

A DESCRIPTIVE STUDY OF THE EXPERIENCES OF GROWING UP WITH A
SIBLING WHO HAS AUTISM

by

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Abstract

This study explores the range of experiences of growing up in a family where one of the children has autism. The experiences of the non-handicapped siblings, their emotional responses, and their coping methods were studied. This was an exploratory investigation in light of the rarity of research; an attempt to try to describe something of the significance of the experiences of siblings. A case study approach is employed using as primary participants three teen aged children with siblings who have autism. In depth interviews focus upon the primary participants to explore the dynamics and their subjective interpretations of the experience of growing up with their autistic brother or sister. The volunteer participants had lived with their handicapped sibling for at least five years and had experienced no recent life traumas such as recent family deaths or parental separation.

Each of the experiences described in this study is unique, describing the experiences of the primary participants from their own perspective. From these experiences, common issues emerged including various forms of responsibility, restrictions, privacy, and acceptance. These issues are examined identifying some common themes as well as variations on the themes.

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Chapter I. Introduction

General Topic

Autism is a pervasive developmental disorder characterized by qualitative impairments in social interaction and communication, and a markedly restricted repertoire of activities and interests (Diagnostic and Statistical Manual of Mental Disorders, 1987). Many autistic behaviors are bizarre and tend to impact negatively on family members. Individuals with autism may demonstrate apparent lack of awareness of people around them or may object to physical contact. They may have unusual body movements such as head banging, etc. Some also demonstrate a fascination with specific items, such as spinning objects, to the exclusion of other activities. They may demonstrate a resistance to any change and a rigid adherence to routine. Many children with autism develop no speech or, if speech is present, it may be unusual.

Like all children, children with autism are members of a family system that interacts to influence and shape the development of each family member. All family members possess areas of need and areas of strength. An ever changing web is woven as family members interact, change, and adjust to their internal and external world. Individual needs and resources are constantly in flux yet these provide the thread with which the fabric of life is woven. The

presence of an autistic brother or sister adds a certain structure to the family unit. What are the experiences like of the family members, specifically the siblings? How does the family interact? What are the individual coping styles and strategies that they have developed? In this study the experience of growing up with an autistic brother or sister will be described.

Growing up can be a challenging process. It is a time filled with opportunity and change. There are times of exhilaration and pleasure as well as times of pain and sorrow. Being a brother or sister adds unique dimensions which both intensify, and broaden this experience. Sibling relationships outlast most other relationships in time (Powell & Ogle, 1985). We know our siblings longer than we know most others in our lives. The sibling relationship is complex, and dynamic. Issues of independence, rivalry, sharing, identity and intimacy are but a few of the hurdles encountered amongst brothers and sisters. It seems logical then that sibling relationships would play a highly influential role in development (Lobato, 1990). Further to this, it follows that the presence of a severely disabled brother or sister would play a significant role in shaping the day to day experience of siblings.

The research dealing with effects of chronic illness or disability on families and siblings is as varied as the

people studied and the findings are conflicting (Seligman, 1983a; Featherstone, 1982; Knafl & Deatrick, 1987; Senapati & Hayes, 1988; Dyson, 1988). Each handicap or disability has different features of its own and within each handicap there are individual variations. Autism is no less diverse than other disabilities. Individuals with autism range from socially competent to socially incompetent, and from being severely retarded to intellectually adept (DeMyer, 1979; Gerdtz & Bregman, 1990). Add to this a variety of external factors such as age, family size, gender, socioeconomic status, religious affiliation, and cultural background and the richness of variation becomes broad indeed.

Being the sibling of a disabled brother or sister alters the daily lives and experiences of children. Often younger siblings must adapt to becoming superordinate in their relationships with a severely handicapped sibling and to bettering him in all areas of development (Rodger, 1985). Non-disabled siblings may have to adjust to increased responsibilities and decreased attention from parents (Seligman, 1983a; Seligman & Darling, 1989). Parental expectations may be very high for the non-affected child putting him or her under pressure to perform in order to somehow compensate for the affected child (Farber, 1975).

Previous Investigations

Referring to the body of literature on effects of chronic illness or disability on families and siblings Knafl and Deatrick (1987) state, "it presents an overwhelming and confusing body of information characterized by competing hypotheses, conflicting findings, and tentative conclusions" (p. 300). Views range from a handicapped person having positive effects on the family system (Cleveland & Miller, 1977; Grossman, 1972; Beavers, Hampson, Hulgus & Beavers, 1986), to having negative effects (Cirillo & Sorrentino, 1986; Breslau, 1982). Rodger (1985) believes that the presence of a handicapped child is a chronic situation which family members may perceive as interfering with successful attainment of goals in family life. Siblings of disabled brothers and sisters experience special concerns regarding themselves, their families, their role in the community and the future (Powell & Ogle, 1985). Seligman (1983b) states that a handicapped child in the family may offer normal siblings "unusual opportunities for growth", or "may lead to adjustment problems" (p. 529). Brothers and sisters learn from each other. The lessons are each in their own way unique. However the lessons learned amongst and between brothers and sisters of handicapped families may be especially unique.

In addition to both positive and negative consequences of living with a disabled sibling, researchers also report

mediating factors such as age, severity of handicap, age difference between siblings, same sex versus opposite sex, family attitude towards the child, and birth order (Grossman, 1972; Farber, 1960; Lobato, 1983; Breslau, Weitzman & Messenger, 1981). These issues will be discussed further in the literature review section in chapter two.

These studies provide a significant amount of information relevant to this topic. However, in many cases it is non-definitive and sometimes contradictory. Relationships and interrelationships are difficult processes to define, describe and understand. However, trends and tendencies can provide helpful clues for understanding, supporting, and recognizing the varied experiences of these important family members.

Research on families with an autistic member, in general, and on siblings of the autistic member, specifically, is more difficult to find. Many aspects of autism are being studied today from a medical and educational point of view in order to help the victims themselves as well as to provide tools to those who live with and care for them. The behavioral and attitudinal difficulties of people with autism represent major hurdles in placing them in job settings and in integrated classrooms. Many of the behaviors, such as head banging, being unresponsive to verbal exchanges, and engaging in

bizarre ritualistic behaviors such as hand flapping, are destructive and disruptive. These and other behaviors are difficult for outsiders to learn to tolerate. How do siblings learn to deal with, understand, and cope with the uniqueness of their autistic brother or sister? Some preliminary research cited in several studies (Seligman & Darling, 1989; Cantwell & Baker, 1984) suggests that the nondisabled brothers and sisters suffer greatly and need support. Autism is a significant and chronic handicap and thereby exerts much stress on each member of the family system (Cantwell & Baker, 1984).

Research Question

This study examines and describes the breadth of experiences of growing up in a family where a brother or sister has autism. The experiences of the siblings, their emotional responses, and their coping methods were studied. This was an exploratory investigation in light of the rarity of research; an attempt to try to describe something of the significance of the experiences of siblings.

Rationale

The rationale for this study is that the information gained will hopefully contribute to the body of knowledge regarding the experiences of the siblings of an autistic child. Thus far, research dealing with siblings of the disabled has been rare and contradictory (Seligman, 1983a;

Featherstone, 1982; Knafl & Deatrick, 1987). The research on siblings of the autistic is even more difficult to find (Cantwell & Baker, 1984). This study will contribute to the body of knowledge to assist in closing these gaps in knowledge.

This study should contribute to a broader understanding of what it is like to be a sibling of a child who is autistic. Some preliminary research suggests that these non-disabled brothers and sisters suffer greatly and need support (Gold, 1990; Seligman, 1987). Other investigators have found that the majority of siblings of the autistic appeared to be well adjusted (Cantwell & Baker, 1984). This difference of findings indicates a need for further study to broaden and deepen our understanding.

This study should assist in broadening the understanding of the experiences of the siblings of the autistic child so that counselors, therapists and researchers can be more effective in the help and therapeutic interventions they offer. Unfortunately siblings have been largely overlooked in most family health care research in favor of the mother-child dyad, (McKeever, 1983). This resultant lack of knowledge relevant to siblings becomes especially problematic when health professionals attempt to deliver family centered care to those affected by the presence of a disability. Ultimately,

with better understanding of these experiences, we can anticipate benefits to the autistic individual that accrue from improvement in functioning in various family subsystems.

Approach

The approach to this study was through field work research methodology, specifically the case study in order to gain an understanding of the day-to-day occurrences and the resultant meaning siblings have placed upon their experiences. How siblings have perceived their experience is the area of interest.

This research is exploratory and descriptive. Its aim is to capture the essence and complexity of the real-life experiences of these siblings while learning to understand them in their own context. Thus a case study approach is appropriate as this methodology and best captures the living elements of relationships and psychological processes (Yin, 1989).

The primary source of information for this study was obtained through in-depth interviews focused upon the non-handicapped sibling conducted in three cases, in order to capture, understand, and describe the essence and impact of life with an autistic sibling. By engaging in in-depth interviews with the siblings, the dynamics and fiber of the experience of living with a significantly handicapped

sibling were explored. Similarities and differences of experiences were drawn from the portraits of these family members.

Participants were selected in an opportunistic manner with a view to obtaining as rich a complement of information for the study as possible. The descriptions of their experiences are illustrations of what the experiences may be of others in similar situations. Participants were chosen to be between the ages of 13 and 17. This is a critical period developmentally during which time the adolescent is leaving the realm of childhood when adults speak for them, to a time when they are having to learn to speak for themselves. To accomplish this task they must crystalize some sense of who they are, providing an opportunity to explore their experiences through this new level of perception (Muuss, 1982).

Chapter II. Literature Review

Autism

Autism is both a behavioral syndrome and a developmental disability. As a behavioral syndrome people with autism frequently display certain clusters of behaviors that distinguish them from those who are not autistic. According to Gerdtz and Bregman (1990), there are four broad categories of behavior consistent with the diagnosis of autism (p. 15-18). These are:

1. difficulties with social relationships;
2. severe deficits in language;
3. severe deficits in communication; and
4. other associated features such as:
 - a. strong resistance to change in the environment;
 - b. insistence on a routine;
 - c. odd movements;
 - d. behavior problems;
 - e. Attachment to inanimate objects;
 - f. very unusual responses to common stimuli in the environment;
 - g. lack of imaginative play; and
 - h. the presence of splinter skills;

As a developmental disability the person is likely to be disabled for life. Diagnosis of autism requires the behaviors to be prolonged, severe, and include elements from all four of the main categories listed above (Gerdtz &

Bregman, 1990). Autism is difficult to diagnose and this fact contributes much to conflict and anxiety for family members (DeMyer, 1979). Originally, autism was considered to be caused by abnormalities in the parent-child interaction, and it was believed that autistic children were potentially of normal intelligence. This laid a terrible burden of guilt and responsibility on parents. It is now widely accepted that over 70 per cent of these children are retarded and indeed severely so. It is widely accepted today that many of the observed abnormalities in the parent-child interaction are the result of the immense difficulty in attempting to relate to an autistic child (Reid, 1985). Delays in diagnosis along with differing opinions offered by professionals also contribute to family stress making it difficult to plan appropriately for the child or to begin dealing with the adjustment process.

People with autism vary tremendously in personality, intellectual capacities, social skills and ability to cope with the everyday demands of society (DeMyer, 1979). Paul (cited in Gerdtz & Bregman, 1990) suggests that a common thread, even with the high functioning individual with autism, is difficulty with social relationships and the use of language.

Autism was first identified by Kanner in 1943 (Gerdtz & Bregman, 1990). Autism is a rare condition with estimates

of prevalence ranging widely, due in part to difficulty in diagnosis (DeMyer, 1979). Reid (1985) reports that incidence rates vary from two in ten thousand to five in ten thousand with males being affected more frequently than females, (a four to one ratio). According to Oppenheim (1974), approximately half of autistic people do not learn to speak. Autism is a devastating disability which lasts for life.

Over the past twenty years there have been encouraging advances in knowledge regarding education, and services for those coping with autism (Reid, 1985). Though causes, and possible cures are being heavily researched, there exist very few reliable answers. Gerdtz and Bregman declare, "Yet so much is still unknown, so much of what we think we know about autism is probably wrong, and there are still tremendous gaps in the services many people with autism and their families need." (p. 14)

Because so many aspects of the individual with autism are so profoundly affected and because the management of the behavior of the individual can be so taxing, the potential for negative effects on the parents and siblings of the individual would reasonably appear to be great. However, until recently, the little research that has been carried out with this population fails to reveal any consistent differences between siblings of children with autism and

siblings of children without autism (DeMyer, 1979; Lobato, 1990).

There is little information dealing with the effects of autism on the family. Gold (1990) states that the few studies that exist focus on the parents and look at constructs such as depression. Within this realm these parent studies have looked mainly at the mother and then have generalized their results to "parents".

One study carried out by Gold demonstrates differences between siblings of autistic boys as opposed to siblings of normal boys. She found that siblings of autistic boys are at higher risk for depression than are others especially those over the age of 12. Gold also showed that parents of autistic boys scored higher on measures of depression and social adjustment problems than did other parents. She found also that they have more difficulty in their spousal, financial, and social roles. In autistic families the marital relationship seems strained by the unusual caregiving demands associated with the autistic boy. Insufficient emotional support from spouses emerged as a central concern. Finally, having a young boy recently diagnosed with autism was more stressful than having an autistic boy who is older.

In her study, Ferrari (cited in Lobato, 1990) compared 48 brothers of children with autism, diabetes, and normal

healthy development. The siblings were from 8 to 12 years of age and were matched for demographics such as marital status of parents, birth order, socioeconomic status, and family size. Responses to self concept questions, were answered by the children, and questionnaires dealing with social competence and behavior problems were completed by parents. Teachers rated them in terms of self-assurance and confidence. No significant differences were found between the brothers and sisters of handicapped and non-handicapped children in the ratings of either the teachers or parents. Similarly there were no significant differences found on the child measure of self-concept. Interestingly the subgroup who showed significant behavior difficulties were the siblings of children with diabetes. The authors judged this differences to be due to more recent diagnosis of diabetes than of the developmental disorders.

DeMyer (1979) studied and reported on three groups of children; those with autism, those who were normal, and those with various types of learning and intellectual disabilities. Some of her findings are as follows. First, there were only a few detectable differences between the effects of stress on families with autistic members and families without such a member. There was no difference in the rate of serious pathological disorders between the two groups of family members. DeMyer did find the incidence of

reactive depression among mothers of autistic children to be twice as high as mothers of normal children. However she is careful to mention that most of the mothers were not incapacitated. She points out that the stress of raising an autistic child can weaken the marital bond while at other times it can strengthen it. She detected no difference in the probability of emotional disturbance occurring in siblings of autistic children as opposed to matched normal index children.

Wolf, Noh, Fisman, and Speechley (1989), studied parenting stress, dysphoria, and social support separately for mothers and fathers of autistic, down syndrome and developmentally average children. Mothers and fathers of autistic children were found to experience significantly more stress. Mothers were found to have more depressive symptoms than mothers of average children though fathers were not found to show any differences. The stress buffering effect of social support was confirmed and viewed as positive for all samples. Social networks of handicapped families are small (Kazak & Marvin, 1984) and offer fewer opportunities for social support. Wolf et. al. (1989) conclude that social support should be encouraged for both mothers and fathers through extended family, counselling, and support groups.

Although any significant handicap creates tension in the family, autism is perhaps more fraught with ongoing uncertainty due to our lack of understanding of its causes, and our confusion as to its treatment. Autism offers the family a myriad of concerns over a long period of time resulting in part from the unpredictability of behavior and the social implications experienced by families. Bristol (1984), states the following as constituting high risk factors for families with an autistic child: ambiguity of diagnosis; severity and duration of illness; and lack of congruity with community norms. Further to this, Cantwell and Baker (1984) cite research indicating that families are negatively affected by the multiple failures of their autistic children. They note that: mothers appear to be the most severely affected; that spousal relationships are weakened; and that siblings are affected and family difficulties do not diminish as the child becomes older. The degree of unfamiliarity of the situation tax the resources of the family and potentially leave them with less energy to deal with the many other challenges of an ever changing family situation.

