were carryovers from childhood which remained problematic until today. Nevertheless, each sibling in this study indicated a family cohesion around their disabled brother or sister.

In the last section of sibling values I addressed prioritizing or placing importance. In the value base of siblings some things were high on the scales and some were low. Minor injury or disability was not an item that required much concern (relatively) for two of the siblings in this study. Since they had experienced major disability, they found it difficult to become upset over minor injury or disability. This is matter of looking at the larger picture and deciding what is really important. For example, from my personal experience, I have never considered money to be particularly valuable. I learned very early that all of the

money in the world would not make my sister able-bodied; therefore, since her welfare was my concern I place little value on money. I have always considered myself fortunate to have learned this truth so thoroughly. In the same manner, the siblings in this study place importance on the things that matter to them. Living with a sibling with a disability means that the basics of life, i.e., being able to walk and talk, are valued. To give another example, Rose pointed out that some people may be upset because they cannot find the right color of nail polish; in the meantime, Rose is not sleeping at night because her brother has broken through his window and is out on the lawn covered in blood. This is an example of prioritizing what is truly important. Perhaps the difference is that siblings of disabled persons do experience traumatic and real situations that need attending and care, whereas, the people whom they described as superficial have not yet experienced such things. All of the siblings in this study agreed that these experiences made them stronger and better able to deal with life's concerns.

Social life and relationships

The informants in this study recalled social interactions from childhood. All of the informants had recollections of inviting friends to their house. Two of the informants invited people regularly if they were friends that showed understanding and acceptance. The three female participants had difficulty with this social event. In all cases there were problems with geographical locations and transportation but the key factor was the home situation. All of the

informants indicated that their parents were not totally comfortable with having friends over. One informant confided that embarrassment was a problem due to the damage cause to the home by her brother. Family disharmony created some strain as well as the intense care and concern for the sibling with the disability. Parental attitudes towards socialization of their non-disabled siblings played a big role.

Many factors come into play when discussing parental attitudes; number of children in the family, resources available, finances, time constraints. For one sibling in this study his parents made certain that he received time and attention and was enabled to develop a healthy social life as a child. Noah speaks well of his parents' effort to ensure that he was allowed opportunities to make friends and enjoy their company. For some of the informants, however, lack of parental time and resources led to an impairment of social opportunities. Concerns for their disabled sibling took much of their parents' attention. In two of the families there were a large amount of siblings.

Sibling conflict was obvious in some of the statements made by the informants. Charles described an experience with his disabled sibling that resembled many "normal" sibling interactions that are designed to tease and provoke. The conflict that resulted drew in the entire family and he feels that his reputation is slightly damaged even to this day with his other siblings since he was branded as "being mean".

Emotional development and issues

In this section, I offered selections from the data that indicated a number of negative and positive emotions that were associated with being a sibling of a person with a disability. Embarrassment was an issue for some siblings in the study but stated not to be a problem by others. Resentment was a feeling that four out of the five informants mentioned that they had felt. The resented both the lack of parental time afforded themselves and the added responsibilities that they were given for care of their siblings. All three of the female informants mentioned difficulty around some special occasions. Christmas and birthdays seemed to be a particularly sensitive time for the informants. Each female informant had an example of emotional upset due to lack of parental time or missed opportunities during these special events in their lives. One informant stated that she needed counselling in order to deal with her anger that she carried with from childhood. Anger grew out of resentment in this case. Some siblings developed behavior problems during adolescence.

Guilt was an emotional issue for four out of the five informants. Reason for feeling guilt ranged from feeling badly for being “selfish” as an adolescent to feeling guilt over not doing enough activity with their sibling today as adults. Irene, the eldest daughter of several siblings, felt guilt that she had not done more

when she was younger although by her own admission she was workaholic and became a “second mom” to her siblings. Fears surfaced in many forms; fear of failure, fear of not performing to the maximum, fear of having a child with a disability. To counteract their fears, siblings were doing all that they could to help. They expressed many positive emotions.

