The Family of a Child with Autism: A case study examination of mothers, fathers and siblings

by

Tanya Marie Davis-Jones
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We accept this thesis as conforming
to the required standard

[redacted]

Dr. D.G. Bachor, Supervisor (Department of Educational Psychology and Leadership Studies)

[redacted]

Dr. W.J.C. Walsh, Departmental Member (Department of Educational Psychology and Leadership Studies)

[redacted]

Dr. R.V. Ferguson, Outside Member (School of Child and Youth Care)

[redacted]

Dr. L. Sheilds, External Examiner (School of Nursing)

Supervisor: Dr. Dan G. Bachor

ABSTRACT

In the present study, the experiences of mothers, nondisabled siblings and fathers of children with autism are examined using ethnographic interview techniques. The purpose of this research was to describe the nature of the 'experience' of being a member of a family when a child with autism is part of the family constellation. A total of 6 families participated in the study. The interview transcripts were analyzed for the presence of themes. Common themes were identified across mothers, nondisabled siblings and fathers including the presence of verbal/physical aggression in the child with autism, and coping mechanisms and social issues (i.e. acceptance/rejection in public and at home) that developed in response to the aggression displayed by the children with autism. Although there appeared to be a common experience of the presence of a child with autism across participants, themes that were distinctive to mothers, nondisabled siblings and fathers were also identified.

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[redacted]

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[redacted]

Dr. R.V. Ferguson, Outside Member (School of Child and Youth Care)

[redacted]

Dr. L. Sheilds, External Examiner (School of Nursing)

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DEDICATION

This thesis is lovingly dedicated to my family who inspired me and provided me with the encouragement to realize this project.

Chapter I

INTRODUCTION

The negative impact that children with disabilities have on their families has been well documented. In general, the parents confront the challenges of additional financial constraints and child-care responsibilities, the diagnosis of their child as disabled, and emotional strain (Kiburz, 1994; Wilgosh, 1990). Currently, public policies for children who have severe disabilities reflect the general trend towards inclusive practice in that parents are encouraged to provide for their children in their home, and to be active participants in their children's habilitation and education (Lobato, 1983). It has also been acknowledged that these families require specific support services (McLinden, Miller, & Deprey, 1991), such as respite services, access to community resources, transportation services, and specialized educational services. Further, the parents of these children often have difficulty obtaining accurate diagnoses, struggle to find support in planning for the children's futures (Pearson & Sternberg, 1986; Wilgosh, 1990), and grieve as they come to terms with the fact that they have children with special needs (Opirhory & Peters, 1982). Taken in combination, the parents of children with disabilities are under considerable stress to meet the demands of caring for their children.

In order to more thoroughly understand the interventions and services required by the families of children with disabilities, researchers (e.g., Dyson, 1991; Mahoney, O'Sullivan & Robinson, 1992) have studied the variables that contribute to the parental stress observed in these families. Dyson (1991) examined the relationships between parental stress and family functioning in families of children with disabilities. She reported that parental stress was related to issues associated with caring for children with disabilities, the level of the parents' pessimism, and the negative views of the disabled children's limitations. These results are consistent with conclusions reached by Friedrich and Friedrich (1981), who reported that mothers of children with disabilities experienced increased levels of demands on their time and more negative attitudes about their children when compared with mothers of nondisabled children. Similarly McKinney and Peterson (1987) reported that mothers of children with disabilities identified more negative child characteristics when compared with mothers of nondisabled children. Conversely, these results are inconsistent with Frey, Greenberg and Fewell (1989), who reported that families of children with disabilities do not experience higher levels of stress than comparison families. Dyson (1991) argued that these inconsistencies result primarily from methodological flaws such as a lack of a comparison group, unequal sample sizes, and heterogeneous groups of disabled children. Thus, further investigation of families who have a child with a disability, to clarify the relationship between the stress imposed by the disabled child and the family's functioning, is warranted.

More recently, Mahoney, O'Sullivan and Robinson (1992) studied the family environments of, and social support required by, families of young children with disabilities. The purposes of their study were to describe these families, and to determine whether the families' reported levels of functioning were related to the severity of the children's disabilities and to the mothers' reported needs for support services. Based on the results of several questionnaires administered to the mothers, Mahoney, O'Sullivan and Robinson concluded that families of children with disabilities have stronger moral-religious orientations and report less participation in cultural and recreational activities. This is consistent with studies conducted by Dyson (1991) and Weisner, Beizer and Stolze (1991), who reported that these families have a distinct style of functioning that emphasizes achievement, moral-religious beliefs, and a greater family orientation. Furthermore, the overall pattern of family functioning of children with more severe disabilities was observed to be distressed. Mahoney, O'Sullivan and Robinson suggested, based on mothers' reports, that this distress was the result of unmet support needs (e.g., help from others and opportunities to discuss their feelings).

Dyson (1993) conducted a follow-up of her 1991 study to investigate parental stress and functioning of the families who had participated. Seventy-four of the original 110 families agreed to participate in a second study. She reported more parental stress in families of children with disabilities, related to parent and family problems in the care of the disabled child, and more pessimism concerning their children's futures and prognoses, than was observed during the initial study. In general, the parents of children with disabilities displayed higher levels of stress both times that they were questioned than comparison families. Conversely, Dyson stated that reports of a cohesive and supportive family environment were correlated with decreased parental stress only in families of children with disabilities.

In general, researchers examining the families of children with disabilities have limited their investigations to the impact that a child with a disability imposes on his/her parents. Adopting a family systems model, it is assumed that family members interact with one another, and develop relationships with each other, in ways that influence how the family functions as a whole (Minuchin, 1985). Based on the previous discussion, it should be clear that the presence of a child with a disability has an impact throughout the family system, influencing the economic situation of the family, family recreation, the opportunities for communication, and the development of social relationships. Therefore, it is important to examine the needs of all members of families of children with disabilities.

Goal of the study. The aim of the present study was to examine the families of children with a specific disability, autism. Families of children with autism have been studied for several decades (e.g., DeMyer, 1979; Holyroyd & McArthur, 1976) because the particular characteristics of autism appear to be more stressful for families than other types of disabilities (Bebko, Konstantareas, & Springer, 1987; Liwag, 1989; Morgan, 1988). Children with autism display sensory and perceptual deficits, developmental delays, cognitive deficits and limited language abilities. However, it is the severe behavioral deficits, including a lack of emotional response and social isolation, and the presence of stereotyped, repetitive and disruptive behaviors, that make it difficult for these children to develop and maintain positive reciprocal relationships within their families and challenge the functioning of their families.

The following section will identify some of the critical limitations of previous literature examining families of children with autism and provide the rationale for the methodology adopted for this study.

Families of children with autism. Holyroyd and McArthur (1976) compared the maternal reports of the effects of children with autism, children with Down's syndrome, and children receiving outpatient psychiatric treatment. Mothers completed a questionnaire designed to measure parent problems, issues in family functioning, and perceived problems for, or in, the identified child. Holyroyd and McArthur reported that mothers of children with autism identified more problems for themselves and their families. The mothers of these children also reported more disappointment with their children, and more concern about their children's dependency and the effect of their children on the family system. Further, children with autism had more limited activities to occupy them and were more restricted in future vocational pursuits. Finally, mothers of children with autism were more aware of the effects of their children's personality and behavioral problems. Taken in combination, as derived from mothers' viewpoints, families of children with autism have long-term physical and emotional demands placed on them that are more stressful than the experiences of families of children with other disabilities.