Autism is relatively rare and is therefore less well known than many other forms of handicap such as blindness, deafness, cerebral palsy and so on. Only recently has autism become somewhat understood. Social awareness and

research is beginning to give some prominence to this once unknown subject. It still remains, however, that information members of the community may have is often culled from sensational magazine articles, emotional television dramatizations (Kaufman, 1976), or unpopular theories (Bettelheim, 1979). Thus the family, and therefore the siblings may feel isolated at school and set apart from their peers due to popular misconceptions. Parents themselves must gain some familiarity with the idiosyncrasies and dynamics of autism and how it is expressed in their child. Research in all areas of autism needs to be more forthcoming in order for progress to be made and understanding achieved.

Family

The family offers one of the most powerful influences in our lives affecting our past, current and future development. "The family shapes the fiber of people's beings in a way no other social force can begin to realize" (Framo, 1981, p. 205). The advent of a child with autism in the family strikes hard and is a catastrophic life event which may predispose them to increased vulnerability.

Given that symptomatic behavior tends to surface at crisis points in the family life cycle (Hoffman, 1981), it stands to reason that the realization of a child being developmentally delayed, specifically autistic, would bring

intense levels of stress to all members of the family system. Stress in this case is defined as an actual or perceived "mismatch between environment and person" (Menaghan, 1983). Powers, Gaudet, and Powers (1986) state that family stress falls into two main categories, "normative and non-normative events". Normative events includes the predictable life events that most families experience while non-normative events includes occurrences which are unanticipated, situational, and which place the family "in a state of instability and require some creative effort to cope with the situation" (p. 520).

As autism cannot be diagnosed at birth, the child is born and celebrated by the family as being perfect. It is not until months and sometimes years pass that the family begin to acknowledge there is something wrong with their child. The period during which diagnosis is sought and finally decided upon is usually lengthy and agonizing. This is a time of prolonged stress enveloping the entire family in a cloud of doubt, fear, and uncertainty.

Hill (cited in Menaghan, 1983) defines crisis as "a product of event characteristics, family resources and family appraisals" (p. 114). Not only are there major organizational tasks to perform in light of new information, there are new and unexpected role adjustments that have to

be made. There is the added stress due to the disintegration of dreams, hopes, and expectations.

Due to the differing amount of responsibilities that a disability incurs, the family will have to change their lifestyle patterns to a greater or lesser degree (Rolland, 1988). Parenthood reduces freedom, flexibility and independence. The addition of a child with autism is bound to intensify these losses (Featherstone, 1982). Patterson (1988) suggests that the nature of the family rather than the nature of the disorder appears to be associated with the ability to cope. Thus the degree to which the child is an intrusion, and how this intrusion is perceived varies with the severity and complexity of disability, the individual and group resources of the family, and the social environment into which the family belongs, its biases and support systems.

Family members do not operate autonomously as though in a vacuum. Members are influenced and changed by other members and the circumstances in which they exist. A basic premise of this study is that when a family has a member with very special needs, all family members will be affected (Kazak, 1989; Powell & Ogle, 1985). There is no fool-proof plan which a family should follow. Each family is unique. Each autistic child is unique and therefore the life experiences of the family in relation to their autistic

member will be different. This is an unveiling of the stories, the experiences, and problems, which siblings in families with autistic members have undergone.

DeMyer (1979) writes of her findings that parents are far from being aloof and disinterested in the development of their autistic child and are deeply affected by the repeated failure of their child to master developmental tasks. In the many interviews held by DeMyer, she reports finding scattered comments about feelings of guilt, anger, sadness and nervousness. She noticed "a general diminution of joy" (p. 150) in these families. The effects on mothers was found to be more direct than on fathers. The chief job of most mothers was mothering. The Persistent failures of their autistic child weighed heavily on their self esteem especially as they by in large had few outlets outside the home. She is careful however to note that fathers were also touched deeply by their autistic child.

The literature dealing with the effects of childhood disability on the family has focused primarily upon the presence of a chronically ill child (Knafl & Deatrck, 1987), or the presence of a disabled child, (Kazak & Wilcox, 1984). This literature has provided conflicting and confusing results (Knafl & Deatrck, 1987; Powell & Ogle, 1985).

Raising a disabled child can be both a positive experience as well as a painful experience. Most authors deal with the emotional pain of parents as they struggle with their role (Bristol & Schopler, 1983; DeMyer, 1979; Featherstone, 1982; Gath, 1978). Various authors (Gath, 1985; Grossman, 1972; Powell & Ogle, 1985; Seligman & Darling, 1989) discuss a variety of effects on the family of raising a disabled child. Seligman and Darling refer to "chronic sorrow" as being a normal reaction to having a handicapped child in the family. Central to this experience is a grieving process (Gath, 1985) or the Kubler-Ross (1970) stages of grief. Feelings of sadness, disappointment, hopelessness, anger, anxiety and guilt result due to a metaphorical loss of the child rather than a literal loss (Jackson, cited in Gold, 1990; Moses, 1982).

These feelings may be projected onto others such as anger directed toward the spouse, professionals, self, or life. Feelings of guilt may arise out of fantasies of escape or because of real or imagined contributions to the cause of the disability of the child. Guilt also may result from having to place the child in a group home (DeMyer, 1979). It is suggested these stages may be passed through either rapidly or slowly. They may be cyclical recurring when the condition of the child worsens or when a normal milestone within the family life cycle is not reached such

as entering school, or obtaining a job. The Kubler-Ross stages of shock, denial, bargaining, anger, depression, and acceptance are amplified in the writings of parents and siblings of children with significant handicaps, including autism (Featherstone, 1982; Kaufman, 1976; Moses, 1982; Hart, 1989)

The classic monograph by Farber (cited in Kazak, 1986) describes family reactions to the birth of a severely mentally retarded child. Farber terms the birth of a handicapped child a point of "arrested family development" with sequelae that continue to affect the entire family system. Waisbren (cited in Kazak, 1986) finds parents of handicapped children as having more feelings of uncertainty, helplessness, anger, and rejection than parents of non-handicapped children.

For many families with a handicapped child there is a relentless burden of care which lasts for most hours of the day, seven days a week, for many years (Sullivan, 1979). Along with possible financial strains the family can run the risk of being physically and psychologically drained (Seligman & Darling 1989).

Kazak and Wilcox (1984) found social networks in families with handicapped children to be significantly different from those of comparison group families. They studied 56 families with children having Spina Bifida and

matched them with 53 families with normal children. Their results show social networks to be smaller for parents of handicapped children than for parents of non-handicapped children. Extended family network size was found to be similar for the two groups. Given the degree to which these families may need to devote themselves to the care of the handicapped child this adaptation may be understandable. Kazak and Wilcox further noted that members of the social support networks for the Spina Bifida parents were more likely to know and interact with one another than was the case for the comparison families. This higher network density may foster a sense of closeness and cohesiveness. On the other hand Kazak and Wilcox suggest that the higher density could indicate an enmeshed network thus inhibiting opportunities for new and open discussion of possible solutions.

One further finding was that mothers of handicapped children do not have the same reciprocal relationships as do mothers of non-handicapped children (Kazak & Wilcox, 1984). These mothers are not as free to call upon or to be called upon by others as their counterparts. These tendencies can lead to feelings of isolation (DeMyer, 1979; Featherstone, 1982; Sullivan 1979).

There is a stigma attached to those who are perceived as different according to Margolis and Rungta (1986).

Whenever a group is singled out for special attention, they typically are experiencing some kind of discrimination in society. Margolis and Rungta claim this population always has issues of "identity (self-concept), self-esteem, a need for validation of personal experience, and a need for empowerment" (p. 643). She develops this further by stating that members of special populations suffer from lack of personal identity because they are so often responded to because of their group membership rather than because of their personal being (Servoss, 1983). Handicapped children and their families certainly fall into this special group category.

Seligman and Darling (1989) state that "to the extent that individuals deviate from the societal norm of physical and mental perfection, they are likely to be shunned, ridiculed, avoided, and or ostracized" (p. 89). Seemingly, associations between the stigmatized and the normal never move beyond a superficial level and often those who do interact more closely with the families of the stigmatized are given a "courtesy stigma" (Goffman, cited in Seligman & Darling, 1989) resulting in their suffering reactions of rejection and avoidance. Such reactions would account for the feelings of isolation and loneliness noted by these family members (Seligman & Darling, 1989). Only in situations where there is extensive and intimate contact do

normal subjects see the physically disabled as fairly similar to the able bodied (Servoss, 1983).

According to Cirillo and Sorrentino (1986) the presence of a handicap provides powerful information around which a family is compelled to change. They point out three areas of family structure which may be affected by the birth of a handicapped child: the equality of the spousal system in decision making; the dependency of the offspring for a prolonged period of time; and the tendency toward nuclearity which excludes the extended family from daily matters. Somehow the role, expectations, and status of family members must be maintained.

The "psychosomatic family" profile described by Minuchin, Rosman, and Baker (1978) is well known by those working in the field of family therapy. They are characterized by being enmeshed (extreme involvement), over protective, rigid, having poor conflict resolution, and triangulation of the patient in family conflicts. These family patterns are thought to play a role in the exacerbation of certain diseases, for example diabetes and asthma. These family patterns are closely related to the internalization of psychological style in the individual.

Marital satisfaction is another topic which has been studied resulting in conflicting information. Fewell (1986) cites an earlier study by Fewell, Bellmonte, and Ahlersmeyer

wherein 80 mothers of children with Down syndrome indicate that their spouse was the most important of 19 possible support persons.

Fewell and Vadosy (1986) report similar findings of deaf-blind children who were surveyed. Gath (1978) studied 30 parents of children with Down syndrome and matched them with 30 parents of normal children. In the five year period marked differences in quality of marital relationship were noted between these two groups of parents. Nine of the families with Down syndrome children were found to have severe marital disharmony while none was found in the control group. On the other hand positive measures of marital harmony were higher in families of children with Down syndrome. It seems possible that reactions are more intensified if there is a child with special needs present in the family.

According to Seligman and Darling (1989) the conclusion that can be drawn from the literature is that marital dysfunction among families with a disabled child may have occurred even without the presence of a disabled child. It is felt that the coping styles of a family remain relatively consistent. Patterson (1988) cites Zucman as stating "the child's illness is not the 'provocateur' of family difficulty but the 'revealer' of it" (p. 69). If a family is coping poorly with a handicapped child then the family most

likely was having difficulty coping prior to the presence of the handicap. The critical incident of the presence of a medical disorder exacerbates unfinished business of a family over issues that were present previously but perhaps were not having to be dealt with in a day-to-day fashion. Conversely positive coping styles most likely are indicators of previous coping styles which were working and now are enhanced and developed further by the presence of a handicap.

Knafl and Deatrick (1987) present and compare two major approaches taken in the literature on how families respond to the chronic illness or disability of a family member. They assert that the studies are predicated on different underlying assumptions regarding the nature of the illness experience and the reaction to it by the family. These differing assumptions result in a confusing and overwhelming body of knowledge which is all but impossible to interpret. One body of knowledge is based on the assumption that having a disabled member is an inherently negative experience and disruption to the family is an inevitable consequence (Voysey, cited in Knafl & Deatrick, 1987).

The second body of knowledge focuses upon trying to understand the subjective definition of the situation by the family and how the family manages the illness or disability. Investigators who focus upon an objective meanings of the

illness or disability tend to conceptualize the response of the family as passive and efforts are made to measure outcome. Investigators who focus upon the subjective meaning of the situation by the family conceptualize the response of the family as active and design research to address the processes of adapting to a child with chronic illness or disability. Results from the first body of knowledge have alerted practitioners to those families at risk and to the kinds of services which might be of help. The second body of knowledge has aided in understanding how families actively define, manage, and cope, and has aided in shaping the more specific role and content of services.

It has been suggested that children from larger sized families are better adjusted than those from small families (Taylor, 1974). It is thought that the nonhandicapped children from two child families carry the burden of all the hopes and expectations of the parents. In larger families these expectations can be fulfilled by several children. McHale, Simeonsson, and Sloan (1984) agree that children from larger families are more well adjusted, provided that the families have adequate financial resources.

The socioeconomic status of the family can also affect the responses of the sibling to a handicap. Siblings from middle class families were found to have a range of positive and negative feelings that were predictable from the

attitudes of their parents (Grossman, 1972). Middle class families often have difficulty in realistically adjusting their high expectations of their handicapped child (McHale et al., 1984). However, middle class families tend to be more financial secure and better prepared to utilize outside services such as camps or respite care. Conversely families with a lower socioeconomic status often have limited funds. Thus siblings, especially females, who are from poorer families may be burdened with extra care-giving responses that cannot be given through outside channels.

Parental attitudes toward the handicapped child are often be a powerful influence on the adjustment of the sibling Grossman (1972). Results suggest that siblings are more well adjusted when their parents are more accepting of the condition of the child (McHale et al., 1984). Gallagher & Powell (1986) have suggested that religious beliefs most likely play a part in this attitude formation though recent research on this matter was not found.

Siblings

Relationships between sisters and brothers are among the most rich and enduring in our human experience (Lobato, 1990). According to Lobato, there is a belief that children develop best in the company of other children. Lobato further states that "one of the most powerful influences that siblings have on one another is their ability to affect

each other's relationships with other people. This applies not only to their parents, but to other adults and children outside of the family as well" (p. 6).

Siblings act as teachers and translators of the their culture. Siblings relate to one another on everything from dating protocol, peer relationships, fashion, to how to handle Mom and Dad. Lobato states that an "uninhibited intense expression of the full range of human emotion from love, affection, and loyalty to hatred, hostility, and resentment" are characteristically expressed amongst and between brothers and sisters (p. 13) .

There has emerged one empirical study dealing with the experience of family members with an autistic brother (Gold, 1990). Her findings were as follows:

1. Parents of boys with autism were found to be more depressed, though not clinically depressed than parents in other families.
2. Siblings of boys with autism tended to be more depressed than other siblings and those 12 years and older tended to show more signs of clinical depression.
3. Parents of boys with autism had more social adjustment difficulties than did other parents.

4. There were no differences between social adjustment of siblings of boys with autism and other siblings in general.

Other than this study, the experience of siblings of a child with autism has only been examined in two anecdotal articles (DeMyer, 1979; Sullivan, 1979). We know nothing about what takes place on a day to day basis in the lives of these siblings.

The research on siblings of handicapped children is inconclusive and sometimes contradictory, (McKeaver, 1983; Grossman, 1972; Lobato, 1990). The well known study by Grossman of college-age siblings of children with mental retardation found that almost one half of the young adults felt they had benefited overall from their family experience while an equal percentage felt they had been harmed. It should be emphasized that each group experienced a full range of emotions at one time or another but the overall tone of the experience was viewed differently. One can only assume that the determining factor is not the presence or absence of a handicapped child but rather a multitude of factors which include family demographics, personal and community resources which are available as well as the presence or absence of other stressful indicators. Lobato (1990) states unequivocally:

In general, review of the carefully controlled studies indicates that a child's disability or illness is not likely to have a negative effect on his or her sibling's self-concept, self-esteem, social competence or behavioral adjustment. There simply is no uniform or direct relationship between a child's illness or disability and his or her brothers' and sisters' psychological adjustment.

(p. 42)

Conversely, others (Breslau, 1982; Gath, 1972) have indicated that siblings may be influenced negatively by having a handicapped brother or sister. Cleveland and Miller (1977) point out that there is a real hazard for an only female sibling of a retarded child. She may feel the conflict between fulfilling the role of vicarious parental expectations while also experiencing parent surrogate responsibilities attached to her female role. This dynamic has a push-pull effect causing stress to the female sibling. Several authors (Cleveland & Miller; 1977, Gath 1974; McHale et al. 1984) have found that older sisters in particular were most prone to psychiatric disturbances, problems with peer relationships, and unpopularity. This is seen as relating to an increase in responsibility rested upon older sisters in helping out with high levels of family demands. This was most apparent in two-child families. Breslau also

supports the notion that older female siblings are at greater psychological risk than are younger sisters or boys in general. There appears to be an interaction effect of age and birth order with younger male siblings also at risk.