Love, kindness, caring and acceptance were all emotions that the siblings in this study expressed. Every sibling interviewed here indicated a deep love for their disabled sibling and their family. These positive emotions carry over into their daily life and all had incorporated them into their daily dealings with people in the performance of their occupations.

Work; Skills Development and Knowledge Acquisition; Characteristics

Three of the five informants in this study worked in what can be termed the helping professions. They were caregivers for people with disabilities. They found comfort and satisfaction in their jobs. The skills and knowledge that they had developed as children translated into the requirement necessary for their livelihoods. They enjoyed their work and from their descriptions they did their jobs well, giving more than required. Two of the five informants worked in the communications field.

Noah and Rose both had siblings with autism. Bennett states that, “Autistic children are unable to form normal social relationships; they have marked difficulty with verbal and non-verbal communication and no inner world

or pretence and imagination” (Bennett, 1993, p. 50). It is interesting to note that some of the skills that Noah and Rose learned while young in attempting to communicate with their sibling can be used in their current employment. They both commented on their skills of observation and that they had been told by friends that they were good listeners. In attempting to deal with his sister, Noah found that he needed and his parents needed to constantly problem solve. As she developed they were required to find new and appropriate ways to teach her to do things. Task analysis comes into play as part of problem solving. It is necessary to break activities down into their component parts, order them, and then teach them to the person with the disability. Rose worked on writing as a child. It was impossible to communicate with her brother; each of them isolated themselves and functioned separately. Rose is a currently a writer who works in the communications field. These skills that were developed while working with their siblings are valuable today in their careers.

The discovery of this link between skills development and occupations seems to be significant. This is a positive effect of living with a sibling with a disability; this offers encouragement and hope that some positive effects do come out of the difficult times. Skills development combined with the fine qualities and characteristics that siblings exhibit make the trials seem more palatable. For most of the siblings that I interviewed they were thankful for the challenges that life

had presented them; from their personal perspective they felt that their experiences had made them stronger and better people.

Research Methods

Qualitative methods proved to be the best method for attaining the personal perspectives of the informants. The participants commented positively on the interview process. They were pleased that they had an opportunity to speak to someone who understood their perspective and asked questions in a structured manner. The questions were opened ended but at times I guided people to be more specific on certain items or to explain more of their perspective. Since I was in a position of being able to relate to their stories I could anticipate reactions and sympathize accordingly. One informant said that the process had been cathartic and two other suggested that it had been a therapeutic experience. There were many times during the interviewing that participants suggested that they had not thought about certain things that I mentioned. Each of the informants spoke to their partners or family between the interviews about the content and results of the session. In short, it seemed that the interview process got the informants talking and thinking about their relationship past and present with their disabled sibling and their family. As a researcher with a personal involvement, I too appreciated this process and the honesty and sincerity of the participants. At times it felt as though emotions were very close to the surface but in true sib fashion we all manage to control our emotions.

During this process I believe that the siblings that I interviewed learned a lot about themselves, their families and their relationships. Talking about and reviewing their lives allowed them to put things into perspective and to analyze experiences and situations from their current perspective. Patton comments on the personal side of interviewing in this respect:

The process of being taken through a directed, reflective process affects the person being interviewed. It is not unusual for an interviewee to say, "You know, I hadn't thought of that for a long time." As respondents think about questions they may surprise themselves with fresh insights, previously unarticulated concerns and new ideas (Patton, 1987, p. 140).

Qualitative methods enabled the subjective view of these siblings to come into focus for examination by themselves and others.

The only limitation of this study, in my opinion, is the small number of siblings that participated in the research. I was limited to five informants due to time constraints and the resources available to do the study.

Suggestions for further research

I believe that this topic requires more research. All of the siblings in this study expressed a desire to participate for the purpose of helping other siblings. There is a need as expressed by these siblings for more support for people who have a disabled brother or sister. I would suggest that a similar study be conducted with a larger number of participants and researchers. Refinements could be made to the selection of informants, i.e., they could be grouped according to age, position in the family, gender, parental attitudes, sibling

attitudes, educational levels and socio-economic conditions, to name a few.