DeMyer (1979) conducted one of the most extensive studies examining the impact of children with autism on their families. The period of investigation lasted 12 years, from 1961 to 1973, during which she interviewed and observed 155 families of children with autism and 700 families of nonautistic children. DeMyer reported that the families of children with autism experienced an inordinate amount of stress and that "one large source of the stress [was] the inability of the autistic child to understand what is expected of him or to master the usual developmental tasks of childhood" (p. 149). Furthermore, these mothers experienced physical and psychological tension in all cases, guilt about something they had done or not done in 66% of the cases, and depressive symptoms, which were related to the stress imposed by the child with autism in the family, in one-third of the cases. Clearly, the specific effects of children with autism on their mothers have been the focus of previous investigations.

Summary. Reports of studies examining families of children with disabilities have contributed to our understanding of families of children with autism, most notably the stress experienced by these families. Until recently, however, conclusions have been based, primarily, on information provided by the mothers. Morgan (1988) was among the first to observe that specific examinations of the siblings and fathers of children with disabilities have been lacking. Thus, to address this limitation in the present investigation, the participant set has been expanded to include siblings and fathers.

Purpose and Definition

The purposes of the present study were to address the need for a more thorough examination of families of a child with autism by expanding the scope of this investigation to include the experiences of mothers, nonautistic siblings and fathers, and to further describe the impact that children with autism have on their families. This was accomplished by adopting ethnographic interview techniques to develop case studies of the participating families. One research question was addressed in the present study: What is the nature of the 'experience' of being a member of a family when a child with autism is part of the family constellation?

The definition of 'family' for the purposes of this examination stretched beyond the limits of traditional definitions (i.e., a married couple living with their biological children). Constellations that were rare two decades ago (e.g. stepfamilies, adoptive families and single parent families) are more common today and need to be taken into consideration when studying families. In fact, researchers have suggested that "despite anxieties about the destruction of the family, it is the 'forms' rather than the 'functions' of the family that have changed...[and that adhering to traditional definitions of the family could] hinder professional interactions with families" (Carpenter, 1998, p. 181). As such, the selection of participating families for this study was intended to reflect the demographic changes in family constellations in the last 2 decades.

Chapter II

REVIEW OF THE LITERATURE

The following section will begin with a brief review of the historical and current approaches to the definition of autism. Subsequent discussion will center on the impact that children with autism have on the family environment, specifically the parents. Finally, a select review of the literature related to siblings of children with autism will be presented.

Autism

Defining Autism

Kanner (1943) provided one of the earliest definitions of autism and described the disorder as "an inborn disturbance of affective contact" (p. 250). Kanner successfully differentiated this disorder from other childhood disorders, primarily schizophrenia. A list of 5 key behavioral characteristics were provided: (a) inability to develop relationships with people; (b) delayed acquisition of speech; (c) abnormalities in speech (i.e. echolalia); (d) repetitive and stereotyped play behaviors; and (e) early onset, usually within the first 2 years of life. With some modifications, subsequent definitions reflect Kanner's early observations. The fundamental characteristics of children with autism typically include (a) impairment in social development; (b) disturbance in speech, language and cognitive processing; (c) preference for routine and the presence of self-stimulating behaviors; and (d) onset within the first 30 months of life (Eaves, 1985; Rutter, 1978).

The most widely accepted definition of autism is currently the one provided by the American Psychiatric Association (1994) in the Diagnostic and Statistical Manual of

Mental Disorders (DSM - IV), in which Autistic Disorder is classified as a "Pervasive Developmental Disorder". Autism is viewed as a disorder that exists on a spectrum from mild to severe. The diagnostic criteria of the DSM-IV address three areas of deficit: (a) a qualitative impairment in social interaction; (b) qualitative impairments in communication; and (c) restricted repetitive and stereotyped patterns of behavior, interests and activities (p. 70-71). Other characteristics observed in individuals with autism might include hyperactivity, a short attention span, impulsiveness, self-injurious behaviors and disturbances of eating, sleeping, mood and emotions.

Although the DSM-IV is perhaps the most popular classification system, other definitions of autism have been developed and warrant mention. These definitions have highlighted different traits, however, all emphasize deficits in language and social skills. For example, the International Classification of Diseases (ICD-10) provides diagnostic criteria related to autism (World Health Organization, 1992). The classification system has much in common with the DSM-IV and its description of Pervasive Developmental Disorders. However, it extends other definitions by including descriptions of several forms of "atypical autism". Creak (1961) and Dorman and Winfield (2000) have also developed similar definitions. To add to the complex task of definition and classification, the variations in behaviors displayed by children with autism has led to the use of terms such as "autistic-like behaviors" and "high functioning autistic" in the literature (Eaves, 1985).

Despite these variations in definition and classification, it has been recognized that children with autism impact and challenge their families in specific ways (e.g., DeMyer, 1979). In fact, Rutter (1985) presented some guidelines in designing an appropriate treatment and service plan for the child with autism: (a) fostering of normal development in the child with autism; (b) placing the child with autism in a structured classroom; (c) emphasizing a multidisciplinary approach to the treatment of the child with autism; and (d) alleviating family distress, including the abatement of guilt in all family members and the provision of support in planning for the child's future. Clearly, Rutter recognized that the child with autism develops within a complex family system and that the needs of the family unit ought to be addressed when implementing a treatment and service plan for the child with autism.

Families of Children with Autism

This section will highlight conclusions and observations made by researchers examining families of children/adolescents with autism. The most prominent report made by researchers is that parents of children/adolescents with autism experience more stress than comparison groups of parents.

Holyroyd and McArthur (1976) compared levels of stress reported by mothers of children with autism, children with Down's syndrome, and children being seen in an outpatient psychiatric clinic. Mothers of children with autism and children with Down's syndrome identified similar problems (i.e. pessimism about their children's future, depression, and excessive time demands). However, the mothers of children with autism reported more embarrassment and disappointment, more physically dependent children, fewer community resources, and more disruptive behaviors displayed by their children. Holyroyd and McArthur concluded that mothers of children with autism experience greater interference with normal personal and family functioning than mothers of children with Down's syndrome. Based on their conclusions, it appears that there are patterns in family functioning shared by most families of children with disabilities. In addition, however, families of children with autism face unique challenges that merit further investigation; thus, in the present study members of such families were interviewed to examine further the impact of the presence of a child with autism on different family constellations.

One of the most significant and extensive studies of such families was conducted by DeMyer (1979). In a longitudinal examination of the impact of children with autism on their families, DeMyer found that reports of maternal stress were in response to the developmental limitations of these children. Further, mothers reported feelings of guilt, depression and anger, and reported more doubt in their parenting abilities. Consistent with previously reviewed literature, these results were based primarily on information that neglected to take into consideration the experiences of the siblings and fathers in these families. These results justify an examination of families where the concept of family includes more than the mother's experience. Thus, siblings and fathers were interviewed to further embellish the portrait of families of children with autism. One limitation to this extension is that the selected fathers were interviewed only when they live in the same home as the child with autism or, in the case of separation or divorce, share custody of the child with autism.