The type of disability does not seem to be a crucial factor in the adjustment of the brother or sister unless the family has a high income and the handicap of the sibling is ambiguous or undefined (McHale et Al. 1984). On the other hand severity of handicap does seem to adversely affect the adjustment of the siblings (Grossman, 1972, Kirk & Bateman, cited in Gallagher & Powell, 1986).

Siblings of the handicapped have more difficulties than their counterparts in families without handicapped members (Schilling, Schinke, & Kirkham, 1988) yet there is a scarcity of research in this area. Patterson (1988) draws our attention to several issues relating to siblings of the disabled and chronically ill. Reactions vary depending on the developmental stage of the child, gender, and how the parents are coping. Possible issues result from lack of time spent with the nonhandicapped child due to the fact that the parents are trying to fulfill the many needs of the handicapped child. Perhaps too there is an unspoken expectation that the nonhandicapped child will compensate for all that the handicapped child cannot achieve resulting in undue pressure regarding school performance, social

relationships and athletic activities. Siblings are often given extra responsibilities in caring for their handicapped brother or sister or extra responsibilities around the home.

Tritt and Esses (1988) report that their research has found siblings of chronically ill children to have more behavior problems than controls. Further, it is illuminating to note the wide degree of difference between siblings as exemplified by answers to the final question of their study. This question asked the brothers and sisters what advice they had to give to children who had just found out that their sibling had a chronic illness. Examples of responses were: "cautions about being prepared for feelings of exclusion; warnings that the ill child should not be allowed to take advantage of being sick; the need to be more responsible and considerate of parents and the ill child; and assurances that the first year following diagnosis was the hardest" (p. 271).

The experiences of siblings must be acknowledged, respected and honored in order for them to participate as fully contributing members of their family unit and thence as integrated members of a broader social network or community. Their feelings with regards to their handicapped brother or sister may well be strong and vary along a wide continuum. However strong feelings do not necessarily result in pathological adjustment. "Though particular

sibling groups tend toward one emotional tone or the other, experiences of both positive and negative feelings and behaviors are a guaranteed reality of all sibling relationships" (Lobato, 1990, P. 13).

Family members together create and define roles and behavior patterns for one another. There is a reciprocal influence which family members effect on one another. All family members need and deserve recognition and validation as individuals who are separate and connected to one another as human beings. Siblings of children with autism are no more or less special than other members of their families. They are equally caught in the interplay amongst family members struggling to fulfill and respond to the needs exhibited both from within and without the family system. Their stories have not yet been told in such a way that they may have an equal voice. In order to better serve the families of autistic children all members of the family system and the full range of their experiences, feelings and perceptions must be acknowledged and understood.

Qualitative Research

The phenomena studied in qualitative research are largely internal processes such as perceptions and feelings. The focus is on how events are perceived by the individual. The researcher is often in direct contact with those involved in the study (Borg & Gall, 1989). The purpose of

this research is first to understand and then communicate the understanding of what it is like to grow up with a sibling who has autism. Qualitative methods help us understand what others are experiencing and see the individual in a context rather than as an isolated variable (Fewell & Vadasy, 1986).

Case Study

"A case study is an empirical study that investigates a contemporary phenomenon within its real-life context; when the boundaries between phenomenon and context are not clearly evident; and in which multiple sources of evidence are used." (Yin, 1989, p. 23.)

It is hoped that the information and knowledge gained through this study will be helpful in assisting professionals and family members to support siblings of children with autism. It is further hoped that this research will add to the information in the literature dealing with autism and various aspects of living with autism

Yin (1989) outlines and addresses three criticisms generally levied at case study methodology. The first is that case studies can lack rigor and are prone to bias. These tendencies are not however applicable only to case studies. They are found in more quantitative and experimental forms of research. The second criticism is

that the case study offers little basis for generalization. Yin notes that the aim of the case study is theoretical propositions and not to populations. The third criticism is that case studies can lead to rather complex, tedious, reports. This later characteristic is dependent upon the abilities and talents of the researcher to glean out the essential patterns or findings.

Chapter III. Methodology

This chapter details the methodology and procedures employed in conducting this study. The first section details my personal perspectives and their significance to the research carried out. The next section outlines a general overview of the basic design of this study. Next is a section on procedures, specifically selection of participants, the interview process, the analysis process, and the presentation of the results. Finally the chapter ends with the issues of reliability and validity and how these pertain to this qualitative study.

Personal Perspective

A basic tenet for qualitative research, is that the researcher is the major research instrument (Spradley 1979). Oakley (cited in Mishler, 1986) believes that the concept of "researcher and the researched as objective instruments of data production be replaced by the recognition that personal involvement is more than dangerous bias -- it is the condition under which people come to know each other and to admit others into their lives." (pg. 31.) Therefore it is relevant to describe the personal context and perspective which I bring to this endeavor.

I was born without vision into a family where none had ever personally experienced any disabilities either through birth defect, illness, or accident. At an early age, through surgical intervention, I was given a limited amount

of vision which has remained relatively constant throughout my life by means of both medical and surgical support. I am the youngest of two daughters. Hindsight and maturity allow me to now realize the diversity and strength of the coping abilities of my family which I believe were of significant assistance in dealing with my handicap.

I attended a special school for children who were blind or deaf until grade eight at which time I was placed into a regular high school. That was before the concept of integration of special needs children into the regular school system, so many battles were fought and resources were found in unconventional ways, mostly through the strength and perseverance of my family. My specialness never really occurred to me at the time. I was oblivious to the extra time, support, and sacrifices required by every member of my family in order to enable me to participate on an equivalent basis with my peers. At the time, I was only aware of the extreme effort I was making in order to keep up.

I chose a career as a special education teacher working with children having learning and behavior disorders. An integral part of my role was to find ways to support these families who suffered from the significant stresses due to lack of resources, lack of positive successful experiences, lack of support and understanding from others. As I worked

with these families, a personal awareness of my own fortunate circumstances and the special support I received from my family emerged. Until this time I had been conscious only of the fact that the special needs child had to put in a concerted effort towards their own progress. Now I came to realize that this kind of effort was more possible if each member of the family was feeling personally successful and was sharing somewhat in supporting the same mutual goals.

More recently, I have worked as a consultant to families with special needs children. Once again I found myself very aware of the impact of the special needs of one member of the family upon each family member. These families dealt with the normal day-to-day realities and issues that all families face. However they often also had the added concern of handling unusual aspects the development of their special needs child; be it schooling, socialization, medical care, or family adaptation. Emotional and practical support was needed by each family member in order to help them achieve as normal an existence as possible. The healing and encouraging elements of joy, pride and humor were enjoyed only by the very strong and well supported.

On a more personal note, although my sister and I have always been close, we have also experienced times when we

have felt worlds apart. She has always been outgoing and a participant in many activities that were beyond my capabilities and therefore a part of my dreams and fantasies. There were times when it was her life I wanted to lead and not mine. She also experienced an assortment of feelings and reactions with respect to our relationship including; love, resentment, guilt, and an extreme sense of responsibility. Although these are emotions that most siblings would normally experience, the fact of my handicap most likely modified and perhaps even intensified these emotions. As an adult I came to realize that perhaps some of her needs with regards to myself had not been acknowledged or fulfilled.

I am fortunate that my sister and my family had the strength to develop positive coping skills and that we have maintained a warm open relationship. This connectedness provided the glue and energy to guide us in times of struggle and in times of intense anxiety when having to cope with our own special family issues.

Through many frank discussions and much personal groping, my sister and I have explored our experiences and our relationship has now matured to become more sharing while at the same time we differ in our individual ways. For us this differentiation has been a process with which we have struggled and benefited greatly. Today we enjoy a

sense of freedom and connection suited to our personal styles.

I have developed an understanding and appreciation for the splendid efforts my family and friends have contributed towards my living a fulfilling life. I bring to this study an awareness and knowledge that not all families who experience such significant challenges fare so well. I bring also to this study a desire to help bring to the brothers and sisters of children with difficulties awareness and appreciation of their roles, their specialness, their individual coping styles and their contributions. These special family members by in large have prolonged relationships with their siblings. Living with a handicapped brother or sister inevitably has an impact as does any other significant experience. This study focuses upon the experience of non-autistic brothers and sisters living with an autistic sibling. Their stories deserve to be heard, understood and shared with others in order that a balance and richness of their experiences can be grasped.

Design

The design of this study uses field research methodology, specifically, the in-depth interview to gather information that describes the range of experiences encountered by siblings of autistic children. The information gathered in this study was derived from

participants who had experienced living with an autistic sibling. These participants were selected in an opportunistic manner through initial identification by the Pacific Association for Autistic Citizens. The dialog or portrait gathered through these interviews was analyzed and evaluated using the principles of reflexivity, a continual process of feedback and evaluation, and triangulation by comparison between participants, the literature, and my prior experience with families of handicapped children. From this information, a series of general issues describing the range of experiences of the siblings of autistic children was presented.

Procedures

Selection of Participants

The primary participants in this study are subjects who have experienced living with autistic siblings and were selected in an opportunistic manner (Burgess, cited in Swain, 1990) through initial identification by the Pacific Association for Autistic Citizens. The criterion for selecting participants required that they be a minimum age of twelve years and have a minimum of five years direct experience in living in a family with an autistic sibling. It was also preferred that the families not have experienced a recent major family trauma such as divorce, death, or

separation. It was also desired that each family be an intact, two-parent family.

In addition to these primary participants, family members who may have special knowledge or be able to provide further insights into the experiences of the primary participants were included in the study. Information from these secondary participants was used to provide a context for the interviews conducted with the primary participants. They also served as a source of convergent information providing a validity check on the information gained from the primary participants. Obviously, the willingness of the families to participate was an important factor in the selection process.

In-Depth Interview

Field research is a complex, non-programmed, interactive process that involves the researcher and all participants in the study with the research problem. Lofland (cited in Mishler, 1986) describes the unstructured interview as a "flexible strategy of discovery ... Its object is to carry on a guided conversation and to elicit rich, detailed materials that can be used in qualitative analysis." (pg. 27) The in-depth interview, which forms the major tool of this research, is a dialog between the researcher and the participants wherein the researcher may formulate and test hypotheses throughout the process.

Mischler conceptualizes interviews as "jointly produced discourses" (p. 96). One of the principles of this research design is reflexivity, a continual process of analysis and review throughout the research project. The flexibility of this research approach is especially appropriate because this research question is concerned with the discovery of the range and nature of the experiences of the siblings of autistic children.

Acknowledging that the specific interview procedures, dialog, and analysis relative to individual participants evolve according to the principles of reflexivity as the research progresses, the interviews followed a broad general outline in order to maintain a commonalty between the interviews (Spradley, 1979). A preliminary interview was conducted involving the parents to provide an overall context and perspective to the family dynamics and the range of experiences of the siblings of the autistic child. The inclusion of the parents was also aimed at forming an overall feeling of trust between myself and each member of the family unit. The inclusion of the parents was also expected to provide convergent data for later analysis. The preliminary interview were immediately followed by an in-depth interview with the corresponding primary participant, the sibling.

An important first step to this interview was to establish rapport with the primary participant. This rapport was a necessary prerequisite in maximizing the quality of the research and allowing more creative dialog. Through the interview, the participants were invited to describe the experience of growing up with an autistic brother or sister. Together we examined the experience of family life of the sibling. The participants acted as my guides and teachers regarding their experiences. Broad areas of interest were social support, family communication, and access to information. This was a search for the meanings expressed about the experiences by siblings of a family member with autism.

As the objective of these interviews was to gather as much information about the experiences of the participant as possible, questions were largely open-ended, although some questions were directed to probe for clarification or to obtain completeness of information. Example questions included:

- Describe some early memories of when you first noticed that your brother/sister, was different.
- Describe a day in your life, so that I can see how your brother/sister influences the way that life goes on.

- Describe some of the behaviors of your brother/sister you have found difficult? What happens in your family when this occurs? How do you feel when this happens?
- What do you think you can not do because your brother/sister is autistic.
- Describe what you have learned by living with a brother/sister with autism.
- How would things be different if your brother/sister were not autistic?

The extent and duration of these in-depth interviews varied as to the specific circumstances of each of the participants, such as; the nature of the experiences, the level of rapport established between the researcher and the participant, and the ability of the participant to express the experiences. In general, a timetable of one hour with the parents and up to three hours of interview time with the primary participant was established. The three hours allocated for the interviews with the primary participants allowed for approximately two hours for a first interview and up to one hour for the follow-up interview.

Each interview was audio-taped. The audio tapes of the interviews were transcribed and the tapes erased to ensure confidentiality for the participants of this study.

Analysis

A portrait description based on each of the interviews was prepared. This portrait discusses the perceptions of living with an autistic brother or sister. According to the principles of reflexivity, these portraits were then validated with the participants in a follow-up interview with the objective of also further clarifying and enriching the portrait.

The portraits and the underlying interviews were analyzed and studied in detail in order to develop a list of common issues and topic areas. The experiences of the participants of this study are discussed in the context of this list of issues.

Results

From the list of common issues, themes, and general topic areas, a description was developed which reflects the best understanding of the information gained from this study. It is hoped that this description provides information and knowledge that will be helpful in assisting professionals and family members to support siblings of children with autism. It is further hoped that this research will add to the information in the literature dealing with autism and various aspects of living with autism.

Reliability and Validity Issues

The major issues or tests that confront any study of this nature are those of reliability and validity. Yin (1989) explains the specific case study tests that are appropriate for dealing with a qualitative study such as: construct validity, internal validity, external validity, and reliability. Yin further details a number of tactics to be employed throughout the conduct of the case study to deal with these tests.

Construct Validity

Construct validity deals with the soundness of the results of the study through the establishment of correct operational measures for the concepts being studied. Yin (1984) has identified three tactics to manage this issue.

The first tactic is the use of multiple sources of evidence in a manner encouraging convergent lines of inquiry. This was dealt with in this study through triangulation by comparison between subjects, the literature, parents of the siblings, and my prior experience with families of handicapped children.

The second tactic involves establishing a chain of evidence that clearly links the individual case portraits and the general discussion to the specific experiences of the participants. This was managed through careful cross referencing of the individual interview data.

Finally, the third tactic is reviewing the narratives with the participants to further validate the results. This formed an integral part of the procedures of this study.

Internal Validity

Internal validity is only relevant to studies that attempt to establish causal relationships or are explanatory in nature (Yin, 1989). Therefore, this test is not appropriate for this study since it is descriptive in nature and makes no attempt to explain or establish causal relationships.

External Validity

External validity deals with the generalizability of the study to a larger population. As this study examines the range of experiences of siblings living with autistic children, an analytic generalization was developed which describes the results of this study and provides a basis for comparison for other similar studies leading to a deeper understanding of the experiences. This study presents one account of a particular set of experiences. As Yin (1989) indicates, generalization is not automatic. Theories must be tested through replication of the findings in other similar studies.

Reliability

The objective of the reliability test is to establish that, if a later researcher followed exactly the same

procedure and conducted exactly the same study, the later study would produce the same results and conclusions as the current study. As the personal experience of the researcher and the individual nature of the participants are such an important part of the research process, and because the interview process is so unstructured, the likelihood of ever exactly replicating this study is very low. Here the approach to dealing with the reliability issue has to be, as Yin (1989) states, to conduct the study "as if someone were always looking over your shoulder" (pg 45). In the absence of a physical person looking over the shoulder, this requires the researcher to explicitly acknowledge their assumptions, biases, and perspective. Only by complete disclosure of thoughts and process and systematic recording of the progress of the study in all detail can we achieve a measure of study reliability.

Chapter IV. Case Portraits

Portrait of Asia.