Research could be focused towards finding best coping mechanisms. There was some indication in this study that informants had certain methods for dealing with the stress that they experienced as children. Knowledge of these methods could be helpful in guiding young siblings and helping them to be better able to deal with their situation and feelings.

Another area of study could focus on developmental level and ages. The data in this study indicates that people deal with things differently at different ages. Bank and Kahn (1982) suggest that their age and developmental stage may influence the manner in which the non-disabled sibling will interpret the behavior of his or her disabled sibling. Three of the five participants indicated that they experienced behavioral difficulties during their teenage years. They rebelled in their own manner but all three expressed regret that they had done certain things and behaved in undesirable ways. A developmental look at the effects on people of having a disabled sibling is a suggestion for further research.

Although somewhat limited in scope this paper does offer some insight into the personal view of persons with a disabled sibling. It becomes apparent that there are differences in upbringing to people that do not have disability in the family. Given the appropriate conditions many skills and much knowledge can be developed as a result of their experiences. None of the informants in this study

regretted their situation in life and, in fact, were thankful overall for their experiences.

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HES Fax No. 261-0325

Protocol # _____

(Assigned by HES Admin.)

Human Subject Research Ethics Protocol Submission Form (Ft. Garry Campus)

Psychology/Sociology REB

Education/Nursing REB

Joint-Faculty REB

Check the appropriate REB for the Faculty or Department of the Principal Researcher. This form, attached research protocol, and all supporting documents, must be submitted **in quadruplicate** (original plus 3 copies), to the Office of Research Services, Human Ethics Secretariat, 244 Engineering Building, 474-7122.

If the research involves biomedical intervention, check the box below to facilitate referral to the BREB:

Requires Referral to Biomedical REB

Project Information:

Principal Researcher(s): Koreen B. Scott

Status of Principal Researcher(s): please check

Faculty Post-Doc Student: Graduate Undergraduate Other Specify: _____

Campus address: Faculty of Education Phone: (204) 474-9018 Fax: (204) 474-7564

Email address: koreenscott@yahoo.com Quickest Means of contact: (902) 449-8776

Project Title: *Personal Perspectives: Experiences of Persons with Disabled Siblings*

Start date: February /03 Planned period of research (if less than one year): 7 months

Type of research (Please check):

Faculty Research:

Self-funded Sponsored
(Agency) _____

Administrative Research:

Central
Unit-based

Student Research:

Thesis (X) Class Project
Course Number: 069.702

Signature of Principal Researcher: Koreen B. Scott

This project is approved by department/thesis committee. The advisor has reviewed and approved the protocol.

Name of Thesis Advisor: Dr. Zana Lutfiyya: Signature: _____

(Required if thesis research)

Name of Course Instructor: _____ Signature _____

(Required if class project)

Persons signing assure responsibility that all procedures performed under the protocol will be conducted by individuals responsibly entitled to do so, and that any deviation from the protocol will be submitted to the REB for its approval prior to implementation. Signature of the thesis advisor/course instructor indicates that student researchers have been instructed on the principles of ethics policy, on the importance of adherence to the ethical conduct of the research according to the submitted protocol (and of the necessity to report any deviations from the protocol to their advisor/instructor).

Ethics Protocol Submission Form (Basic Questions about the Project)

The questions on this form are of a general nature, designed to collect pertinent information about potential problems of an ethical nature that could arise with the proposed research project. In addition to answering the questions below, the researcher is expected to append pages (and any other necessary documents) to a submission detailing the required information about the research protocol (see page 4).