Donovan (1988) examined mothers' perceptions of family stress and ways of coping with adolescents diagnosed with autism or mental retardation. She reported that mothers of adolescents with autism experienced more stress and displayed less effective coping styles than mothers of adolescents with mental retardation. She suggested a relationship between the number of areas of impairment in the adolescent and the mothers' reported level of stress. Similar patterns of stress have been reported when the experiences of mothers of children with autism were compared with those of mothers of children with cystic fibrosis (Bouma & Schweitzer, 1990).

Donovan also reported that mothers of children with autism had lower coping scores than mothers of children diagnosed with mental retardation. In fact, she identified that these mothers were less likely to cope with the challenges of parenting an adolescent with autism by maintaining their social support system, self-esteem and psychological stability. This pattern suggests a need to interview these mothers to add to our understanding of their experience. For example, these mothers might have developed coping mechanisms that were not examined using these questionnaires.

Robbins, Dunlap and Plienis (1991) examined the functioning of 12 families of children with autism. Family functioning was measured as a function of the progress made by the children with autism in a family-oriented training program. Parental stress was established as a key element of family functioning. They reported that all of the mothers displayed high levels of child-related stress and concluded that children with autism are a significant source of stress for their mothers. Secondly, they identified an inverse relationship between parental stress and the amount of progress observed in the training program. It should be highlighted, however, that this relationship was correlational in nature. Examining families using a methodology that allows a more intensive examination into how families cope with the presence of a child with autism may allow the sources of stress to be identified by the parents during the interviews and upon further examination of the data by the primary investigator.

Kostantareas and Homatidis (1992) examined the reported involvement of three groups of parents: parents of developmentally delayed children; parents of children with autism; and parents of normal children. Mothers and fathers were asked to independently keep a log in which they reported their direct involvement with the target child on two separate days when they both were at home. Parents were also asked to report whether this involvement was fun, neutral or an imposition. The researchers concluded that self-reported interactions were shorter for the parents of children with autism. Further, parents of children with autism were least likely to rate any caregiving activities as fun. They suggested that these results might be explained by the lack of social reciprocity parents experienced when they interacted with their child with autism and the distress that they experienced as a result of this pattern of interaction.

Wadden (1994) examined the relationship between stress, social support and psychological health in 25 mothers of autistic children, adolescents and young adults. She compared these experiences to those of 25 mothers of learning-impaired and normally developing children, adolescents and young adults. The learning-impaired group served as control for the developmental level of the autistic group. As hypothesized, Wadden concluded that mothers of children with autism reported more stress than the other two groups of mothers. These mothers also reported more needs and, additionally more of them were unmet, than the other groups, which contributed to their reported level of stress.

Clearly, parental stress has been an important focus in the studies examining families of children with autism. In order to make sense of this stress, Bristol (1984) identified a pattern in the focus of parents' stress. Initially, the stress is focused around concerns for their child (i.e. their physical welfare) and the functioning of their family (i.e. maintaining family stability and balancing the needs of nonautistic siblings). This parental focus later shifts to ensuring that their child develops the necessary skills to survive in the community (i.e. self-help skills, behavior management, and development of the adolescent's sexuality), that their educational needs are met, and that they have reasonable and appropriate vocational opportunities.

Taken in combination, it is clear that the identification and development of effective support services, continuing into adolescence and adulthood, and which are designed to alleviate the stresses imposed by a child with autism and promote positive family relationships, are critical. The most feasible way to meet this outcome is to identify the needs of all members of these families and learn more about the strategies they have developed to cope with presence of a child with autism in the family.

Siblings of Children with Autism

Research examining siblings of children with autism has been limited and conclusions primarily drawn from maternal reports of the sibling experience. For example, DeMyer (1979) concluded that the effects of having a sibling with autism are both negative and positive. She stated that the stress and worry experienced by the parents inevitably affected the siblings of children with autism. Mothers reported that the siblings were more likely to display a variety of helping behaviors and only 30% of the siblings felt neglected; however, siblings were not interviewed so these reports may not be an accurate reflection of their feelings.

By contrast, McHale, Sloan and Simeonsson (1984) interviewed siblings of mentally retarded, autistic and nondisabled children. These children were asked to talk about their feelings for their brother or sister. Mothers were also interviewed and asked to discuss the impact that their disabled or nondisabled child had on the family environment and the target child's relationships. Siblings of mentally retarded and autistic children reported less family cohesiveness and involvement in family activities. They also rated the sibling relationship more positively than their mothers did.

McHale et al. further reported that the mean scores of the siblings on other variables were very similar; however, the range of these scores was greater in the handicapped groups. Therefore, there are siblings who appeared to be functioning very well and those who displayed considerably more distress about issues related to the child with autism. What can be concluded from this study is that mothers and siblings report different experiences and that there is variability in how nondisabled siblings report their experience.

Other researchers have used questionnaires to describe the experience of nondisabled siblings. For example, Mates (1990) examined the functioning of 33 siblings of children with autism in 4 areas: self-concept, academic achievement, home adjustment and school adjustment. He reported that there were no significant differences between this group and the normative sample. In fact, the mean self-concept score of the siblings of children with autism was greater than the normative sample. He concluded that there is some evidence that the presence of a child with autism in the family is associated with a positive self-concept.

Gold (1993) used similar techniques to compare siblings of children with autism and siblings of nonautistic children in terms of social adjustment and depression. In direct contrast to Mates' conclusions, Gold reported that siblings of children with autism scored much higher on measures of self-reported depression and were considered depressed depending on the adopted criteria for depression. With respect to social adjustment, no significant differences were found. However, conclusions regarding this report remain tentative. The questionnaire designed to measure social adjustment was administered only to the parents and may not accurately reflect the sibling experience. This highlights the need to ask the siblings of children with autism about their experience.

As with previous research, Rivers (1998) examined the sibling relationship in families of children with autism by interviewing parents and nonautistic siblings. Consistent with the results reported by McHale et al. (1984) siblings rated their relationship with their brother/sister with autism more positively than their parents. Additionally, Rivers reported a correlational relationship between the quality of the sibling relationship and marital distress; siblings of children with autism were more likely to report directing negative behaviors towards the child with autism in families where a parent reported more marital stress. This pattern of results highlights how the family unit works as a system and the need to consider the experiences of all family members in the examination of families of children with autism.

In summary, it appears that the experiences of siblings of children with autism are contradictory and inconclusive, primarily, because mothers have been the main source of information in previous studies in this area. As such, there is a need to include nonautistic siblings as informants in all examinations of families of children with autism.

Characteristics of Siblings of Children with Autism

Siegel (1996) examined how nonautistic siblings cope with the unique challenges of living with a child with autism. He summarized and described three patterns of coping displayed by siblings of children with autism: (a) the parentified child, used to describe siblings who act like a parent to the child with autism; (b) the withdrawn child, used to describe siblings who have become overwhelmed by the demands placed on them by the behaviors of their autistic sibling or parents; and (c) the superachiever or family mascot, used to describe the extroverted sibling who attempts to compensate for the perceived losses that the family is experiencing.

Minimizing the Effects on Siblings of Children with Autism

Although children with autism will inevitably have an effect on their siblings, the nature and extent of this effect can be mediated by informed support service delivery to the families of children with autism. Howlin (1988) suggested several ways to minimize the negative effects of the child with autism on the family by specifically considering the needs of the nonautistic sibling. She offered five types of suggestions: (a) increasing family interactions that do not center on providing care to the child with autism, perhaps by making use of respite care; (b) meeting the social and educational needs of the other children, for example by validating their need for privacy and time alone; (c) avoiding undue physical and emotional pressures on siblings, by encouraging outside interests and remaining sensitive to signs of resentment or jealousy; (d) explaining and discussing the nature of autism to lessen feelings of confusion and guilt; and (e) involving the other children in planning for the treatment and care of their brother or sister.