Asia is the eldest daughter in a family with three children. She has a 10 year old adopted brother, Tyler, who has autism. Tyler arrived in the family at five days old. She also has a younger brother age seven named Blair. Asia and Blair are the natural children of their parents. Asia lives with her two parents, a cat and a dog.

Asia is attractive, healthy, and sociable. She enjoys the company of her friends who in turn seek out and enjoy her companionship. She freely brings her friends, both male and female, into her home where they are welcomed. A certain amount of privacy is provided along with warmth, friendliness, and cheer. Her mother is on a first name basis with her friends. Both her brothers are openly greeted by many of the friends. This home belongs to all five members and the needs of all five members are observed and negotiated. No one member, including her brother with autism, is allowed to rule supreme although this proves to be difficult at times. This management of individual time is a major stress factor to this family.

Asia belongs to a very creative family. Her father is a successful, active, versatile musician who both plays and teaches. Her mother is talented in the arts being an accomplished soloist as well as being involved in many crafts which require extreme care, perseverance and

creativity. She, like many other parents of children with autism, has been an active advocate for her son as well as an able volunteer for parent organizations working for the recognition and establishment of policies and rights for those with autism.

Asia likes "lots of things". She enjoys the arts, having fun participating in modeling, dance, theater, and most importantly her church group and choir. "That is one of the most important things I do. I'd die without that choir. It's my world." Her ambition is to be an actress. Her consistent love of the arts is demonstrated by the fact that art class at school is her most favorite subject while French is her most difficult and least liked.

Asia remembers little about the early days with her brother with autism. There are five years between them. She recalls only "that there was something different. I think he was able to speak when he was five months and like perfectly." She recalls thinking that her mother thought this was "pretty amazing, like, he's a genius". Her young perception was that her brother was "really smart" and that one day he would "get a really good job and be one of those people who can tell everybody all the answers. He can help me." She says this laughingly. This is and was a little girl fantasy which she has let go of but nonetheless was present and had to be changed.

She does not recall finding out about his autism as an event. Somehow he just was and that is what she is used to. She remembers little back then with the exception that "he had a problem". Asia believes her brother became autistic due to birth trauma. She thinks his head was squeezed too much during delivery and some of the brain cells were damaged as a result. She remembers how pinched his head looked when he was brand new. Her theory is a no blame theory and this sets the stage for much of how she thinks about and deals with her brother's handicap and its implications.

Her memories are blurred. She remembers before Tyler came and quite a long time after. However, the in-between memories are hard to reach. She does recall one incident which still brings up for her troubled feelings, "spooky". While visiting her grandmother one day her brother mysteriously fell off a bed when he was a very few months old. She remembers the blood, and her fear as her mother and a friend rush him off to hospital. "I was scared cause I saw all that blood and usually when you see blood you relate to dying." She is left with feelings that still haunt her, "whenever somebody mentions body parts or blood" she feels queasy. This is a powerful memory for Asia and still needs to be dealt with and resolved so she can move on.

Asia's recollections grow with age. She was aware that something was "wrong" but "it didn't affect me that much". Yet as she grows older, "things changed". Asia had been an adored only child until her brother arrived and she had to adjust to someone new in the family. However this someone new also had a problem, "so they kind of paid more attention to him than me." She recalls feeling very angry with everyone at this time. Her thoughts are mixed however as she goes on to say that it did not really affect her that much then because her parents still paid a lot of attention to her. Her memories revolve around feelings of unstated concern regarding her brother. "everybody was not talking about him not being right, but showing it or something."

Her brother is difficult to handle and she was recruited as a helper, (as a third adult) according to her parents. She remembers being treated like an adult and feeling very angry. She also recalls the time when her parents made the decision to no longer use her as a third adult. This turning point was met with relief.

"It affects me more now I think", says Asia. Asia has feelings that are diverse and some of them are painful. "My Mom's not here for all her meetings a lot of times. Just having to explain to everyone of my friends when they walk in what problem he has. Just ... sometimes I get embarrassed. it's because he runs around and he's

different and some people don't understand and it gets me embarrassed. But then I realize that he can't help it." Asia has ambivalent thoughts and feelings. She wavers between understanding acceptance and feelings of embarrassment and impatience and guilt.

Asia gives herself permission to feel sad and angry about her loss. In these moments Asia imagines having a brother she can talk to, a brother who would understand. She is developing her individuality and strives to share and explore her feelings and experiences with those close to her. These relationships teach her about herself and others. Her brother's lack of understanding is a barrier between them. His inability to relate is both painful and frustrating. This is clearly portrayed when she says; "It's also harder because he's older now and he knows a lot more stuff. He just, like, now he bothers me more, like, he'll run downstairs and he'll get into my things and just really bugs me. I don't think I've had one thing that he hasn't really touched and tried to break and it just really bothers me that he does that stuff and sometimes I just sit there and I'll think about what would be if he was normal? How different it would be, like to have a normal brother. I could talk to him about a lot of things if he was He's 10 right, and usually 10 year olds understand a lot of things and I mean I have to talk to my 7 year old

brother and he doesn't understand really. But he would, he would if he was normal and that's hard." She comments, "lots of people say it'd be cool to live with a brother like that and it's not. You know once you've lived with them and then you want to switch back because you just want somebody who, that, you know, will understand."

In terms of her everyday life Asia feels trapped and stifled. She says they really can not go away on vacations or trips. "It's really hard because we can't go anywhere really in the summer without somebody having to arrange everything; without somebody having to take care of him and a lot of times there's nobody there." Therefore the family simply stays at home. Respite was available for one week this past summer which they used.

Asia, however, celebrated the good fortune of being invited to go away with a friend to California for three weeks last summer. Her lucky break is remembered fondly and with excitement and appreciation. She returns to the theme of frustration saying that the lack of freedom also applies to weekends. "It's really hard and we just don't get to go away or anything Our weekends are always screwed up and I always have to baby-sit and that means that my time always gets screwed up and I don't get to do a lot of things cause my parents need a break too. I just want to leave I just want to go and be with my friends"

Asia wavers between two polarities. She is aware of the need for time out for her parents and is willing to help provide them with some relief. She has a good sense of how to deal with Tyler and feels confident in herself and her abilities. She longs for the freedom to be able to offer her support as a contribution rather than feel it is a requirement. There is the pull for independence and freedom which drives her to want to just get out from under it all. These opposing poles are not resolved. They are lived with and dealt with according to which is pulling the hardest at the time.

The reality of the behaviour of her brother causes Asia to note the differences and contrasts in her life to those of others. All doors are locked including the fridge. Nothing can be accomplished without an ordeal. "It's maddening cause every time you want to go somewhere or do something you just can't open up the door you have to go run and get a key. If you're in a hurry and I mean that takes a couple minutes to go run get the key, run upstairs, open up the door, get something, lock the door, run downstairs and put it back again. Then the next time you have to do the same thing you know. It's maddening."

Nothing is sacred. He breaks or at least takes everything. "people usually do have personal things that they can have that are personal that nobody's going to

touch. That's theirs and nobody will go near. Yeah and that's very upsetting because when you don't have anything that's really personal you kind of feel empty." Asia is desperate for something to call her own be it space, time or treasures.

It is not always easy to handle Tyler and his behaviour the way she is supposed to. The family is working on a behaviour modification program that calls for specific behavioural consequences for his aggressive and hurtful behaviours. "He also, like, hurts a lot more than probably a normal one would and it makes you nuts sometimes Yes physically". "He hurts "he can't express himself a certain way. That's the only way he can express himself." He gets "negative attention" instead of "positive attention" by hurting her and her youngest brother. Dealing with these situations on a daily basis takes a long term toll on Asia She does not like being hurt. She feels angry with him but is not allowed to show it. Asia does not always have the necessary control over her own emotions. Occasionally she reacts showing some display of emotion which is just the reward Tyler is trying to get. "My life would probably be totally different without him here. I mean all of us would probably be less frustrated and it would be a lot smoother and we wouldn't get angry as much". A lot of pent up anger spills out from each of them in other little incidents.

"He'll bite himself and it looks so stupid and you just want to tell him not to, and he can't. You can't stop him and it's really frustrating to like pull him away from that." There is a sense of dilemma as she struggles with the futility and necessity of preventing her brother from doing harm to himself or his surroundings.

Her utter lack of control over the situation is compounded when she does take what few steps are available to her and her motives are misunderstood by her father. "and it's really frustrating , when he, (Tyler) does something to you, not to be able to do something back cause you just want to, but you can't. You know you just end up putting him in his room and then it's awful frustrating when my Dad thinks that I can't handle it but, like, I know how to do it I just want to do it. I just want to be able to discipline him." Parent interference is frustrating for Asia. Her anger, and resentment are founded in her desire to become more independent, handling situations which she perceives as her own affair.

The presence of her brother with autism has taught her about a part of life which is hidden from many people. "I know so much and without having him as a brother I wouldn't know about anything and I just would probably make fun of those people, just as people do." The view Asia has of her world and the part her brother has in it has been honed and

mirrored through the varied reactions of her friends and the public. She has felt understanding, compassion, and acceptance as well as rejection, fear, awe, and embarrassment. "you know my other friends understand him and they always say "hi" and they know, like, who he is and stuff."

Asia has witnessed many and wide variations of reaction towards her brother. She has experienced the initial anxiety felt by many when first meeting her brother. She feels relief and understanding when this anxiety can melt into acceptance. On the other hand she has felt the misunderstanding and hurt when this anxiety remains and becomes rejection. She says, "I mean I live with him and if they don't like him then that's their problem because this is his house too." She remembers a friend coming over and not being able to tolerate her brother and telling him to go away. Her mother stepped in to remind the friend, "this is his house too and if you don't like it that's your problem." Although this family rule has been adopted and incorporated into her world view, the memory and occurrence of such incidents are uncomfortable and embarrassing.

Asia recalls excruciatingly embarrassing moments when her brother is running around, screaming and touching anything in sight. She hates these scenes and hates having to chase after him. "I tell my Mom I'm not going to chase

him because I just can't. You know you're running around the store chasing this little kid whose doing everything and it's just really embarrassing." Her dignity is shattered at these times as she too clearly imagines the thoughts of others.

In addition, her turmoil has elements of alarm for the safety of her brother, "He'll run outside and that's what I worry about more. He'll escape and we can't find him." She is profoundly aware of his utter dependence on their care and management. Part of her inner struggle is a critical awareness and belief that, "He's a person just like you and me. He just has a problem and it's not his fault. It's not like he chose to have that problem." Back and forth her emotions wander, the pain, the embarrassment and the caring, the concern.

Asia can and does speak openly to others about her brother. She made a class presentation including a video on autism, explaining some of the behaviours of her brother as well as what is known about the condition. She remembers asking for the respect of the class as she requested that they not laugh as her presentation was about her brother. Asia was moved and honored by the respect and understanding of her classmates exemplified by receiving both high grades handed out by her peers along with comments spoken and written recognizing the reality of her brother's handicap.

The manner in which Asia handled this experience demonstrates her courage in being able to openly discuss her brother and clearly define her terms in so doing.

A further strength of Asia is her ability to allow the laughter of her friends to penetrate and lighten some of the heaviness surrounding the condition of her brother. The humor of her friends helps soothe some of the embarrassment, frustration and isolation that are part of everyday life with her brother and the consequences of his handicap.

The hardest part for Asia is the behaviour of her brother, "just that he is different and he'll always be like that. Like it won't change." She knows how difficult his life will be. As a teen she is now able to speculate and her speculations lead her to the conclusion that "it's going to be hard because a lot of people just feel stay away from him because he's different." Asia differentiates between the world out there and their world at home. She has experienced the antagonism and ignorant judgement of strangers and it makes her angry as well as deeply sad. She knows the community is not as understanding as their home. Asia recalls incidents when people have said that her brother should not be allowed in public. Asia's angry response has been that those who cannot understand someone with a difference should not go out in public.

At times Asia feels she receives the brunt of the family strain. There are days when she feels that her mother seems to be having a particularly bad day "and he'll be doing stuff and then I'll do one thing, just one little thing and she'll get mad at me." In times like these Asia talks to her friends. She selects which friends she talks to about issues dealing with her family. Her church group is like a safe extended family wherein she can "be yourself I love my church group. It's fun. I can talk to them. I trust a lot of people there. I know that if I tell them something they won't tell because a lot of things, I know that they believe the same thing I do they're my favorite group to be with." This closely knit group is her private treasure which she cherishes deeply.

She is quick nonetheless to point out how fortunate she feels to have a mother who is there for her when she has a need. She knows a friend less fortunate in this respect. It is this friend she turns to when she is feeling down about how hard her situation sometimes is. Both girls have aspects of their lives which are hard and which they can do little about. These aspects they share together.

Asia can and does turn to her parents for understanding and knowledge about autism. According to Asia, "she, (her mother) understands it more I could probably talk to both of them but my mom goes to all the meetings and

understands it more". She goes to her Dad for help with interests and things she is doing and her mother provides a sounding block for some of her problems. Asia seeks out emotional support from her friends and practical support from her parents.

Asia is aware of provisions made for the future care of her brother and the role of her and her youngest brother in caring for him. She acknowledges that aspects of her responsibility for her brother may "screw up a lot of things. If he had a problem that would be my responsibility. It's scary that I don't know what's going to happen to him when he's older." Once again she has accepted her part saying, "No it doesn't make me angry cause I know that I would and I just have to accept that cause you can't change it."

Asia has learned so far through her experience "to live with something that's different. Learning to have a problem that will never go away and you know that for the rest of your life they will never change. You know your life will always be the same. You can't just change it. I mean once he hits a certain age it won't go poof you know and it's gone." Coming from an idealistic youth this sounds depressing. Asia is not depressed. She has accepted the lesson and believes she will be more able to handle difficulties which will inevitably come her way as they come

for everyone. Her optimistic side shows when she says, "You always let yourself shine through no matter what."

Asia's advice to other brothers and sisters living with a sibling with autism is to "treat them like they're different from you They're not to blame You can't give them a label like society does Everybody is different." Asia believes that everyone one day will have a problem. Living with and caring for Tyler is the problem in the life of her and her family and she feels she has learned to handle it.

Portrait of Mark

Mark is 15 years old and the eldest son in a family with two children. His 12 year old sister Karen has autism. Mark is quiet, friendly, and intelligent. His interests are varied ranging from athletics to music to hands on hobbies.

Mark is a capable athlete having played soccer for the past eight years. He presently participates as a member of his high school football team. Mark's friends for the most part enjoy athletics and in their spare time they join in such activities as roller blade hockey and listening to music. Mark likes to ski and has been a member of the Nancy Green ski club. He is in the school band playing electric base. Mark also builds model airplanes that are radio controlled and can fly. He likes video games as well.

Mark's current career ambition is to become a dentist. He is good at sciences and has a natural interest in dentistry as he has been the recipient of a considerable amount of dental work. He also likes the idea of the earning power of a dentist. Mark is eager for the freedom and independence that money can buy. He presently enjoys his part time job working at McDonalds.

Mark's father is a professional engineer and is a dedicated and interested father involving himself in the upbringing of both his son and his daughter . Because their daughter, Karen, is unable to dress herself, Mark's father plays a very active role in her daily physical care. He is also active in the development of his son, sharing in the building and flying of model airplanes and joining him for the occasional day of skiing. "My dad and me will fly the plane together or build it together. We get the time." Mark and his father have a close, easy relationship.

Mark's mother is highly informed, involved and present for both her children. She has taken on the role of manager and care-taker for her family. She is a talented and dedicated teacher working part time. She spends the remainder of her time running the household and negotiating on behalf of both her children to ensure that each receive the benefit of resources and opportunities that are available to them. This mother is nurturing, creative and

resourceful and continues to work and fight hard in order that each family member can pursue some semblance of normalcy and independence. Both parents are highly verbal, intelligent, and openly communicative. Both parents seem to be able to find some time for their individual interests. Mark's mother plays the piano and takes lessons while Mark's father loves to participate in sports activities such as skiing and wind surfing whenever possible. This negotiation of free time is no easy matter but in this family has been established as a priority.