1. Will the subjects in your study be **UNAWARE** that they are subjects? ___ Yes ___X_ No

2. Will information about the subjects be obtained from sources other than the subjects themselves? ___ Yes ___X_ No

3. Are you and/or members of your research team in a position of power vis-a-vis the subjects? If yes, clarify the position of power and how it will be addressed. ___ Yes ___X_ No

4. Is any inducement or coercion used to obtain the subject's participation? ___ Yes ___X_ No

5. Do subjects identify themselves by name directly, or by other means that allows you or anyone else to identify data with specific subjects? If yes, indicate how confidentiality will be maintained. What precautions are to be undertaken in storing data and in its eventual destruction/disposition. ___X_ Yes ___ No

6. If subjects are identifiable by name, do you intend to recruit them for future studies? If yes, indicate why this is necessary and how you plan to recruit these subjects for future studies. ___ Yes ___X_ No

7. Could dissemination of findings compromise confidentiality? ___X_ Yes ___ No

8. Does the study involve physical or emotional stress, or the subject's expectation thereof, such as might result from conditions in the study design? ___ Yes ___X_ No

9. Is there any threat to the personal safety of subjects? ___ Yes ___X_ No

10. Does the study involve subjects who are not legally or practically able to give their valid consent to participate (e.g., children, or persons with mental health problems and/or cognitive impairment)? If yes, indicate how informed consent will be obtained from subjects and those authorized to speak for subjects. ___ Yes ___X_ No

11. Is deception involved (i.e., will subjects be intentionally misled about the purpose of the study, their own performance, or other features of the study)? Yes No
12. Is there a possibility that abuse of children or persons in care might be discovered in the course of the study? If yes, current laws require that certain offenses against children and persons in care be reported to legal authorities. Indicate the provisions that have been made for complying with the law. Yes No
13. Does the study include the use of personal health information? The Manitoba Personal Health Information Act (PHIA) outlines responsibilities of researchers to ensure safeguards that will protect personal health information. If yes, indicate provisions that will be made to comply with this Act (see document for guidance - <http://www.gov.mb.ca/health/phia/index.html>). Yes No

Provide additional details pertaining to any of the questions above for which you responded "yes." Attach additional pages, if necessary.

In my judgment this project involves: minimal risk
 more than minimal risk

(Policy #1406 defines "minimal risk" as follows: ". . . that the risks of harm anticipated in the proposed research are not greater nor more likely, considering probability and magnitude, than those ordinarily encountered in life, including those encountered during the performance of routine physical or psychological examinations or tests.")

06 / 01 / 03
dd mm yr

Koreen B. Scott
Signature of Principal Researcher

Additional Information:

5. I will know the informants by name. Pseudonyms will be used in writing the thesis in order to protect confidentiality. Data will be stored in private files and on computer disks for my exclusive use only. After the study, all audiotape will be erased, papers will be shredded and computer disks with confidential information will be destroyed.

7. Since the results of the study will be published, there is a risk of confidentiality being breached. The study is intended for the research community and all attempts to protect confidentiality will be taken. The participant is alerted to the possibility that some cross-references may be possible so that there is a risk that the participant may be identifiable.

12. There is a slight possibility that some allegations of abuse may be revealed. In my position as a teacher, I am obligated to report any suspicion of abuse. Suspicions will be reported to the Children's Aid Society, if such a situation arises.

All participants will be 18 years of age and older. Consent will be obtained from the participants. No parental or guardian consent will be required due to the age of the informants.

**Ethics Protocol Submission Form
Required Information about the Research Protocol**

Each application for ethics approval should include the following information and be presented in the following order, using these headings:

1. **Summary of Project:** Attach a detailed but concise (one typed page) outline of the **purpose** and **methodology** of the study describing **precisely** the procedures in which subjects will be asked to participate.
2. **Research Instruments:** Attach copies of **all** materials (e.g., questionnaires, tests, interview schedules, etc.) to be given to subjects and/or third parties.
3. **Study Subjects:** Describe the number of subjects, and how they will be recruited for this study. Are there any special characteristics of the subjects that make them especially vulnerable or require extra measures?
4. **Informed Consent:** Will consent **in writing** be obtained? If so, attach a copy of the consent form. (see guidelines on informed consent). If written consent is not to be obtained, indicate why not and the manner by which subjects' consent (verbally) or assent to participate in the study will be obtained. How will the nature of the study and subjects' participation in the study be explained to them **before** they agree to participate. How will consent be obtained from guardians of subjects from vulnerable populations? If confidential records will be consulted, indicate the nature of the records, and how subjects' consent is to be obtained. If it is essential to the research, indicate why subjects are not to be made aware of their records being consulted.
5. **Deception:** Deception refers to the deliberate withholding of essential information or the provision of deliberately misleading information about the research or its purposes. If the research involves deception, the researcher must provide detailed information on the extent and nature of deception and why the research could not be conducted without it. This description must be sufficient to justify a waiver of informed consent.
6. **Feedback/Debriefing:** Describe the feedback that will be given to subjects about the research after they have completed their participation. How will the feedback be provided and by whom? If feedback will not be given, please explain why feedback is not planned. If deception is employed, debriefing is mandatory. Describe in detail the nature of the post-deception feedback, and when and how it will be given.
7. **Risks and Benefits:** Is there any risk to the subjects, or to a third party? If yes, provide a description of the risks and the counterbalancing benefits of the proposed study. Indicate the precautions taken by the researcher under these circumstances.
8. **Anonymity and Confidentiality:** Describe the procedures for preserving anonymity and confidentiality. If confidentiality is not an issue in this research, please explain why. Will confidential records be consulted? If yes, indicate what precautions will be taken to ensure subjects' confidentiality. How will the data be stored to ensure confidentiality? When will the data be destroyed?
9. **Compensation:** Will subjects be compensated for their participation? Compensation may reasonably provide subjects with assistance to defray the costs associated with study participation.

Ethics Protocol Submission Form

1. Summary of Project

Purpose:

In the study titled, *Personal Perspectives: Experiences of Persons with Disabled Siblings*, I intend to examine the experiences of siblings of persons with a disability and their view of those experiences. My goal will be to collect and interpret data that will help to reveal the personal perspectives of my informants concerning their disabled sibling.

Methodology:

Qualitative research methods will be used in order to attain a perspective of the person's view of his or her sibling with a disability. Specifically, in depth interviewing, with the use of open-ended questions, will be the source of data collection. Three sets of interviews will be scheduled with each of the five participants. Each interview will be one hour in length. The purpose of the first set of interviews will be to gain information about the participant. In the second set of interviews, questions will be geared to explore the influence on the participant of his or her disabled sibling. The third set of interviews will serve to check information attained in the first two sets and elaborate on themes that have been established.

Data analysis will take place in three phases. The initial phase will consist of identifying themes. Data will be group, coded and sorted. The identification of themes may be an ongoing process as more data is brought into the study. The second phase involves encoding the data. In the third phase, the researcher will attempt to bring meaning to the situation specific datum.

All interviewees will be protected by the use of pseudonyms. At the end of the study the results will be made public and shared with the participants.

2. Research Instruments:

Interview Guide

Interview One

1. Tell me about yourself.
2. Who is in your immediate family?
3. Where do you live? Go to school?
4. Are your siblings at school with you?
5. What does your mother/father/guardian do for a living?

Interview Two

1. In what way has your sibling influenced you?
2. Can you describe some of your experiences with your sibling?
3. Tell me about some of your feelings towards your sibling.
4. How do you feel about those feelings?
5. How do you feel about the way you act toward your sibling?
6. Do you have any feelings/thoughts about your social life?
7. How has your sibling been a part of your social life?
8. What would you describe as a negative experience or feeling involving your sibling?
9. What would you describe as a positive experience or feeling involving your sibling?
10. How has your sibling affected your view of life? Your philosophical or religious framework?

Interview Three

I would just like check some of the things we discussed.

1. It seems that when you told me... and..., there are some similarities in the way you felt at that time. Do you agree? Can you explain?
2. Your statements about ... seem to contradict each other. How do you feel about the situation now that we have had these discussions?
3. What do you think about the process of interviewing? Is there anything that you have learned? What have you learned?
4. Has your participation been worthwhile in your opinion? What are the important components of this process for you?
5. Is there anything you would like to add?

3. Study Subjects:

The study will involve five participants eighteen years of age or older with a sibling with a disability. Their disabled sibling will have one or all of the following difficulties: non-ambulatory, non-verbal and/or cognitive delays. Ideally, disabilities will be labeled as an Autism Spectrum Disorder. Siblings with severely disabled persons with Cerebral Palsy as their brother or sister will also be considered as candidates.