Acknowledging the important role siblings of children with autism play, Celiberti and Harris (1993) examined the effectiveness of a treatment program designed to teach siblings to use social skills while playing with their autistic brother or sister. The goal was to improve the experience of the nonautistic sibling. They argued that siblings of children with autism want to interact with their siblings; however, they often lack the necessary knowledge of autism and training in behavior management techniques to successfully interact with their brother or sister. The nonautistic siblings were trained in three skill areas: (a) delivering play-related commands; (b) praising their sibling's desired behaviors; and (c) responding appropriately when their sibling does not comply with a request. The nonautistic siblings were interviewed before and after training. The details of the interview process and analysis were not provided. Celiberti and Harris reported that all siblings mastered the target skills engaged in more activities with their siblings, and in more contexts, following the training. They also reported that the nonautistic siblings were less likely to stop playing with their brother or sister as result of their disruptive behaviors. This study provides support for asking children about their relationship with their brother or sister with autism.

Belchic and Harris (1994) also highlighted the benefits of using nonautistic siblings in the treatment of children with autism and the positive influence that this has on the family unit. However, there is a need for a more thorough understanding of how the nonautistic sibling feels about his/her relationship with their autistic brother or sister. This is especially important when the nonautistic sibling is encouraged to act as ‘teacher’ to his/her brother or sister, or when they have some responsibility for managing their sibling’s behavior. As discussed in the following section, the nature and perception of the sibling relationship is an important part of the developmental process.

Sibling Relationships

In this section, a review of the literature on sibling relationships is presented. Reviewed are the normal sibling relationship and what is currently known about siblings of children with disabilities. In this review the normal sibling relationship and its developmental importance are described; the characteristics and concerns of nondisabled siblings are summarized; the factors that appear to mediate the adjustment of these siblings and the support required by these siblings are noted; and, the relationship between disabled and nondisabled siblings is examined. The assumption underlying the inclusion of this research is that the conclusions drawn from this literature justify further investigation of the sibling relationship and provide insight into the experience of being a sibling of a child with autism.

Normal Sibling Relationships

Dunn (1983) reviewed the literature examining the relationship between normal siblings. She concluded that siblings spend more time together than they do with their mother and sometimes spend twice as much time together than with either parent. She also reported that siblings learn from each other by imitation and exhibit positive social actions toward each other by supporting each other in times of distress. Finally, she suggested that sibling interactions influence the development of future relationships and personalities of each sibling. Therefore, the sibling relationship is an important one in a child's overall development.

Bronfenbrenner (1977) argued that a child's development is influenced by the direct and reciprocal interactions between the child and his or her immediate environment. The child's immediate environment includes his or her mother, father, sibling(s), school, peers and neighborhood. According to Bronfenbrenner "the relevant features of the [child's] environment include not only its objective properties but also the way in which it is perceived by the [child]" (p. 516). Therefore, ethnographic interview techniques were incorporated into the present investigation to ask siblings of children with autism about their relationships with other family members and their role within the family system.

Characteristics and Concerns of Siblings of Children with a Disability

In the literature examining families of children with disabilities siblings have too often been neglected members of the family (Atkins, 1991). However, Post-Kammer and Nickolai (1985) cited research indicating that these siblings are often affected by the demands that a child with a disability places on them. They described the seven most common characteristics and concerns of siblings of children with disabilities: (a) denial, or the avoidance of contact with their disabled sibling and parents; (b) anger, often directed at the financial and emotional constraints imposed by their disabled sibling; (c) bargaining, or playing the role of mediator; (d) depression, feelings of neglect, or behaviors designed to get the parents' attention; (e) guilt, as a result of negative feelings directed at family members; (f) fear, which includes apprehension that they might "catch" the disability, that their peers will ridicule them and their sibling, that they will be responsible for their sibling if the parents die, and that they will have a child with a disability; and (g) acceptance, as observed in the development of a positive sibling relationship, in which the nondisabled sibling adopts the role of the older sibling regardless of birth order, and/or in outward displays of appreciation for individual differences and family ties.

By contrast, Atkins (1991) reported that siblings of children with disabilities experience only negative feelings, including loneliness, confusion, resentment, embarrassment and jealousy. In fact, Trevino (1979) suggested that they were at greater risk, than other siblings, for developing emotional and psychological problems. Others have simply concluded that the findings remain inconclusive (Fisman & Wolf, 1991).

In an effort to clarify these contradictory results, Lobato (1983) reviewed the literature examining the impact that children with disabilities have on their siblings. She concluded that only certain siblings are vulnerable to the stresses imposed by their disabled brother or sister. Some of the key variables identified by Lobato included gender, socioeconomic status and birth order. In general, younger siblings, older sisters and siblings living in lower socioeconomic homes appear to be more vulnerable than other siblings. However, Lobato also argued that there have been few well-designed studies in which the dynamic relationships between variables affecting the development of the nondisabled sibling have been examined.

In more recent investigations, there have been few, if any, conclusive results. For example, Kiburz (1994) examined the experiences of siblings of children with myelomeningocele. Nondisabled siblings were asked open-ended questions about their knowledge of myelomeningocele, their feelings and their family life. Mothers and nondisabled siblings were asked about the sibling relationship. Kiburz reported that nondisabled siblings experienced an overall warmth and love for their disabled sibling, which included a desire to protect their sibling and concern about their sibling's physical well-being.

Kiburz suggested that caution was necessary in interpreting these results, however, as siblings may have been reluctant to express negative perceptions of their relationship with their brother or sister. This is consistent with the findings of Pearson and Sternberg (1986), who suggested that siblings are aware of the pressures that their parents are under and choose to cope with their feelings and thoughts by not talking about them. Clearly, the development of an accurate conceptualization of the experience of having a sibling with a disability is limited and worthy of further exploration.

Atkins (1991) suggested that siblings of children with disabilities adopt specific roles in the family. She described three roles that are often adopted by these siblings: (a) "the superachiever", working very hard to receive recognition in many areas; (b) "the mediator", mediating between the parents and the sibling and protecting everyone; and (c) "the unmotivated underachiever", focusing energy on achieving recognition in one area. As such, it appears that the presence of a disabled brother or sister has an impact of his or her nondisabled sibling(s), and that the overall functioning of their families is affected as well.

Mediating Factors

There are factors that appear to mediate the adjustment of children with disabilities (Lobato, 1983; Post-Kammer & Nickolai, 1985; and Trevino, 1979). Based on a review of the literature in this area, Trevino (1979) suggested four variables that interact to cause conflict for the sibling of a child with a disability: (a) the number of siblings; (b) the age of the siblings/birth order; (c) the sex of the siblings; and (d) the level of parental acceptance of the disability. With this knowledge, Trevino identified four circumstances which might place nondisabled siblings at risk for poorer emotional and psychological adjustment: (a) when there are only two siblings (with one who is disabled); (b) when the nondisabled sibling is close in age to the sibling with a disability, or is the oldest female child; (c) when the siblings are the same sex; and 4) when the parents do not to accept their child's disability.