Mark has few early memories of his sister. "I was three, like so I don't remember a thing. ... But she's always been there so it's just seemed normal for me All I can say is I've never really known anything else cause she's been here all my life. I don't really know what it's like to have a sister or an older brother whose normal or anything." He recalls noting her difference from other little sisters. Now and then "she'd do certain things but it's nothing important". Mark was very much protected from the daily routine of caring for his sister. The family rule was set at an early stage whereby each member would lead as normal and independent a life as was conceivable given their circumstances.

Mark paints some lovely cameos of himself, his father and his sister sharing some simple pleasures together. He

remembers, "when we were about eight we used to gang up on dad and wrestle with him and that kind of thing." or, "me and my dad we go outside and we'd take her. This would be in the summer and we'd just throw a ball around and we'd throw it to her and she'd laugh and she'd try to catch it and sometimes it would hit her and sometimes it wouldn't and sometimes she'd drop it and then throw it at us it doesn't necessarily go directly at you but most of the time it does." His tone is easy, warm and gentle.

Mark is comfortably interested and able to interact with his sister without having his identity threatened. Mark remembers very little about the early times when his sister was more acting out. She can now be quiet and unobtrusive when there is company and according to Mark "actually none of my friends, it didn't really occur to them that, sure she is handicapped and they like understood that but, really, the way my friends would take it is just like she's a baby or something and you just have to watch her the whole time".

Mark's social life and his ability and willingness to bring friends home is similar to that of other boys his age. He is not preoccupied with the presence of his sister. Rather at his present age he prefers to go out with his friends or meet them outside of his home. Mark has lived in his neighborhood for most of his life and his friends, both

in and out of the neighborhood, are for the most part long time associates. The new friends he has met through his work and school belong to a new part of his life that is more independent from his home. In combination with this growing independence Mark maintains some close friendships resulting from long term family relationships. In addition, he and his same age cousin are mutually close and they look forward to visiting one another. Mark's friendships are based on the mutual ability to talk easily to one another as well as the ability to share mutual interests such as sports and music.

Mark's direct responsibilities towards his sister include occasional babysitting. "like sure my parents will go out for brunch and I'll sit there. But every kid has that". Included in Mark's duties in order to receive an allowance has been the 20 minute or so routine of watching his sister just prior to the dinner hour. To Mark, this is not an issue, "I think with child care workers and that stuff it isn't much different I guess Sometimes my parents will go out and I want to do something with my friends but I can't cause I have to watch her. But most of the time they let me have a friend over anyways. So it doesn't really make a difference." Again this seems to fit comfortably into a family routine as Mark explains that he

simply watches TV with her or looks at one of her books. His sister intrudes little or not at all into his life.

Through the years Mark has been able to lend support to his parents during certain times of stress due to his ability to either interpret the wishes of his sister or at least gain her co-operation when the efforts of his parents have failed. His sensitivity has led to some compatibility between the two siblings. Mark is comfortable with her in his room while he is doing homework as she will be absorbed by his fish and not disturb him. "If I'm doing homework or something, I've got a fish tank in my room and she likes my fish and she'll just sit there, sort of mesmerized and just watch my fish for hours while I can do my homework. And if you put on music or something she'll dance. So she really stays wherever you are."

Activities that can be shared are few. Mark and his Dad will take Karen outside and throw the ball around for a while. "It's just like having a six or seven year old sister really. So I have to watch them whether she's handicapped or whatever", says Mark. On a few occasions Mark has gone with a child-care worker to the pool to watch and assist. His role is a facilitative one. Mark describes watching her "squabble" a bit and then actually "she kicks a bit" and is able to float for a few seconds. He assists with small tasks like putting on her beach shoes while at the lake or

helping out with other incidental tasks. His manner while describing these events is kind, gentle and sensitively amused.

He is observant, sensitive, and interested. He seems to have a special intuitive relationship with his sister. For example, Karen will sometimes not eat at mealtime. Although this does not create a scene in the family, Mark has observed that, " A lot of times she eats best when no one's even at the table or when I'm just sitting there reading something." Mark is a person of few words and his manner fits the communication style of sister. Mark has learned some of her signing and is able to understand and communicate a few limited messages. His sister is neither a threat to his identity nor a burden in his life. He has the freedom to explore a world outside his home while still maintaining a connection with his family, their interests, values and standards.

Mark is a good student and maintains respectful behaviour in class as well as high grades. This is not to say that Mark is sliding through adolescence without some areas of tension and struggle. He wishes for more freedom, independence, and flexibility from his parents and resents many of the restrictions placed upon him regarding school, homework and in-house responsibilities. Suggestions or guidance from his parents with regards to style of homework

or style of behaviour is seen as an intrusion and for the most part is not welcomed. His ambition is, "I'm going to move out as quick as I can." His adolescent struggle for freedom from his parents is evident at this juncture.

Mark has learned about aspects of autism, epilepsy and signing by living with his sister. His mother is a special education teacher and therefore his education has been tutored. In terms of his feelings about those other than his sister who are different Mark says he does not really notice it much. He admits that he might be with those who laugh at others and although he does not laugh he will not necessarily speak up either as that leads to other complications at the time. "I'll be with people that laugh at other people and I won't necessarily laugh myself but I'll be there and then I'll be alone and all that kind of stuff. It depends on what I'm doing and who I'm with." A firm stand in this regard has not yet been taken. Such life decisions are not yet solidified as he is in transition between childhood and adulthood, between parent values and setting his own. His attitude is, let well enough alone which coincides with his quiet and somewhat shy manner.

Mark's theory concerning his sister's autism centers around the belief that his sister can and does take in much of what goes on around her. She is impaired, however, in how she responds to the world. Mark states, "it's like

scrambled She can't, I don't know if she can't talk. She tries but, She seems to know sign language, well some of it, most of what we've taught her. so she seems to catch onto that, but when it comes to speaking, I don't know, she just can't talk."

Mark feels his biggest loss is the inability of his family to go away on vacations. He lives in a community where trips to Hawaii, or ski trips to Whistler are relatively common and Mark has not had these opportunities. He claims that when he was younger the consequences of not being able to participate in these kinds of adventures left him feeling somewhat left out. Mark however says that if his father had more than two weeks holiday a year this loss might have felt more significant but under the circumstances the family could not go very often anyway. "Seeing as my dad only gets two weeks off in the summer it doesn't really tend to bother me at all much."

Mark has spent his latter summer holidays getting job experience in preparation for his future. He has worked as a volunteer in a local pet clinic and as a volunteer camp counsellor at the community recreation center. He enjoyed both jobs but preferred working when there was lots to do. Mark also enjoys children and finds them easy to be with. Mark has an active mind and prefers a challenge.

Mark's day is much like that of any other teen. He is awakened in the morning by his mother. He proceeds independently to shower, dress, read the paper, eat and get himself off to school. His sister is usually at the table for a part of his breakfast though she does not intrude on his space. School takes up the greater portion of the day at the end of which, if there are no practices, he rides the bus and walks a good distance to his home. Once home he says he will either do homework or "vege".

His father and sister generally return home around six o'clock at which time he watches his sister while his mother is arranging dinner and his father is changing. Dinner is eaten together as a family with his sister joining them usually once the salad is served. The family clean up together with some working and others watching his sister. Mark then does homework or watches TV. Mark's parents take on the major role of caring for and amusing his sister. According to his parents the evenings are regimented around their autistic daughter as she takes up all their time. Two nights a week they have a short one and a half hour relief while a child-care worker takes her to swimming or girl guides. Mark seems to be somewhat untouched by the tremendous amount of energy, time and concern that his parents give to his sister. He views his life as pretty natural with his parents doing what parents do and himself

doing what most kids his age do. He is at a stage where the opportunity for independence is welcome thus he is in no way concerned with their need to be present for his sister.

On the other hand Mark is aware of the sacrifice his mother has made with regards to her career. "Before she had me she was a principal so she might be able to go back and become a principal or she could go back and be full time if Karen was normal or she could do that. But she isn't so." His attitude is one of acceptance and finality.

Mark accepts his future role regarding his sister as being similar to that of any other brother towards his sister. He is aware that his sister will probably be moved into a home and be cared for by others. He has been asked to visit her and have her visit him occasionally for family dinners and special events.

There are hard times too in Mark's life. He wholeheartedly admires the ability of his father to handle his sister. "My dad, he, he's great with her I guess is all I can say." On the other hand he sees the frustration of his mother at times, "My mom being a lot weaker than my dad is, I don't know. Now and then my sister will just overpower her and she just can't handle it. So it doesn't happen often, but every once or twice a week she'll not be able to handle it." Mark himself is bigger than his mom and is able to simply pick his sister up and move her if she is

not fighting too hard. Her most difficult behaviour is "squatting" according to Mark. She does this when, " she just gets frustrated cause she can't get her way". Mark's reaction at these times is one of frustration but not anger. "She doesn't do anything for me to be angry about".

His relationship with her is "she's my sister". She does recognize him and will wave or try to get his attention. Mark has no trouble going up to her whenever he sees her in public to say "hi", and to check out with the child-care worker how things are going. He comments that the whole "concept of her having autism is sad". He knows there have been changes in her behaviour since she was little but as he has lived with her daily the changes have been so gradual that he has not noticed them.

Mark considers Karen a part of the fabric of his family life. In his words, "It's not that the family revolves around her. It's just certain families will go on a long weekend or a vacation but if we have Karen we can't do that sort of thing We can't go shopping for the day. We can go for walks and stuff." She is his sister and thus he is fond of her and somewhat protective. However he is a adolescent and his own issues of autonomy and identity are presently his main focus. He has decided to not dwell on some of the negative aspects regarding his

sister. It is fruitless to dwell on matters that cannot be changed. His focus is positive and accepting.

Mark believes that his parents have carried the major portion of the daily responsibility towards his sister. By so doing, Mark's space as a person has been protected. He also recognizes that what may appear as difficult or awkward situations to some are natural to him because "after 10 years of living with such situations you get used to anything". His family has given him a sense of competence as his parents have successfully taken a leadership role to ensure that the presence of autism in the family is accepted and managed.

Portrait of Stuart

Stuart is 14 years old and is the youngest of two boys. His brother, Alex, is 18 and has autism. The family has lived together until a few months ago at which time Stuart's brother moved into a residential home. Stuart's parents are both intelligent, highly academic, and investigative people.

Stuart is a long term Canuck hockey fan keeping informed and involved through the games by TV. He used to play hockey until he broke his leg and could not continue. At lunch time Stuart plays recreational football while after school he enjoys street hockey. He is seriously contemplating returning to hockey for next season.

Stuart has good friends with whom he shares mutual interests and activities. He is timid, kindhearted, playful and intellectually adaptive. Stuart has attended catholic church with his family where he has received and incorporated many of his values.

Stuart participated in the scouting movement when he was younger. He describes the leaders as "amazing". "They were probably some of the best people you could know. ... you could really talk to them". These leaders played a significant role in his life by providing an outlet and a safe environment to explore new independence. They were also role models from whom Stuart learned new ways to react to his world. "They were a little lighthearted, not as dead serious it's fun to joke around a little more." He enjoyed their lack of rigidity and their love of freedom, fun, and spontaneity. "I always felt good usually about them." He since has developed more friends and left scouts in preference for spending time with them on weekends.

Stuart loves computers and finds that most of his close friends are also interested in and conversant with many aspects of computers. His hope is to be an engineer working in the area of robotics. Stuart claims to be an average student though, at this time, he is excelling in science and all of his grades are well above average.

When asked if there was anything in school he disliked he answered that he "probably disliked" riding his bike in the cold every morning and having his hands cold on the handle bars. He dislikes physical discomfort. "you usually don't have a jacket on or something like that and you usually get cold somehow cause its not very warm in November. He repeats his dislike of physical discomfort when talking about camp. "when it rained it was horrible Sometimes your tent just got all muddy and you never felt good." Stuart enjoys intellectual challenge more than the great outdoors.

For Stuart there was no particular moment of realization that his brother was different from other brothers. Stuart believes he always realized his brother was different. "My parents told me very much when I was really young and I didn't think much of it at the time." He remembers being happy and content with his own interests, activities and friends.

Stuart recalls some annoying incidents concerning the behaviour of his brother. "... cause if you're trying to eat in the morning and you've got someone clearing their throat regularly you just don't feel great ... it was a little unnerving." He continues, "sometimes he got to you if he asked your friends questions a whole bunch of times and the friend just didn't want to talk or it was someone

new you were trying to meet. You didn't want to put a hex on them right away." There were times when his brother would simply not go away.

Similarly, Stuart comments on his lack of privacy. "It seems to me that I don't have anything that's really mine." Stuart's brother would take things and sometimes destroy them. "I have my school annual and whenever he comes over he wants to look at it. It's my only annual and it was gone for about six months and it was gone and I'm supposed to have this for years he used to rip out pictures. I don't want him destroying it." These incidents are irritants to Stuart as well as frustrating. Stuart handles these situations by hiding his important things. His brother would search for them but he did not always find them. The difficulty was that after hiding things so well often Stuart could not find them either. Stuart comments, "I didn't notice it that much though. I usually had things I could go off and do and forget about it."

Some of the behaviours of his brother left him feeling awkward and embarrassed. "He'd ask people what their name was a lot and I don't know I guess that embarrassed me a lot of times ... I just wanted to drag them away He'd persist I wanted to break the chain before it even started." He recalls telling his friends not to think about it much and, for the most part, he feels that they were able

to accept his brother. However, there were moments and times when he sensed confusion, fear or awkwardness in others. "I asked them not to think much of it and they'd sort of, they wouldn't say much. But I could sort of tell if they were interested or disinterested and it was confusing enough." "But all in all I really stayed out of his way most of the time. I tried to keep down the impact or something like that." Stuart tries his best to live his life separately from the chaos and strain of his brother.

A typical day for Stuart would consist of early wake up, shower, possible finishing of homework, seldom breakfast and off to school. He would return late, do homework and watch TV. His brother for the most part would be on his own, "He liked to keep to himself a lot". There would be the occasional eruption which was handled by his parents sending his brother to his room and, if need be, compensating Stuart in some small way for any injustice inflicted on him by his brother. Meals were always eaten together when they were young with no particular disruption. "It was just sort of set the table and eat and go away." More recently, however, "Well it's interesting. We never really eat together." Stuart retreats quickly after the meal while his parents converse about matters that do not interest him.

About his life, Stuart believes that he did not feel like an only child, but rather as "an observer half the time. Someone who's sitting on the sidelines watching the football game or something like that". Stuart had friends with older brothers whom he admired and who were kind to him. They served as role models for him allowing him to choose and create a sense of identity.

In his elementary years Stuart attended a private, Catholic, French immersion school on the other side of town from his home. Therefore his school life and many of his friends were not connected to his family life. He remarks, "the most amazing thing is most of us didn't know each other's sibling until grade six or something. I knew them since grade one and everyone was amazed to find out that I had a brother and they probably didn't realize that he was autistic until grade seven and by then they probably didn't even realize what autistic was." Occasionally Stuart would bring a friend home on a Friday for a sleep over. The presence of his brother did not deter or influence these occasions. His brother mainly kept to himself. He feels that the fact of his separate school life was due to the distance of his school not due to the presence of his brother with autism.

In contrast to this separate existence, Stuart lives in a very stable neighborhood where everyone knows and

interacts with one another. His brother was integrated into the neighborhood and accepted for who he was and what he could or could not do. These are the long time friends to whom Stuart does not have to explain himself or his bother.

Stuart developed many more close friends once he entered his neighborhood secondary school. He enjoys a more accessible world and is gaining a growing feeling of belonging and independence. Now in his second year of high school Stuart finds himself occasionally answering questions regarding his brother from his new associates. Often their question is, "What's it like living with him?" Stuart's reply is "What's it like living with your brother?" "How do you explain a life time in one or two sentences? How do you begin to become accurate? Also there is the underlying question of are they really interested or are they just momentarily intrigued?" Further Stuart says, "Well if people are trying to trick me I don't like it. If people are genuinely curious then that's okay, but not the other." This feeling of betrayal is not a frequent experience for Stuart but nonetheless he knows it and does not like it.