Other than the above-mentioned disorders of their disabled sibling, there will be no special characteristics required of the subjects that would make them vulnerable or requiring extra measures.

4. Informed Consent:

Consent in writing will be obtained (copy of consent form included).

The nature of the study, and their part in it, will be explained to the informant prior to inviting them to participate. The researcher will discuss any questions and concerns with the participant before the study begins. No confidential records will be required.

5. Deception:

All aspects of the study will be discussed thoroughly since no information needs to be withheld from the participant

6. Feedback/Debriefing:

All participants will be given a copy of the completed study, if so desired.

7. Risks and Benefits:

No risk to the participants is anticipated.

8. Anonymity and Confidentiality:

Pseudonyms will be used for all participants, their siblings and families.

Places and other persons involved, such as agencies and personnel, respectively, will not be identified by their names so as to preserve confidentiality. No confidential records will be consulted. Data will be retained and stored by the researcher and shredded at the end of the study. All audiotapes will be erased at the completion of the study.

9. Compensation:

No compensation will be offered for participation in the study.

Consent Form

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

The purpose of my study titled, *Personal Perspectives: Experiences of Persons with Disabled Siblings*, is to collect information about the perspectives of persons with a disabled sibling. This will be done through a series of three one-hour interviews with participants. The three sets of interviews will be completed within a two-month period and will be done at mutually agreed upon times and in mutually agreed upon locations. There will be a total of five participants. Participants will be chosen according to their age (18 years of age or older) and for being a sibling of a person with either Autism Spectrum Disorder or Cerebral Palsy. Participants will be asked questions about their experiences as a brother or sister of a person with a disability. The interviews will be taped so that the researcher can transcribe and interpret the information. The study will be submitted by the researcher in partial fulfillment of a Master's Degree in Education from the University of Manitoba.

Information will be used only for research purposes. Copies of the completed study will be given to each participant upon request. A request form is provided here for that purpose. To maintain confidentiality there will be nothing presented in the data that will reveal the identity of the participant. Pseudonyms will be used for the participant, all family members, friends and associates referred to in the data. All possible identifiers, such as agencies, schools, institutions, etc. will be omitted or disguised in the completed study so that identification of participants will be impossible. Gender and age of participants, family members and associates will be altered, if required, to protect the privacy of the participant.

Participation in this study is totally voluntary. If you do decide to participate, please be aware that you can terminate that participation at any time without prejudice.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institution from their legal and professional responsibilities. You are free to withdraw from the study at any time, and/or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as you initial consent, so you should feel free to ask for clarification of new information throughout you participation.

Principal Researcher: Koreen Scott
Thesis advisor: Dr. Zana Lutfiyya,
Mailing Address: Dr. Zana Lutfiyya
Faculty of Education, University of Manitoba
71 Curry Place
Winnipeg, Manitoba R3T 2N2

This research has been approved by the Office of Research Services,
Education/Nursing Research Ethics Board at the University of Manitoba. If you have any
concerns or complaints about this project you may contact any of the above-named
persons or the Human Ethics Secretariat A copy of this consent form
has been given to you to keep for your records and reference.

Participant's Signature

Date

Researcher and/or Delegate's Signature

Date

Request for a Copy of the Completed Study

I, _____, participant in the above-mentioned study, hereby, request a copy of the completed study.

Please call _____ for pick up, or mail to _____.

Thank you.

Participant's signature

Date

March 27, 2003

Hello,

Please read the enclosed participant information and consent letter. This will give you more information about my study.

As a sibling of a sister with a severe disability, this study is important to me personally. I am sure that you as a sibling will feel the same.

If you are interesting in participating as one of my informants, please contact me :

I live in Clayton Park in Halifax and would be pleased to meet with you whenever and wherever is convenient for you.

Your consideration is appreciated. If you require any further information or, as previously stated, are interested in becoming a participant, please contact me at either number above at your earliest possible convenience.

Sincerely,

Koreen Scott