Furthermore, Lobato (1983) suggested that the socioeconomic status of the family contributes to the functioning of siblings of children with disabilities. In general, families with a higher socioeconomic status are more likely to access community support services, while families with a lower socioeconomic status are more likely to rely on nondisabled siblings to help with the daily household chores and responsibilities.

In an effort to develop ways to support siblings of children with disabilities, Post-Kammer and Nickolai (1985) identified four specific needs of siblings of children with disabilities: (a) information about their sibling's disability; (b) a supportive environment in which they are encouraged to express their feelings of guilt, fear, anxiety, and anger; (c) an identity apart from their disabled sibling; and (d) coping strategies, including the acquisition of communication skills, to interact with their disabled sibling. Recommended actions to meet these needs were sibling support groups, sibling education, individual counseling, and involvement in meetings concerning the care and treatment of their brother or sister.

Support for Siblings of Children with Disabilities

In general, controlled investigation into the support that siblings of children of disabilities receive has been insufficient. For example, Pearson and Sternberg (1986) presented a brief outline of a support program for parents and siblings of children with disabilities. Pearson and Sternberg, however, neither evaluated this program for its success at providing the necessary support, nor did they describe the challenges faced by these families. Although inconclusive, this study is included in this literature review to highlight the importance of identifying the supports used by the families of children with disabilities and the need to evaluate the effectiveness of these programs.

More recently, McLinden, Miller and Deprey (1991) evaluated the effectiveness of a 6-week support group for siblings of children with disabilities. The focus of the group was to promote an acceptance of both negative and positive feelings for their disabled siblings, and to provide factual information about their siblings' disability. Comparisons were made between pre-test and post-test measures of self-concept, social support and parental reports of the nondisabled siblings' behavior. McLinden, Miller and Deprey reported significant differences between pre and post-test measures of social support; participants in the support group reported increased social support. No other analyses revealed statistically significant differences. When mothers' perceptions of the effectiveness of the group were examined, they reported some improvements in the nondisabled sibling's feelings toward their disabled brother or sister. The most significant limitation of this study is that the nondisabled siblings' perceptions of the program were not examined.

Similarly, Marcenko and Smith (1992) examined two programs designed to provide support services to families of children with developmental disabilities and chronic health conditions. Mothers were interviewed during the first month of participation in the program and again a year later. Mothers reported an increase in their ability to access necessary services for their disabled child (e.g., respite, nursing, educational services and transportation). However, they reported no differences in how well their nondisabled child was coping with the demands placed on them by their sibling with a disability, how well they were sleeping, or their feelings of fear, anger and resentment. Again, nondisabled siblings were not interviewed.

In summary, mothers have provided the basis for our understanding of the experience of having a sibling with a disability and the effectiveness of sibling support groups. Furthermore, it might be that nondisabled siblings are reluctant to talk about their experiences. Therefore, there is a need to interview these siblings about their experiences of sibling support groups, in addition to other relevant issues, in a safe setting that would allow for open and honest communication of their thoughts and feelings. The challenge for researchers is to develop the rapport necessary to create this safety.

The Relationship between Disabled and Nondisabled Siblings

Lobato, Faust and Spirito (1988) provided a critique of select studies that have examined the relationship between a child and his/her disabled sibling. In this critique they emphasized the fact that there have been few controlled studies describing how this sibling relationship differs from the normal sibling relationship. They concluded that, in general, interpretations of the findings of a number of these studies have been contradictory and inconclusive.

More recently, Dallas, Stevenson and McGurk (1993) observed and recorded the interactions of 64 cerebral-palsied children and their siblings at play in their homes. They reported that siblings of children with disabilities displayed more directive, facilitative and prosocial behaviors than the comparison group of children. The interaction styles adopted by disabled sibling pairs were characterized by the authors as "hierarchical in nature"; the normal sibling adopted the role of the older sibling regardless of birth order, and the disabled sibling displayed higher levels of compliance and fewer dominant behaviors. This mode of interaction was intensified when the nondisabled sibling was the eldest.

In summary, it appears that the reciprocal nature of the sibling relationship is absent from the relationship between a disabled child and his/her brother or sister. Furthermore, it can be suggested that this will impact the psychological and social development of the nondisabled sibling. The potential impact of a child with a disability on the nondisabled sibling, and on his/her family, justifies a more thorough examination of the nondisabled sibling's experience.

Siblings of Children with Disabilities

In an effort to determine the factors that inhibit or promote the positive emotional and psychological functioning of the nondisabled sibling, McHale and Gamble (1989) conducted a longitudinal study examining the effects of having a younger brother or sister with a disability. Measures taken in interviews with the nondisabled siblings included self-esteem, depression, anxiety, sibling interaction, and a rating of the nondisabled siblings' satisfaction with the sibling relationship. Measures taken in interviews with the mothers included demographic information, the disabled sibling's level of functioning and behavior, and ratings of the nondisabled siblings' conduct problems and the sibling relationship. Seven follow-up telephone interviews were conducted, with both the nondisabled siblings and their mothers, in the 2 or 3-week period following the home interview. Nondisabled siblings were asked to report on the type, frequency and duration of a variety of activities with their disabled brother or sister in the weeks following the initial interview. Mothers were asked to report on the type, frequency and duration of activities, with both of her children, in the weeks following the initial interview. McHale and Gamble reported that siblings of children with disabilities recalled spending more time engaged in caretaking activities, and displayed more symptoms of depression and low self-esteem, than other brothers and sisters.

Although this study seems to provide justification for concluding that siblings of children with disabilities are at greater risk for emotional and psychological maladjustment, Dyson, Edgar and Crnic (1989) recognized that the effects of having a disabled sibling are not uniform. They hypothesized that predictors of sibling adjustment would include parental attitudes, social support, and their family's psychological environment. They collected demographic information, parental reports of nondisabled siblings' behavior, family support and resources, and took measures of the nondisabled siblings' self-concept and the family environment. Dyson, Edgar and Crnic reported that nondisabled siblings' self-concept was best predicted by parental stress and resources; increased parental stress was related to decreased self-concept. Similarly, their behavior problems were best predicted by the family relationship; nondisabled children in supportive family environments with free expression of feelings and minimal interpersonal conflict displayed fewer behavior problems. Finally, in homes where there was an emphasis placed on independence, moral-religious beliefs, and cultural-recreational activities, nondisabled siblings were more socially competent. Conversely, social support was not a significant predictor for the group of comparison children.

More recently, McHale and Pawletko (1992) examined the differential treatment of siblings in families of children with disabilities. They conducted home interviews with both the mothers and nondisabled siblings. Additionally, they conducted 7 telephone interviews with the mothers in the 2 or 3 weeks following the home interview. During home interviews, the mothers and nondisabled siblings completed structured questionnaires evaluating the nondisabled children's psychological well-being and the sibling relationship. Furthermore, mothers were asked to rate the frequency with which they used 11 disciplinary behaviors (as discussed in Steinmetz, 1979). Three summary scores were computed reflecting the proportions of positive love (including use of reasoning and explanation of the other's point of view), negative love (including ignoring, criticizing and isolating the sibling) and power assertive techniques (including physical punishment and the use of rewards or privileges) used by the mothers. During the telephone interviews, mothers were asked to report on their involvement in activities with each child and on each child's participation in household tasks. McHale and Pawletko reported that less involved children were better adjusted and had more positive sibling relationships. Conversely, those siblings who reported the most positive sibling relations displayed symptoms of poorer adjustment, while those who reported the least positive relations reported the highest levels of adjustment. Further, there were greater levels of differential treatment observed in families of children with disabilities.