Further and more important is the fact that Stuart knows only the life he has led. He says it is not all that different from living with any other brother. It is only that "when he's away from the house or something or when he's not around, he'll usually do something not particularly

normal." Stuart's friends do not make an issue of these incidents. People do not talk about it. "they sort of knew that it wasn't a great thing to talk about."

Stuart for the most part is clear that these situations have not really hindered him. However, he wonders if perhaps indirectly there have been subtle consequences. "Somebody probably told somebody else and somebody probably didn't like it or something and they didn't think much of me at the time. But if anybody was immature enough to not really accept it" Stuart's attitude is one of well what can you do?

When he is experiencing difficult feelings of hurt, anger or sorrow he walks away from it and tries to think about it. He has no one with whom he talks about these very deep feelings. His preference is to work it out by himself. "I run away. I try to get away from everything. I try to do something to try to forget about it. I don't want to dwell on it and get madder." When this does not work Stuart says, "I usually try to think about them. I watch other people and try to adapt to them, try to be a little more like them or not like them I see someone really blow a fuse and I think I don't want to be like them. I try to calm down and try to understand what I'm really mad about."

Stuart's closest friends share his values and beliefs. When speaking of his friends he says, "I usually like to

think of them as a lot of nice people." They have worked out a mutual means of supporting each other without talking about the troubling parts in their lives over which they have little control or power. What Stuart values in a friend is the ability to have fun and "just talk to without them giving you the ugly look like "what". Stuart does not want to always have to explain himself, his actions or his brother.

In terms of the reactions of others to his brother Stuart has noticed an air of artificial friendliness, "a trick like a shield a fake face." These reactions disturb him as he witnesses their effect on his unsuspecting brother. His only defense is to tell them to "cut it out" and then just walk away. These occurrences leave him with a sense of hopelessness and powerlessness. He has also experienced occasions when the behaviours of his brother have been exaggerated to the point of disbelief. When this occurs, Stuart is torn between a sense of certainty that what he is hearing cannot possibly be true and a sense of incredible fear "What if it is true?" Once again, Stuart's response is to retreat hoping that the memory of the incident will disappear with time enabling him to get on with the more enjoyable parts of his life. He says that some reassurance during these occurrences and some direct information would have helped. He is all too aware,

however, of how these same incidents affected his overwrought parents who were left having to deal with the events.

He admits that it is hard to understand what it must be like to be his brother. "I never really had to go anywhere with my brother and I never really felt handicapped myself." He recalls the time when he broke his leg, "I felt really alone a lot of the time cause I couldn't go outside and play and I watched them outside and they were outside having fun and I was stuck in the TV room with the TV". He focuses rather on living his life to the best of his abilities without infringing or encroaching on the rights and space of his family. His explanation for his brother's autism is simple. "It like being mentally handicapped. He doesn't understand things the way we do."

Stuart has had few responsibilities as a direct result of the handicap of his brother. Once in a while he was asked to baby-sit. "I sort of had to keep an eye, to make sure He'd do stuff." This was a relatively easy matter as his brother would watch videos or TV. He could do very little with his brother in terms of activities due to their vastly different abilities and interests. Stuart remembers liking to watch him draw sometimes. He thought his brother was quite artistic. However he did not draw often. "He usually kept to himself." Stuart does not

really have a relationship with his brother. He cares for him as his brother but cannot share with him or relate to him. "I don't think it's really possible to have a relationship with him but, cause it's awkward in a way." Whenever Stuart did try to play a game of some sort with his brother he would not understand and would then just walk away. His father is the one who spends time trying to do things with, and communicate with Stuart's brother.

Stuart enjoys a lot of freedom in his life. He values this independence and believes this is a benefit he has reaped as a result of having a brother who has needed more time and attention from his parents. "See I get all these pluses and things that other kids probably wouldn't have had. Then I get all these minuses. So everything sort of evens out." He believes that if his brother were "a real brother" he would probably get "a whole lot more attention" at times but then again I would feel really strict and tight." Continuing with this theme Stuart remarks that, "there are a lot of troubles apparently that come along with a brother. Getting seriously beat up and you're small, or him hogging the TV or the video or something like that. So I don't know if it'd be better then". Stuart further fantasizes that if his brother were not autistic, "my brother would probably be doing excellent in school ... I'd sort of be the second one who's got to keep up or something.

I'd have a lot less freedom." Stuart perceives his life as pretty good the way he has it.

Stuart spends his time learning new things, getting to know new people, and striving to his achievements. His approach is positive and constructive. His parents are available to him if and when he needs them for help but at this point in his life he is seeking independence and his own sense of mastery and identity. He openly acknowledges that "they seem to know a lot ... most adult anything", and that his father in particular is great to have around for math homework. He is, however, proud of the A he has earned in science, "science is the only class I don't really want to trust them with, cause that's my A and I'm going to keep it." Stuart comments that he finds his father more approachable than his mother, "He's a little easier to get along with."

Stuart seldom if ever brings up the topic of his brother to his friends. "It's usually not that subject cause it's a little touchy cause it's hard for them too." He has tried to not have his brother play a larger part in his life than is necessary. There are times when Stuart feels sad and sorry for his brother. However he chooses not to discuss this with his friends. His feelings are deep painful ones that are hard to share and difficult for others to understand. "I wouldn't want to be them. If someone

walked up to me, so I'm really feeling sorry for my brother lately they'd probably just ... feel really bad cause that puts you in a position that you just don't like. I don't like putting people in that position." In a sense a part of him grieves for his brother's loss. He chooses not to share these difficult feelings with others as he does not wish to burden them with this sadness. "It's not something I'd really want to start with my friends cause then from then on it'd sort of be like a whole topic of conversation, sad things or autistic people." Stuart keeps this part of his life locked in a compartment away from the rest of his life. In this compartment is his awareness of the probable loneliness and isolation of his brother. "Sometimes it was kind of hard. It's like seeing someone who's really nice being put down." He is torn by feelings of helplessness, and concern yet he feels he must fight for and protect his own sense of identity as separate from that of his brother.

Stuart as a teen is now more self aware and more conscious of the thoughts and feelings of people in his surroundings than he was at a younger age. As a young child he was less concerned with the reactions of others. The departure of his brother from the home has occurred at a time in his life which coincides with the expansion of his own consciousness. He recalls shopping with his brother in the past and not being bothered by the experience. He knew

few people then and was occupied by his own thoughts and actions. He recalls it not being a "big social down or anything."

The difference in his family now that his brother is living elsewhere is explained as, "Well I guess it's kind of nice to have peace around here, cause most of the time my Dad was chasing after him and I don't know, I feel a lot more comfortable now that I don't have to worry about it half as much." Although his brother kept to himself most of the time he did play his stereo rather loud and was prone to banging on doors late at night. "I usually manage to get to sleep. I drowned it out with pillows."

When speaking of the future and Stuart's possible responsibility towards his brother, Stuart speaks of his brother being in a home wherein he is wanted and which is meant to be permanent. "I don't really think I'd be able to do much for him. He's in a permanent home now and he should stay there." Stuart will visit him now and then but direct handling of problems or difficulties will be managed by someone other than himself. For the moment thoughts of visiting his brother are disturbing. "It wouldn't be that much of an experience. It would probably just be ... It would be more saddening than happy if anything." He wants to think of his brother as "just a brother, nothing else. It would be nice if I had a self sufficient brother, just a

plain old brother. Nothing that you have to support later on. That's what I don't want." Stuart would like his life to be uncomplicated, less stressful, "more simple".

On one hand Stuart wonders what it might have been like for his whole family if his brother had been normal. Yet he says, "Maybe my parents were half lucky. I guess they could say that Alex may have been a bad apple but then they got me and they can be grateful for me." Stuart comments that some people can not even have children and that others end up having difficulties even when their kids start out physically normal. "Some kids get into drugs and all kinds of trouble, Alex would never do that. He's not that kind of kid." Stuart does not spend his energies on wishing for things that are not possible. He has accepted the presence of his brother in his family and has turned his resources to living his life moment by moment to the best of his abilities. He intends to have a family of his own one day and he does not dwell upon the issue of possible problems in his own offspring. After all, he claims "people always have kids and they don't seem to consider that this kid may have cancer".

He says he always wanted to have a cat for a pet because, "They give you affection and you don't have to take care of them." Cats are independent and, according to Stuart, when they encounter danger, a cat will climb a tree

unlike a dog which will bark and get run over. Stuart is equally intelligent, independent and observant. Stuart is like the cat, "They take care of themselves." His family has allergies to cats so, unfortunately, this pet remains a fantasy.

His advice to others in his position is not to criticize their parents for anything. "It's hard enough on them already." Stuart's major contribution to the plight of his family was to "stay out of their way most of the time." He learned by watching how other people did things. By modeling parts of himself after portions of others. He is self-creating a style and life for himself. "I've gained self sufficiency." He says it has been "very hard to do". One of Stuart's final comments is, "If life gives you a lemon, then make lemonade out of it." Stuart is essentially content and happy with his life. He is struggling to grow and is working on one piece of his life at a time.

Chapter V. Discussion.

Introduction

This chapter deals with the findings of this study. The first sections summarize the findings of the study in the context of emergent issues of each of the participants. The following sections outline some of the limitations as well as theoretical and practical implications of this study. Finally, suggestions are also made for future research.

Findings

Overview

The portraits of the siblings of children with autism in this study support the view of a varied and diverse set of experiences. Each of the portraits in this study describes the experiences of growing up with an autistic member in the family from the specific perspective and context of the sibling. Some similarities could be found between the cases studied to the extent that there were contextual similarities. For example, in two of the cases, the siblings were older than the autistic member of the family and in both cases they had established family ties prior to the arrival of the autistic member. Although similarities such as this could be found, the experiences of these two siblings also varied greatly. In this study, all individual portraits varied greatly and it would appear that

the experiences of each sibling of growing up with an autistic member in the family is best understood in their own context. However issues did emerge for each of the participants and though each issue was dealt with in differing manners these issues were constant for each family.

Elements of this context that assist us in understanding these experiences include appreciation of the degree of autism, the characteristics of the behaviour of the autistic member, the birth order of the siblings, the sibling genders, and the scope of the family resources, both internal and external. We also need to appreciate the family, social, and economic environment of the siblings studied in order to gain understanding of their experiences.

The experiences and the views of the experiences of growing up with an autistic member in the family will not only vary between the individual siblings studied but for each individual will also vary over time. This study captures the experiences and perceptions at the point of time where the subjects are transitioning their adolescent development. Therefore, a degree of commonalty between the expression of the experiences of the participants was observed relative to this developmental stage. One can speculate that these perceptions may change if examined at a later stage in life.

Living with an autistic member in the family is a life time process which begins soon after the member begins to reveal different behaviour. Regardless of the hopes and aspirations of the family, some degree of awareness and adjustment is required. In each of the cases in this study, the families addressed this need for adjustment in varying fashions, striving to minimize the stress on the family through balancing the available resources, both internal and external, to achieve the diverse needs of the family. This variety of ways in which the families addressed this need provides the variety of the context and the richness of this study.

Each of the experiences described in this study is unique, describing the experiences of the individual from their own perspective. Each of the experiences provides interesting insights as to what it is like growing up with an autistic member in the family. The following sections examine the common issues in the cases studied as well as some of the variations on the issues.

Background

Each of the participants in this study comes from a secure environment. Their families consist of two parents who have been with them since birth. They live in stable neighborhoods where they have established long term family relationships. These participants all have family

atmospheres in which the parents care for one another and their children thus providing secure environments for personal growth.

In each of these families, one of the offspring has autism. In one family, the sibling was an eldest female child with a younger autistic brother. In the second family, the sibling was an eldest male child with an younger autistic sister. In the third family, the sibling was a youngest male child with an older autistic brother.

Through this study, it became apparent that each of these participants have experienced many of the normal day-to-day dynamics of family life. Division of labor around the home has been negotiated according to individual personality, ability, and expectation. In each of the families the mother has had the major care-taking role of supervising, initiating, and organizing activities around the home. In all three homes the father has also become involved in the day-to-day activities of the children including both the handicapped and the non-handicapped child.

Each of the participants had accepted their sibling with autism as an integral part of their family unit. Although accompanying their sibling with autism in public situations often resulted in feelings of extreme embarrassment coupled with righteous indignation, none of

the participants expressed any reluctance or resistance to bringing friends into their homes. All three brought friends home trusting in the fact that the friends would learn to ignore, accept, and understand the behavior of their sibling. Each sibling rallied to the support of their sibling with autism whenever their rights or dignity as a human being appeared to be in jeopardy.

In the interviews, these young people described what it is like to have a brother or sister with autism. They spoke with amazing candor and clarity about their experience. They allowed their own personal experience to guide their words. They talked about frustration, guilt, pain, anxiety, fear, anger, sadness and embarrassment. They also talked about love, hope, and about personal growth and of special family and outside relationships. Emotions are not pure and singular to an event. The reaction to a specific incident may have many facets and layers. This was certainly the case for the brothers and sister in this study.

Each of the autistic siblings required almost round the clock care. Bedroom doors were locked at night in order to preserve some time wherein the rest of the family could sleep without fear of the child with autism escaping or harming themselves or damaging their surroundings. Super vigilance was necessary during all waking hours and someone had to be responsible for the child at all times. No

element of daily life could be taken for granted. Parents dared not be sick. Siblings did not leave precious things lying about. Mothers and fathers were one hundred percent available even when a respite worker was on duty in case the child misbehaved and could no longer be handled.

Each child with autism was physically normal and attractive in appearance. Each child with autism had a means of communication in order to have some of their needs met, however, they did not appear to be able to reciprocally respond to the needs of others. Further to this, the style of communication ranged from "squatting", to screaming, to biting, to semi appropriate speech.

As an observer in the family it was evident that the anomalies of the behavior had long since been adjusted to by the family members and it was only highly irregular from the point of view of the outsider. These family members had called upon resources from within and without the family unit to accomplish this adjustment. They seemed to have developed a high tolerance for disruption, be it by their autistic child or by the presence of child-care workers caring for their child with autism.

The many ways in which the participants have learned to cope with the experience of living in a family where one of the members has autism were not necessarily at a conscious level. These adolescents had learned to adapt largely

through following the example of their parents who each had accepted their autistic child as an integral part of their family. Each set of parents cared deeply for each of their children and each family had an expectation that their autistic member be accepted wholeheartedly as a person within their own right. Each family was seeking integration into society for their handicapped child in order to promote acceptance on as many levels as possible. This, then, provided the atmosphere and background for the non-handicapped children to deal with and integrate their handicapped siblings into their lives.

A common stress factor for both mothers and fathers of autistic children was their care giving responsibilities. The constant and persistent amount of care that is required when keeping a family member with autism in the home is draining and exhausting. There were times recalled by each parent when the needed support to continue was no longer available from within the home and outside help was sought in order to continue. It has been noted in the literature that, just when parents of disabled children need each other most, tragically they are unable to help each other (Featherstone, 1982).

A high amount of personal sacrifice on the part of the parents of the autistic child became evident during the parent interviews. These sacrifices were in terms of career

limitation, financial security, social isolation, and physical and mental health. All parents were required to provide inordinate amounts of long term care-giving to their dependent child. This caring is often very routine. It is wearing and chore-related, consequently lacking in many of the perks normally associated with child-care such as visiting, exploring and discovering together. Burn out then is a constant threat for these families and their only hope for relief lies in the availability and accessibility of outside resources to supply both a break and relief from their incessant routine.

An observation regarding the parents, most notably the mothers, was their strength, tenacity, and courage. These parents had to learn to deal with the shattering of one of their most precious dreams, a life filled with the hopes and pleasures of a healthy child. One of the fathers said that the present condition of his child was "his worst nightmare". These same parents had found educational settings for their children, therapy for themselves when needed, respite, and child-care services. None of these services were automatically delivered to them upon diagnosis of their child. For each vestige of care or relief, letters had been written and battles fought.

Thus these parents risked being perceived by some outsiders as overly aggressive, angry, or non-cooperative.

Each of these families had been negatively judged and consequently bruised and scarred by various outside support people whose functions were to understand and assist in the very difficult task of caring long term for a family member with an extreme handicap. At these times the families felt discouraged, hurt, angry, and betrayed. In my experience these parents had to learn to be fighters so that their children and families could gain some semblance of normalcy and acceptance in our community.

On a more positive note, however, these same families reported true appreciation for those in the field who did provide practical, long term understanding and support. These were professionals who had stuck by them over the years without judgement and who had helped solve many of the multitudinous problems encountered. They had listened and helped enable the families provide the care they needed and expected for their children. This trust is critical and can be fragile for anyone who wishes to work in this field.

As the interviews progressed issues emerged that appeared to arise out of living with a member with autism. Increased burden of care is endemic to autism, therefore issues surrounding responsibility arise. How the family portioned out and dealt with the extraordinary amount of care necessary for their autistic child became pivotal in influencing the development of the non-autistic child as

well as the experience and perceptions of the non-autistic sibling.

Restrictions in the over-all life experience and opportunities of the non-autistic sibling seemed to arise out of the extreme amount of intrusiveness of the autistic child. Many normal family activities were restricted due to the inability of the autistic member to participate or accommodate to spontaneous or non structured activities. Their obtrusive behavior also prevented or discouraged others from volunteering to care for the child in order to allow the family to take a much needed break.

In two of the cases the autistic child intruded upon the personal private space of the family. There appeared to be little to no peace in the home while the child was present. Neither psychological nor physical space was sacred. The autistic child did not sleep through the night, did not attend to any one activity for any length of time, did not respect personal items, and did not respond to verbal admonition or reasoning. Thus issues of privacy, identity, and uniqueness had to be dealt with in novel and creative ways.

A clear sense of identity that was separate, yet connected to family, was emerging for each of the participants in this study. Each sibling was emerging as a strong, mature, and compassionate individual. Each has had

the support and benefit of parents who have worked hard to maintain a semblance of normalcy in their daily lives in spite of the disruption caused by the presence of an autistic family member. The parents in all three cases had skills and resources which enabled them to be leaders and advocates for their children. The parents in all cases were able to be in charge and had the self determination to fight for the help which is necessary in order to raise a child who is autistic. Each participant had found a place and space either in the home or outside the home which was private and separate from their family. This separate space was respected by each parent. Responsibilities were in all cases shared and divided in such a way that the non-autistic sibling was free at times to escape into the normal world of their peers without guilt or negative consequences. The restrictions in all cases, though present, were shared and managed by all and communication was permitted for feelings to be expressed regarding the accompanying frustrations.

The three participants had created a philosophy of life which allowed them to deal with the disruption in their lives. They had each positively evaluated aspects of their lives at such a level that they were in fact empowered by elements of their over all experience.

Responsibilities

Each of the participants had varying degrees of responsibilities towards their siblings. Asia, being the eldest daughter in her family, carried the most responsibility with regards to both of her brothers. Both Mark and Stuart did occasional baby-sitting though in neither case did this responsibility seem onerous. Neither boy complained that their responsibilities interfered with their own private time. Asia, however, commented that frequently, especially on weekends, she found herself caring for her brother if she could not make plans with her friends. She would much rather have been simply spending some quiet, private time on her own.

This difference in responsibility of each of the participants in this study is also reflected in their individual early memories. Asia was five years old when her brother with autism entered her family. She remembers vividly having to adjust to the new family member. In this case the child did intrude very much into her established pattern of living and she recalls being called upon as a resource to help out in instrumental ways. She remembers that life changed for her at this time and she recalls feeling very angry about that change. Her memories are mixed however as she also recalls still being very special in the eyes of her family. Her recollections reflect the

struggle of her family to deal effectively with two young children who needed them.

Mark, the eldest child by three and one half years remembers very little change in his life, including his responsibilities. In this case the parents absorbed most of the stress of dealing with a new and difficult child and reached outside the family for needed support and services. In this instance little change was required of the sibling. His place in the family was protected and he was able to continue to grow according to his own needs. It should be mentioned at this point that the new sibling was a girl and perhaps gender factors help account for his ease in adjustment.

Finally, Stuart, the youngest sibling was born into a home where the older brother with autism preceded him by three and one half years. He entered into a predetermined situation and never knew anything different. His brother with autism had already established his presence and the younger brother adapted to this situation by taking up as little extra space as possible. He took on the responsibility of his personal growth needs by looking to outsiders. Stuart found mentors and role models from whom he could shape and borrow ways of being. He did not want to infringe on the already overworked space of his parents. "It was difficult enough as it was".

These young people felt varying degrees of responsibility for their handicapped sibling with regards to the future. In each case the siblings had talked to their parents about arrangements which had been made for their sibling. In each instance plans were established for the child with autism to be placed into some form of residential care. None of the participants would be held financially responsible for the well-being or maintenance of their sibling. Asia, the eldest girl, had taken on the greatest amount of responsibility for her brother with autism. She expected to take on the maternal role of being present in emergency situations as well as maintaining an acceptable standard of dress and hygiene for her brother. She was more intimately aware of the details of her future relationship with her brother than were either of the males in this study. She was fearful of what that might mean in terms of her daily life and how that might affect her career.

Stuart and Mark were both somewhat fearful of not knowing what was ahead but were less anxious about of their responsibilities than Asia. Mark, the eldest brother, is comfortable with keeping a family connection with his sister and including her in special family events such as Christmas dinners, birthdays and the like. Stuart, the youngest brother, seems comfortable with knowing that his brother is

in the permanent care of others. His involvement with his brother will be casual and self initiated.

The participants in this study felt a strong sense of personal responsibility for the behaviour of their sibling and expressed feelings of guilt, often in conjunction with their conscious embarrassment with some of the behaviour of their sibling. Stuart vacillated between guilt, shame, and embarrassment when his brother was being obnoxious to his friends. Asia too wavered between frustration, shame and guilt as she realized that her brother was not in charge of the way he behaved. Asia, Mark, and Stuart all spoke of feelings of embarrassment and frustration when they felt they could not prevent their sibling from pursuing a certain behavior pattern that they felt was damaging.

Embarrassment is a painful emotion and is very closely linked to feelings of shame. This sense of shame reflects to a degree on the sense of being strong and okay in the world. The behavior of the autistic sibling is seen as an extension of the self and as such acts as a threat. The non-autistic sibling is aware of the outside world judging their sibling as being unacceptable and the vulnerable parts of themselves fall prey to an internalization of these feelings. As young people they are particularly vulnerable as their sense of self is not yet fully developed. A concern for practitioners might be that if these feelings

are not expressed and resolved then that part of the inner self might not ever grow and develop the strength to overcome such feelings.

Restrictions

Due to the extreme nature of the behavior of the sibling with autism, many aspects of normal life had been restricted. In all three families the siblings shared in the belief that they had lost out in terms of vacation time. Not only was there a limitation in the amount of time available to the family for vacations, but, whenever a holiday or excursion was to be planned, there was always the added stress of determining who would care for their autistic sibling and for how long.

All three siblings felt they had lost out on experiences and opportunities that result from planning, participating, and enjoying new and different adventures. Each one yearned to just get away and see and do something different from their daily routine. In addition, the siblings pointed out their inability to participate in many normal and spontaneous family excursions, such as ski trips or shopping. They felt that these losses, in part, contributed to their perception of the separateness of their family. To my knowledge, the consistency of this response has not been reflected in the literature.

In addition to these more obvious restrictions, there were many more day to day tedious restrictions. As an example, refrigerators were locked and keys kept in hidden places away from the reach of the child with autism. This resulted in an irritating series of steps required in order to retrieve the simplest of items such as a snack or a drink after school.

On yet another level, restrictions were placed upon the non-autistic siblings in terms of their natural behavioural response to behaviours of their siblings with autism. They were not permitted to strike back when and if they were abused in some way. They were often obliged to conform to a formal behavioural program for handling and modifying the behaviours of the autistic child that deemphasizes physical response and emphasizes being part of a social situation.

The participants in this study expressed feelings of frustration in situations where they were unable to easily participate in vacations, spontaneous activities or what they considered to be normal family activities. For Stuart and Asia, frustration was often associated with feelings of embarrassment, anger, pain, and sorrow.

None of the siblings felt that their career choices had been restricted or influenced by the presence of an autistic brother or sister. Mark had chosen dentistry because of his abilities in the sciences and his desire for a high paying

job. Stuart had chosen computer robotics due to his gift in that area. Asia had likewise chosen an area of expertise that gave her enjoyment and in which she was presently successful. Each of the participants had also chosen a career which conformed to a family trend. Asia's family was involved in the arts and both Stuart's and Mark's parents were involved in professions which emphasize science and mathematics.

Privacy

A major concern for the siblings of children with autism in this study was the invasion of privacy. Children with autism often have little sense of personal boundaries whether these refer to the physical self or to possessions. Asia anguished over not having anything that was personal and private. She had no symbols in the external world that represented the sanctity of being unique and apart from others. Stuart too felt that he owned nothing that was sacred to himself. Even his precious school annual was not safe from his brother.

In each of the cases, there was very little private space in the family. In some instances, doors had to be locked in order to provide a measure of privacy and some protection of personal effects. The autistic sibling would intrude at will on the personal space of the sibling. The effect of this intrusion varied with the degree of the

autistic behaviour expressed. This is most certainly an area of concern and should be addressed by those who work in the field with families of children with autism.

Angry feelings were noted by the siblings. Asia and Stuart's siblings would hurt them at times. Asia's brother would reach out and hit her as she came down the hall or Stuart's brother would pull his hair. The anger felt by both was short lived and a natural consequence of the behavior, an emergency reaction. Asia wanted to hit back while Stuart, being much smaller, would yell out for help and his rescue from his parents. Neither attached permanent blame to their autistic sibling though both felt frustrated and confused as to how to deal with their abuser. Both thought the intent of the actions was not personal or malicious. They each believed their sibling did not have the social skills to express their needs or feelings and so at times resorted to negative, physical acts. Their anger would sometimes lead to feelings of guilt, and resentment.

Mark on the other hand is no longer dealing with destructive or hurtful behavior from his sister. However, he did have vague memories from the past of instances when she would tear something of his and this reminded him of momentary flashes of anger.

Acceptance

The issue of acceptance is one which permeates all aspects of the daily dealings of the non-autistic sibling with their autistic brother or sister. Regardless of degree of intrusive behaviors, the siblings all feel compassion for their sibling with autism. All feel a familial loyalty and have accepted the autistic sibling as an integral part of their family and as a brother or sister. Each have felt the pain of external judgement and misunderstanding, although each have rallied to the support of their sibling and their basic human rights. Each have also suffered feelings of shame, guilt, and embarrassment.

Each of the non-autistic siblings expressed their feelings that the permanent condition of their sibling caused them to feel deeply saddened.

Asia: "Just that he is different and he'll always be like that. He won't change It's so sad"

Mark: "Just the whole concept of her being autistic is sad."

Stuart: " ... I'm really feeling sorry for my brother lately but I don't like to start a whole conversation about that topic because then it would always be about sad things"

This sadness was, in part, an expression of the feelings of loss on behalf of the autistic sibling. They grieved for the inability of their sibling to partake in the

normal aspects of life, such as dating, good friendships, and fulfilling employment. It was also an expression of the feelings of loss felt by the non-autistic sibling. The continual permanence of the difficulties of their sibling meant that they would never share a complete and fulfilling sibling relationship.

All three siblings expressed a sense of pride in some area of accomplishment of their autistic sibling. Asia commented on the excellent memory and sense of humor of her brother. Mark was proud of his sister learning sign language and her ability to act in a socially acceptable manner. He was also proud to greet her in public whether he was with friends or by himself. Stuart thought his brother was talented at drawing and regrets that his brother did not do more art.

There was a sincerity to the caring all three participants felt for their sibling. When asked to describe their relationship with their autistic sibling, each stated their love: "Of course I love him, He's my brother," or "She's my sister". Their autistic sibling was viewed as a permanent part of their sense of family.

Each participant identified strongly with a sense of loyalty. Each sibling actively defended their less fortunate family member whenever their dignity as a person was threatened. In addition, Asia enjoyed her brother's

sense of humor, Mark was fondly amused by his sister's habit of entertaining herself in front of his fish tank or dancing to music. Stuart was comfortable with his brother returning home for his birthday and felt familial attachment to him.

All three siblings expressed interesting personal philosophies which they attributed to learning to accommodate to the unique behaviors of a sibling with autism. Each perceived difficulty in life to be a part of our natural condition rather than as a major hurdle or threat. They viewed the world through nonjudgemental eyes. Religion has played an elemental role in the lives of two of the three participants. The teachings of forgiveness, acceptance and love have given these adolescents a source of strength from which to draw.

The coping strategies of the three participants differed somewhat according to gender expectations. Asia dealt with her emotions through talking with friends and seeking moral support and understanding. She turned to a friend whose family situation was less supportive and loving than her own to express some of her concerns and emotions regarding conflicts and misunderstandings between herself and her parents of over her means of disciplining her brother. This provided an understanding outlet for her feelings while it also enabled her to reframe her view of

her family to include the more positive qualities of helpfulness and thoughtfulness.

The boys on the other hand dealt with their more painful emotions through putting them aside and involving themselves in activities that altered their perceptions of themselves. Instead of focussing on feeling trapped and powerless, their activities enabled them to gain mastery over skills and to gain a sense of agency in their own lives. Stuart involved himself in academia, computers, and hockey while Mark involved himself in athletics, job preparation and his hobbies.

A compartmentalization of feelings was more evident for Mark and Stuart than for Asia. "Stuart claimed, "I tried to keep down the impact". This camouflaging of emotions appeared reasonable in that these participants had little power over the situation associated with the condition of their sibling. To dwell upon the negative aspects that touched their lives seemed, for the moment, non-productive and depressing.

Each of the participants found for themselves a strong support group outside the home. Asia was deeply involved with her church group which she cherished above all else. Mark had good friends who shared similar interests, while Stuart enjoyed his computer wizard friends and his hockey pals. They each had developed a large part of their lives

separate and apart from their sibling with autism and their immediate family. They each enjoyed the fruits of this normal healthy outlet.

The participants all had made positive interpretations of aspects of living with a sibling with autism. According to Mark "It's like having a baby sister. You just have to watch them all the time It's no different." Stuart talked about there being "plusses and minuses" and how he felt that he had more freedom from parental interference due to his parents having to be so involved with his brother. Asia believed that she had learned at an early age how to accept the difficulties of life and still be able to go on with her life. "You always let yourself shine through". All the participants in this study appeared to have emerged as strong agents in their acceptance and dealing with their sibling with autism.

Limitations

One obvious limitation to this study is due to the use of volunteer participants. It is possible that only families who were comfortable discussing their life surrounding their autistic member or who felt a need to discuss their experiences participated in the research. As such, the recollections of voluntary participants may not be representative of the experiences of a wider group of siblings.

A further limitation of this study is due to the age range of the participants. This study only focuses upon the stories of adolescent siblings of those with autism. What was captured was the perception and feelings of siblings who were at this one crucial phase of development. These perceptions and feeling may well have been expressed differently if a different age group had been chosen.

Finally, a significant limitation of this study is due to the fact that the findings cannot be generalized to a larger population. The number of informants was small and all participants were Caucasians and of a similar socioeconomic status. The study does provide insight into the experiences of the siblings of autistic family members that, when combined with further study in this area, could lead to better understanding of the process of growing up with an autistic sibling.

Theoretical Implications

At the present time there appears to be no adequate theoretical model developed dealing with the impact of growing up in a family where a sibling has autism. This is an evident gap in the research in the area of autism. The issues that were identified in this study will hopefully provide the beginnings of this much needed research toward development of a fundamental way of looking at autism and its effects on the family members.