These results were interpreted as a reflection of the ambiguity that the siblings experience. Although they may believe that it is "fair" for their sibling to be treated differently, there may be the simultaneous experience of negative emotions. Furthermore, it can be suggested that nondisabled siblings' expression of negative perceptions of the sibling relationship contribute to their positive emotional and psychological adjustment.

Dyson (1996) examined the functioning of families with learning disabled children. They took measures of family stress and resources, the family functioning and environment, and the nondisabled siblings' self-concept. Additionally, parents were asked, "Has learning disability in your child caused any problems in terms of family, siblings and school?" and, "What has been your experience with regard to family, siblings, and school that is related to your child's learning disability?" (p.282). Dyson reported that families of children with a learning disability experienced increased parental stress and placed greater emphasis on personal growth, and that nondisabled children scored higher than the norm on the Piers-Harris Children's Self-Concept Scale (Piers, 1984). Next, she evaluated the families' experiences in three contexts: family relations, sibling relations, and issues concerning school. Within the family context, parents often reported denial of their child's learning disability and concern about the learning disabled child's behavioral deficits. With respect to sibling relations, parents reported that this relationship was generally positive. However, parents also reported that they felt guilty about the amount of time they gave to the learning disabled child in comparison to their nondisabled child. Finally, parents reported feelings of anger and frustration with the length of time that it took to assess their child's learning disability and find an appropriate placement. Again, nondisabled brothers and sisters were not asked about the family environment or their relationship with their disabled sibling.

Taken in combination, these results highlight the complexity of the dynamics that contribute to the overall adjustment of the sibling of a child with a disability. However, these studies have not focused on families of children with autism.

Siblings of Children with Autism

Since mothers experience an increased amount of stress, it seems reasonable to suggest other members of the family (i.e. nonautistic siblings) would be affected by the unique circumstances presented by a child with autism. Fisman and Wolf (1991) stated, "the increased stress in the families of handicapped children and its impact on both parents, particularly the psychological well-being of the mother, affect the well sibling as well as the handicapped child" (p. 212). Therefore, several studies were designed to describe what it might be like to be the sibling of a child with autism.

For example, Holl (1998) provided nonautistic siblings with the opportunity to talk about their experience using ethnographic interview techniques. She interviewed the nonautistic siblings and parents in 5 families. The nonautistic siblings in this sample gave inconsistent reports when asked about the overall view of the sibling relationship and some of the siblings had mixed feelings. Others did not answer the question or were indifferent in their description of the sibling relationship. All of the siblings described special challenges they experienced living with a child with autism. They also displayed considerable knowledge of autism and empathy towards the child with autism. However, both the nonautistic siblings and parents reported spending little time together as a family. To conclude her discussion of the results, she identified some clinical implications for families of children with autism. These included recommendations for psychoeducational groups for the nonautistic siblings and family therapy.

In a similar effort to understand the nonautistic siblings' experience, Mates (1990) examined the adjustment and performance of siblings of children with autism at home at in school. He examined the effects of gender and family size on such variables as home adjustment, school adjustment and self-concept. Mates reported no significant differences on measures of sibling adjustment between male and female or between siblings from two-child and multi-child families. Nonautistic siblings' scores were similar to those of normative samples. In fact, the mean self-concept score of the nonautistic siblings was greater than the normative sample.

The results of previous examinations of siblings of children with autism have been inconsistent. This pattern justifies providing additional opportunity for siblings of children with autism to talk about their experience.

Fathers

In this section the lack of studies investigating the fathers in families of children with disabilities or autism is discussed. Further, the assumptions that have previously guided research in this area are highlighted.

As stated, mothers have been the primary focus in studies examining families of children with disabilities. Further, researchers appear to have equated the word "parental" with the word "mother" and have assumed that there is a perfect relationship between maternal and paternal reports of the family experience and the sibling relationship (e.g., Dyson et al., 1989; Erickson & Upshur, 1989; Rivers, 1998). For example, Dyson et al. (1989) reported that mothers alone completed 87% of the questionnaires. However, when reporting their results, they discussed the effects of increased parental stress and parental support on the family environment.

Erickson and Upshur (1989) investigated the mothers' perception of fathers' participation in caring for an infant with a disability. Mothers rated the frequency with which fathers performed each task. They reported that fathers of infants with disabilities displayed less participation in the care of their children when compared with fathers of nondisabled infants. Although Erickson and Upshur recognized that fathers are an important part of the family unit, they drew conclusions based solely on mothers' self-reports.

Similarly, Rivers (1998) identified only one father as a participant in her study of siblings of children with autism. However, she focused her discussion and conclusions on her interpretation of "parental reports".

These patterns of investigation highlight the need to further investigate the role that fathers play in the families of children with disabilities. Although it is expected that there is a relationship between maternal and paternal reports, it is also anticipated that there will be differences in these reports reflecting their unique experiences and interpretations of the family environment.

This limited study of fathers has occurred "despite widespread recognition of the important roles that fathers play" (Bailey, Blasco, & Simeonsson, 1992, p. 1). In fact, Ballard et al. (1997) suggested, "Our understanding of fathers of disabled children is based on little more than a handful of studies" (p. 238).

For example, DeMyer (1979) included a very brief description of the effects on fathers of children with autism as individuals. She stated that fathers are not as involved in childcare as the mothers. Further, approximately 45% of fathers were concerned about their wives' concern and preoccupation with their child's condition. Several fathers reported concern about the mothers' physical and emotional health.

Similarly, Margalit and Heiman (1986) compared how mothers and fathers of learning disabled (LD) children perceive their family environment. Parents of LD children completed a structured questionnaire evaluating their family environment and anxiety levels. Margalit and Heiman reported that parents of LD families displayed higher levels of anxiety. Furthermore, differences between mothers and fathers emerged when measures of anxiety and family environment were compared. Fathers of LD and Non-LD children reported that they were concerned about the conflicts in their families. However, only the fathers of LD children related this concern to their anxiety. As for mothers of LD children, increased anxiety was related to lower expectations for achievement of family members.

Bristol, Gallagher and Schopler (1988) examined how the presence of a young child with autism or a child with communication impairments affects the adaptation and roles of mothers and fathers. They reported that mothers of children with disabilities were more at risk for depression, and were more likely to report more marital adjustment problems and more disruption in daily life, than mothers of nondisabled children. Furthermore, fathers of children with disabilities assumed less responsibility for family tasks when compared with fathers of nondisabled children. However, the lack of father involvement appeared to be specific to the care of the child with a disability and not their sibling(s). Finally, there were no differences in adaptation and support when families of children with autism and families of children with severe communication impairments were compared. Bristol, Gallagher and Schopler concluded that this pattern reflects the similarities in social skill deficits displayed by the two groups of disabled children.

Similarly, Beckman (1991) compared mothers and fathers of children with and without disabilities in the areas of reported stress, care giving requirements, and social support they received. Based on a review of the literature, she hypothesized (a) that there would be differences in the amount and type of stress reported by mothers and fathers; (b) that parents of children with disabilities would report more stress and care giving demands; and (c) that this stress would be related inversely to social support and positively related to increases in the unique care giving requirements of the child with a disability. Consistent with previous research, mothers reported more depression, more adjustment difficulties in the area of parenting competence, more marital dissatisfaction, and more adverse effects on their health. Fathers of children with disabilities reported more problems in the area of attachment. Moreover, parents of children with disabilities reported more stress when compared with parents of nondisabled children. Conversely, there was an inverse relationship between reported stress and informal support for both parents. However, only fathers of children with disabilities reported that decreases in their stress levels were related to increases in formal support. Finally, care giving requirements were not associated with increases in stress levels reported by fathers of disabled children; the opposite pattern was observed in the mothers of these children.

It is important to highlight, however, that there was considerable variation in stress scores within the families of children with disabilities. This reflects the complexity of these family dynamics and the variations in adaptation achieved by these parents. Thus, Beckman concluded "researchers should [continue to] distinguish between mothers' and fathers' perceptions in order to obtain a more accurate description of the effect of a child on the family" (p. 592).

Bailey, Blasco and Simeonsson (1992) examined parental adaptation to children with disabilities by comparing the needs expressed by mothers and fathers of children with disabilities. Parents were asked to rate specific needs (e.g., "I need more information about my child's condition or disability") on a 3-point Likert scale (i.e., definitely do not need help, not sure, and definitely need help). They reported that mothers expressed more needs than fathers and that low-income mothers identified a greater need for financial support. Furthermore, mothers appeared to view the addressed needs and concerns differently than fathers; Bailey, Blasco and Simeonsson concluded that mothers do not separate personal concerns from family concerns, while fathers differentiate their individual needs and concerns from those of the family as a whole. Finally, mothers reported a need for more time to self, a need for help in explaining their child's condition to others, and more of an interest, than fathers, in meeting other parents of children with disabilities. They concluded, "these findings reinforce the importance of ascertaining the particular needs of each family [and] key family members...[and highlight the need to gather] information in other areas...and with other procedures (e.g., interviewing or observational strategies)" (p.9).

Rodrigue, Morgan and Geffken (1992) also recognized that fathers of children with autism have been neglected in previous research of families of children with disabilities. They compared fathers of autistic, Down's syndrome and normally developing children in the areas of intrapersonal functioning, family environment and social-ecological functioning. It was hypothesized that fathers of children with autism and Down's syndrome would report more concerns when compared with fathers of normally developing children, in these areas. Based primarily on the unique characteristics of autism (e.g., deficits in social development), and greater difficulty in accessing support services for the children with autism, they hypothesized that fathers of children with autism would report greater difficulty in these areas than fathers of children with Down's syndrome.

Overall, the first hypothesis was partially supported; fathers of children with disabilities reported more disruption in family planning and more financial struggles. However, reports by these fathers in other areas (i.e., perceived parenting competence, marital satisfaction and social support) were similar to reports of fathers of normally developing children. With respect to the second hypothesis, they reported that fathers of children with autism used coping strategies, such as information seeking and wish-fulfilling fantasy, more frequently than fathers of children with Down's syndrome.

Rodrigue, Morgan and Geffken argued that these strategies were adaptive and did not support the hypothesis that fathers of children with autism would report more intrapersonal adjustment problems. They concluded that the presence of a child with autism does not contribute to a general experience of parental stress. Further, the experience of mothers and fathers of children with autism appear to be very different and may reflect the perceived differences in their parenting roles (i.e. financial support from fathers and primary care from mothers).

Fisman and Wolf (1991) explored the effects of children with developmental disabilities, including autism, on their families. Parents completed questionnaires measuring parental stress, depression, marital adjustment and social support. They reported that mothers and fathers of children with autism perceived greater stress than parents of children with Down's syndrome. Moreover, mothers and fathers of children with autism were at greater risk for depression than the other groups, a pattern that appeared to be mediated by increased social support. Finally, both parents of children with autism scored lower on measures of intimacy.

Kostantareas and Homatidis (1992) examined the reported involvement of three groups of parents: parents of developmentally delayed children; parents of children with autism; and parents of normal children. Mothers and fathers were asked to keep a log in which they independently reported their direct involvement with the target child on two separate days when both parents were at home. Parents were also asked to report whether this involvement was fun, neutral or an imposition. The researchers concluded that self-reported interactions were shorter for the parents of children with autism. Further, fathers of children with autism reported the least amount of involvement.

More recently, Ballard et al. (1997) interviewed 15 fathers of children with disabilities in an effort to describe the experience of being a father of a child with a disability, including their interactions with professionals, educators, and other support services. They identified eight significant issues when the interview transcripts were analyzed: (a) three were related to the organization and delivery of resources and support (i.e., importance of the itinerant teacher, access to a computer and lack of occupational therapy and physiotherapy within the school); (b) three concerned professionals and their accountability to parents (i.e., professionals promising services that were not made available, resolution of conflict between parents and educational staff, and lack of ongoing support in the face of reports that some children with disabilities were not treated with respect by other students); and (c) two issues were related to educational mainstreaming (i.e., the exclusion of children with disabilities from classroom and school activities, and a perceived lack of resources in mainstream settings). Ballard et al. suggested that a lack of support services might contribute to stress for the family system, most significantly for the mother, and stressed the need to actively include fathers in the process of providing support to their child with a disability.

Gray (1997) asked parents of children with autism about their perceptions of 'normal family life'. The data were collected using semi-structured interview techniques. Parents were asked about such things as the onset of symptoms, the diagnosis and the effects of autism on the family. He reported that parents identified being able to engage in family outings, maintain family rituals (e.g. eating together and doing things as a family) as part of what constitutes normal family life. Further, the mothers in this sample were more likely to indicate that they were impacted than the fathers. Finally, the presence of aggressive behaviors displayed by the child with autism was associated with parents' reports that their family was abnormal.

In sum, there is a need for a more thorough examination of the complexities of the relationships that develop in families of children with autism. As such, one goal of this study was to describe more completely the experience of fathers in families of children with autism.

Support for a Qualitative Examination of the Family of a Child with Autism

In this section, some methodological strengths and weaknesses of previous studies examining families of children with autism/disabilities are explored. This brief review is intended to justify the use of ethnographic interviewing with families of children with autism.

Methodological Issues in Previous Examinations of Families of Children with Disabilities

Research methodologies used to study families of children with disabilities can be classified into three categories: (a) structured questionnaires/surveys; (b) interviews and observation; and (c) a combination of these techniques. Select studies falling into each of these categories are reviewed below.

The bulk of these studies fall into the first category. To summarize previously reviewed studies, mothers and fathers have completed structured questionnaires to measure their stress, anxiety, marital satisfaction, use of discipline, family environment, feelings about their child's disability, their children's relationship, nondisabled sibling's social adjustment, depression, and social support. Similarly, nondisabled siblings have completed questionnaires to measure their self-concept and depression. The most significant limitations of these methodologies include a reliance on parental reports for our understanding of nondisabled siblings' experience, the implicit assumption that maternal reports accurately reflect how other family members might respond to the same questions, and the limited opportunity for the respondents to elaborate on their answers.

In sum, although these studies have provided important information about these families, I argue that the inconsistent and contradictory results previously reported reflect these limitations. Further, as highlighted by Dyson (1991), the interpretation of questionnaire/survey data is limited by the heterogeneity of the disabled children and unequal sample sizes. Most importantly, however, a description of the unique ways that each family, and family member, adapts to the presence of a disabled child is limited by this type of analysis.