The presence of a family member who has autism influences the total family dynamic and everyone in the family. Therefore it is crucial to develop a theoretical model that has a family perspective. One of the more interesting theoretical models that may be appropriate in working with siblings of autistic family members is the Murray Bowen concept of differentiation (cited in Hoffman, 1981). Bowen noticed in his studies that families with, in this case, a psychotic member exhibited an intense clinging interdependence which he called the "undifferentiated family ego mass". The concept of undifferentiation or fusion describes the sense that none of the parts or pieces can move independently of the others or the whole and according to Bowen was a sign of trouble in the family. In contrast, Bowen suggests that families will do well where the individual members maintain a high degree of differentiation.

In the case of families with a very dependent member such as a sibling who has autism, it would appear reasonable to expect that the degree of total family commitment to support this family member offers a fertile ground for over involvement and potential fusion of the family members. In many ways, the issues and the experiences expressed by the participants of this study suggest that this model may be an appropriate starting point for working with these families.

Each of the participants shared experiences that showed that they felt significant responsibility toward their sibling with autism. This responsibility ranged from day to day care taking to feelings of personal responsibility for the behaviour and safety of the sibling. The continued well being of the autistic family member relied upon the co-operation and interaction of the remaining family members. This strong sense of responsibility must be balanced with a strong sense of differentiation for the family to do well.

Another indicator that this may be an appropriate theoretical model to use is the issue of privacy. Each of the participants expressed strong feelings of lack of privacy, of possessions, physically, and of personal space. As privacy is a normal means of expressing differentiation, the difficulty of providing this privacy would reasonably seem to heighten the need for differentiation.

Finally, the issue of restrictions, which was also a common issue among the participants of this study, would seem to further indicate a potential for greater fusion in these families. The fact that they were unable to easily participate in the community, partake of vacations, or engage in spontaneous activity forced them to rely on each other for their personal relief.

Practical Implications

Autism is a significant long term stressor for the family and places immense pressure on each member of the family. This extreme pressure can result in magnifying the normal push and pull of family members; the push for distance and the pull for togetherness, as in the Bowen concepts of differentiation and fusion. Consequently, the family will need to take significant measures to manage and cope with the situation. These measures will include turning to the helping professionals for support and assistance. This study has identified a number of areas that could be significant in providing this help to families that have an autistic member.

The siblings of the autistic family member expressed strong feelings with regard to their lack of privacy. Their inability to own and cherish items symbolizing their uniqueness was an important issue. This need and its lack of fulfillment should be considered as a significant issue when working with these individuals. The needs of each member to be connected yet separate from all other members represent boundary issues which may be at risk in families with autistic members.

A further implication of this study is that encouragement of social support groups can be a facilitating factor for the siblings of autistic children. The unique experience of living with a sibling with autism, as well as

the fact of being an adolescent appeared to be dual reasons for social networking providing an effective environment in which to admit feelings and to gain insight into their total family relationship. Additionally, the strength of the social network can also provide a helpful milieu to learn techniques for handling problems which may arise when interacting with their sibling with autism.

A third implication of this study is the need for establishing clear open communication within the family regarding the difficult as well as the more routine aspects of living with an autistic member. In the cases studied, there was a range of experiences expressed. From a therapeutic perspective it is not the event of living with an autistic sibling that may be damaging to an individual. Rather it is the perception of the event. It is important to explore and validate the perceptions of the individuals and their experiences. Parents may need to be helped to hear and validate the feelings and experiences of their children in order for them to feel strong and real. Misunderstandings regarding discipline, parent involvement, or responsibilities are all possible topics on which parents and children need to speak directly and clearly to one another. Similarly, how each family member is dealing with the difficult behaviors of the autistic member should be explored.

A further implication of this study is the need for creative approaches to facilitate the acquisition of the extraordinary level of family support services these families require. The families need to be helped to restructure responsibilities and to obtain outside resources in order to facilitate the family needs. Each of the siblings in this study commented upon their inability to partake in normal family outings as well as vacation opportunities as a consequence of living with a brother or sister with autism. Free time shared amongst the non-autistic family members is limited by the availability of outside respite and day-care facilities. Professionals working with these families need to become advocates for the development and acquisition of such services.

Implications for Future Research.

Research regarding all aspects of families with autistic members is needed. This research can provide effective insights from the perspective of each of the family members and can offer approaches for helping these families.

Specifically research is needed in the area of sibling experiences and response to living with a brother or sister with autism. There is a lack of information concerning how young people react to this experience and how they are impacted by it. These studies are needed to broaden the

knowledge gained from this study and hopefully an effective model can be developed that will assist in working with these families.

Patterns of interaction over the long term could lead to valuable insights as to how these individuals perceive themselves over time and how they internalize their experiences. This study focussed on siblings in their adolescent phase of development. Their perceptions of their experiences may well differ if examined at some later time such as early adulthood.

Another intriguing aspect of the sibling experiences might be to examine patterns that are set when dealing with intrusiveness of the autistic sibling. This topic was a strong expression for two of the participants of this study and may well be an indication of a worthwhile area of further study.

The participants in this study were all from highly functional families. It would be meaningful to expand the knowledge through examining the experiences of siblings in families that are not functioning as well as the ones in this study.

Research into generational differences in response to a family member with autism could also help fill the gaps in our knowledge of families with an autistic member. From previous research we know a little about the responses of

mothers and much less about the responses of fathers. This information could prove useful to provide professional service and support to these families.

Currently there is a lack of knowledge of how families with autistic members differ from families with normal members. Family processes and patterns need to be identified and compared. Our understanding of these families remains incomplete and creates an obstacle to effective intervention.

A further concern for the professional assisting families of children with autism is to determine whether the feelings of embarrassment, helplessness, and fear are being internalized into feelings of low self esteem. Is this the experience by which the sibling is defining him or herself or are they momentary or incident related experiences with which the sibling is learning to cope?

Summary

A case study approach was used to examine and describe the breadth of experiences of growing up in a family where a brother or sister has autism. The experiences of the siblings, their emotional responses, and their coping methods were be studied. This was an exploratory investigation in light of the rarity of research; an attempt to try to describe something of the significance of the experiences of these siblings.

The participants were three adolescents who had lived with siblings with autism for a minimum of ten years. These participants were from stable two parent families. They were selected in an opportunistic manner through initial identification by the Pacific Association for Autistic Citizens.

A portrait was developed capturing the experiences of each of the participants from the personal interviews with the participants and their parents. These portraits were then validated by the participants as well as expert authorities involved in the counselling profession.

The portraits developed support the view that living with a sibling who has autism is a varied and diverse set of experiences. Some of the experiences expressed showed similarities such as the expression of need for privacy by two of the participants. Other similarities included the feelings of loss associated with not being able to take vacations or freely go on family outings. However, on the whole, the experiences varied greatly.

It would appear that the experiences of each sibling of growing up with an autistic member in the family is best understood in their own context. Some of the elements of this context that assist us in appreciating and understanding these experiences include: the characteristics of the child with autism, the scope of the family resources,

and their means of utilizing them. In general the experiences of these participants indicated that there were common issues of responsibility, restrictions, and privacy and that they had developed ways of accepting their circumstances and accommodating their sibling with autism.

As there does not appear to be an adequate theoretical model for dealing with siblings of family members with autism, further research is needed to fill this gap. From this study, it was evident that living with a sibling who has autism raises the issues of responsibility, restrictions, and privacy, all of which have the potential for limiting individual differentiation and increasing fusion within the family. Therefore the Murray Bowen concept of differentiation may prove to be one of the more relevant theoretical concepts for work in this area.

The practical implications of this study include the need to develop and facilitate the access to outside resources for these families, the need to facilitate the establishment of clear family communications, the potential benefit to facilitating social support networks, and the potential benefit to facilitating privacy and a separate space for the siblings of the family members with autism.

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Appendix A - Letter of Introduction

Dear.....

I am in the process of writing a proposal for a Masters thesis in the Department of Counseling Psychology at the University of British Columbia. My topic is sibling adjustment to significant disability. I will be doing qualitative research using a case study approach. I plan to explore the range of effects on family members, especially siblings, resulting from their experiences and relationships with their significantly disabled family member. Specifically I plan to explore the nature of the coping strategies that family members develop in order to deal with the presence of autism in their family. I am writing to request your participation in recruiting participants for my research project.

I would like to interview non-disabled family members, (mothers, fathers and siblings) focussing upon the day-to-day impact of having a brother or sister with autism. I plan to study variations in sibling perceptions and responses to the presence of autism. The participants will be at least twelve years of age and will have lived with their disabled brother or sister for at least five years. If possible the participants will be from two parent families with no recent family trauma such as divorce or separation.

I will conduct an in depth interview with each participant. The focus of the interview will be on each sibling's experience and perception of the meaning of disability in their life and how it has impacted their place in the family, school, and relationships. Open-ended questions will be employed to focus on the sibling's experience, feelings and thoughts relevant to the meaning of a disabled brother or sister in their life.

During my initial contact with each family, arrangements will be made to hold the interview at a mutually agreed upon private location and time. This could be a quiet room in their home. At present I anticipate requiring approximately 3 hours in total with each family. The primary interview will take appropriately one and one half hours. If extra time is required through the need or request of the family this time will be made available.

If more than one interview is needed, a second interview will be scheduled at the earliest convenience of the family participant. A compacted time-frame will ensure that participants can share their experience without major breaks between interviews.

Please be aware that all interviews will be audio-taped. In order to ensure participant confidentiality, the data will be accessible only to myself and my thesis supervisor, Dr John Allan (229-4625). All tapes will be erased at the conclusion of the study. Participants' names and identifying information will be omitted from all transcript materials. Participants will be identified by pseudonyms only.

Please be aware that all participants will be informed that withdrawal from the project or the decision not to answer any specific questions will be honored, respected and complied with immediately.

At present the information we have on the effects on family life and on individuals of growing up with a significantly handicapped sibling, is contradictory and therefore misleading. There is even less information on autism and the coping mechanisms used by family members. This study will shed light on an as yet unexplored area specifically the impact of growing up with an autistic brother or sister. Information gained from this study may have broad therapeutic implications for families of the significantly handicapped. This information will be especially relevant for health care professionals and family members who deal with autism on an on-going basis and whose goal is to serve the needs of the whole family system.

Enclosed are copies of this letter to be distributed to prospective participants. Also enclosed is a summary sheet outlining the purpose, objectives, procedures and subjects selection criteria of the research project. These may be of help when providing relevant information to prospective participants.

If you have clients who would be available for and interested in participating in this study, please contact me at (926-9625). I will contact you by telephone approximately five days after delivering this letter of request. This is simply to ensure that you received this letter and to answer any questions you may have. Please feel free to call me at the above number.

Thank you very much for your time and anticipated cooperation.

Sincerely,

Shirley Jensen

I have a B.A. and a teaching certificate as well as a Diploma in Special Education. I have taught children with learning and behavior disorders as well as regular classes in elementary school math and language arts for the North Vancouver School District. I have been a special Education consultant for two year for the Gibson's School Board helping primarily with their visually impaired and multi-handicapped children and families. Last year I co-led a group for abused children and did one workshop for mothers of abused children for the Batter Women's Support Services. My degree in counseling is in the family specialty.

I Have two children aged nine and twelve. I have had limited vision throughout my life. As a member of a special needs family I would like the literature to more fully understand and address the needs of all family members in dealing with the unique circumstance of living day-to-day with profound special needs.

Appendix B - Summary Sheet

Title

A Phenomenological Study of Growing Up With A Severely Handicapped Sibling.

Researcher

Shirley Jensen. Former Special Education teacher and consultant with 9 years experience dealing with special needs families.

Present research project is for M.A. thesis at U.B.C. in counseling Psychology.

Purpose and Objectives

To explore the nature of the experience of growing up with an autistic brother or sister.

The interviews will focus upon the sibling's experience and perception of the impact of autism in their day-to-day life.

To explore and determine the dynamics that affect the meanings placed upon the experience as viewed by the sibling of an autistic child.

Subject Suitability Criteria

Twelve years old and over siblings of Autistic children.

Have lived with their disabled sibling for at least 5 years.

Procedure

In depth interviews will be conducted with each participant focusing upon sibling's varied feelings, perception and thoughts about the experience of having an autistic brother or sister.

At a mutually agreed upon private location.

Length and number of sessions will be dependent upon participant's needs for comfort. Researcher does not anticipate she will require more than three hours of total time with each participant.

All interviews will be audio taped.

Participation

All participation is volunteer.

Withdrawal from the project or decision not to answer specific questions will be honored.

After being contacted by social worker, if client is interested in participating in study, they will contact the researcher AS SOON AS POSSIBLE by telephone (926_9625).

All participants will be asked to sign a consent form. A copy of the consent form will be given to each participant.

Confidentiality

Contents of audio-tapes will be utilized only for the purposes of the present study.

Data will be accessible only to researcher and her supervisor Dr. John Allan (228_4625)

All identifying information will be omitted from transcripts. Participants will be identified by pseudonyms only.

All tapes will be erased after transcription.

Benefits

Participants may gain a deeper understanding of the dynamics of living with an autistic brother or sister.

Participants may gain a broader appreciation of some of the unusual opportunities as well as problems of living with autism.

With greater self-knowledge often comes greater self acceptance. It is hoped that participants will gain a deeper sense of self and thus a more enhanced appreciation of self.

The literature will be broadened to include information about the experiences of family members and their perceptions feelings and experience of day-to-day life with an autistic family member.

Appendix C - Consent Form

April 15, 1991

Dear Participant.

I am writing as a follow-up to your conversation with Natalia Bouvier from The Pacific Association for Autistic Citizens regarding your participation in my research. I am conducting a study to explore the range of effects on siblings of growing up in a family where there is a child with a significant handicap. This research is being conducted as a Master's degree Thesis at the University of British Columbia. The focus of the research will be on the perspective and experience of the non-handicapped brothers and sisters.

Your participation will involve meeting with me to engage in a dialogue regarding the range of effects of living with a sibling with a significant handicap. I would then interview the sibling(s) separately with the aim of allowing him/her to express him/herself in an uninhibited manner. Interestingly siblings have rarely spoken for themselves. Descriptions of siblings in families with a special needs child have been based largely on the observations and interpretations of either the parents or the health professionals.

I do not anticipate needing more than 3 hours of your time. If more time is required to comfortably tell your story, I will make the time available. I will schedule a second interview if one is needed. It will be necessary to hold the second interview as near to the first as possible so as not to distract or interfere with the flow of the story. All efforts will be made to find a setting which is comfortable, convenient and private.

The interview(s) will be audio-taped. The audio-taped data will be transcribed onto a disc on my personal computer. The audio-tape will then be immediately erased. All names and any identifying information will be omitted from the transcripts. The interview data will be accessible only to myself and my thesis supervisor, Dr. John Allan who

is a professor in the Department of Counselling Psychology at U.B.C. He can be reached at 228-4625. The data will not be used for any purpose outside the present research project.

Your participation in my research project is purely voluntary. You are under no obligation to participate and are free to withdraw from the study at any time. If you choose to withdraw from the study or decide not to answer specific questions, your wishes will be immediately respected, honored and complied with. If you do not wish to participate or choose to withdraw from the study for any reason whatever, this will not jeopardize your relationship with the Pacific Association for Autistic Citizens. If you agree to participate, please sign two copies of this letter of consent. You will keep one copy of the consent form and I will keep the other. If you have any questions or concerns about this procedure, please feel free to contact me at the number below. If you agree to participate in my research project, please sign your name below.

Yours sincerely,

Shirley Jensen
926-9625

I have read this form and consent to participate in this study. I understand that my participation is voluntary and that I am free to withdraw from the project at any time.

Date_____Name_____.

Phone_____Signature_____.

_____.

I consent)
I do not consent) to my child participating in this study.

Guardian or Parent Signature_____.

_____.

I acknowledge receipt of the signed participation consent form.

Researcher's signature.