With respect to the second category, family members have both answered interview questions and completed a questionnaire/survey. Occasionally, select family members were interviewed while others only completed a questionnaire/survey (e.g., Dyson, 1996). The focus, for the most part, has been the examination of parental perceptions of the experience of their families. For example, Marcenko and Smith (1992) analyzed open-ended questions presented to mothers regarding the adjustment of nondisabled siblings in addition to the administration of an intake and follow-up questionnaire. A critical limitation of this study was the lack of description concerning the collection and analysis of the responses to this open-ended question.

Similarly, Dyson (1996) examined families of children with learning disabilities by recording verbatim the responses of parents to two open-ended questions concerning the impact of having a child with a learning disability on the family. Data were analyzed using the constant comparison method (Glaser & Strauss, 1967). Although nondisabled siblings' self-concept was examined using a structured questionnaire, they were not asked about their experience of having a sibling with a learning disability.

Parents of children with disabilities have also been asked about their perceptions of the support services available to their families. In one case, Brodin and Paulin (1997) examined parents' views of respite care services for families of children with disabilities in Sweden. They mailed questionnaires to 141 families and interviewed 25 of these families. Interviews were tape recorded, with the exception of one interview, and were transcribed. Interview protocol and data analysis techniques were not described. Select, characteristic quotations from the parents were presented.

Families of children with autism have also been interviewed. For example, Liwag (1989) conducted an exploratory study designed to study the stress experienced by families of children with autism. The research design was described as a multiple case study approach using a semi-structured interview and a modified sentence completion form. The parents of the children with autism were the focus of the study; nonautistic siblings were not interviewed. Further, the data analysis methodology was not described. However, it appears that the evidence was categorized into themes and that characteristic responses to interview questions were presented as a means to further describe these categories. The major limitation of this study, acknowledged by the researcher, is that it only "began to tap the complex family dynamics involved in [being a member of a family of a child with autism] (p. 15). Although she recognized that the family operates as a system, she did not describe the experiences of the entire family unit (e.g. including the perceptions of siblings in the data collection process).

Gray (1997) asked parents of children with autism about their perceptions of 'normal family life'. The data were collected using semi-structured interview techniques. Parents were asked about such things as the onset of symptoms, the diagnosis and the effects of autism on the family. This study was limited because Gray reported his results using statements made by select and limited parents. Further, he neither identified how many participants had made similar statements nor reported how he had developed the themes he discussed. These issues relate to how well a researcher has established trustworthiness (i.e. credibility criterion) (Lincoln & Guba, 1985). This issue has been addressed in the design of the present study.

In addition to interest in parents' reports, nondisabled siblings have been asked about their experiences and perceptions of their families. For example, Kiburz (1994) interviewed school-aged children with a sibling who has myelomeningocele and asked them twenty open-ended questions related to their knowledge of their sibling's disability and their perceptions and worries about self and the family, emotions, family life, and how siblings perceived the sibling relationship. The responses to these questions were categorized according to the themes that emerged from the analysis of the responses and were compared with categories developed from mothers' responses to the Sibling Inventory of Behavior (Schaefer & Edgerton, 1979), a 28-item, 5-point Likert scale measuring aspects of the sibling relationship. Kiburz recognized the difficulty in correlating interview and survey data. Furthermore, she acknowledged that the relationship between the sibling interview and the scale completed by the mothers has not been established. Thus, questions remain regarding the relationship between mothers' and siblings' perceptions of the impact of the child with a disability on the family. Further, this methodology does not allow the mothers, their nondisabled children and us to examine the relationships between, in this case.

Finally, I will review select studies that have used interview and observational techniques alone. To do this I have increased the scope of my investigation to include examinations of families of children with special health needs. For example, Martin, Brady and Kotarba (1992) conducted an ethnographic study of the ways a child with a chronic illness impacts the daily life of his/her family. The participating families were interviewed and observed for 4 months. Participant observation was conducted at support groups for the parents of the participating families. Extensive observations and interviews were also conducted in the families' homes. The interview questions focused on descriptions of the families, family life before and after the birth of the child with a chronic illness, the everyday life of the family and descriptions of the extended family and/or social network. All interviews were recorded and transcribed. Furthermore, artifacts (i.e. pictures, journals and medical records) were collected for analysis. The lead investigator collected all of the data. Data analysis was described as typological analysis (Lofland & Lofland, 1984) involving the first author coding the data according to two categories, which were later validated by the remaining authors. Finally, two independent readers reviewed the coding for plausibility. Martin, Brady and Kotarba reported two findings in the study involving the ways that children's illnesses affect the lives of their families and how these families make decisions.

More recently, Parker (1996) interviewed the parents of children with Tuberous Sclerosis Complex (TSC). The parents were asked eight questions related to the diagnosis of their child, the perceived impact on the family (including emotional and financial effects), access to support services, and coping strategies adopted while caring for their child. Themes were developed using a grounded theory approach (i.e., described as coding and constant comparative method of analysis). Fourteen themes emerged from the data. Although Parker stated that the purpose was to describe how families cope with the stresses of caring for a child with a chronic illness, only the perceptions of the parents were described. Again, the emphasis was on describing the parents of children with special health needs, rather than describing the families.

In addition to conducting studies examining families of children with chronic illnesses, researchers have examined families of children with other types of disabilities (e.g. Ballard et al., 1997). Ballard et al. (1997) described the experience of fifteen fathers of children with unspecified disabilities and their involvement with the education system in New Zealand. Data collection techniques were described as semi-structured, open-ended, qualitative interviews. All interviews were transcribed and analyzed for thematic content using NUD•IST, a computer software package for qualitative data analysis. Methods of triangulation were not described. The researchers identified eight significant issues and used characteristic interview quotes to further describe each of these issues.

Similarly, Wilgosh (1990) interviewed parents of children with disabilities. These data were collected over a number of years and with more than 80 one-parent and two-parent families. Parents were asked to tell their own story about being parents of a child with a disability. The interviews were analysed according to procedures described elsewhere (Becker, 1986; Colaizzi, 1978; Giorgi, 1975, 1985; Polkinghorne, 1983). Six themes were identified by Wilgosh and verified by the parents. Again, other family members (i.e., siblings) were not included in the interview process.

In general, a major theme throughout most of this literature is the evaluation of the stress experienced by, primarily, the parents. What we know is that most parents of children with autism/disabilities display symptoms of stress. However, as Beckman (1991) highlighted, there are parents who adapt to the challenges of their disabled child, and considerable variation in the symptoms of stress displayed by these parents. As such, another purpose of the present study was to also ask parents about the positive ways in which their child has impacted their family. The intention was to add to what we know about the mediating impact of social support and resources on parental levels of stress.

As previously described, most of what we know about the experience of these families is based on interviews with the mothers and surveys where the respondents were, in most cases, the mothers. However, it is clear that all family members are affected by the presence of a disabled child. Therefore, siblings and fathers in select families of children with autism were interviewed in the current investigation.

In summary, numerous studies have focused on specific areas of psychological, emotional, and social adaptation using surveys/questionnaires and have examined the experiences of a limited number of family members. Similarly, when family members have been interviewed, researchers have failed to focus their examinations on the complex dynamics of the entire family unit.

Research Questions

The purpose of the present study was to extend previous research on families of children with autism by describing the 'experience' of being a member of a family of a child with autism. To describe the effects of a child with autism on their family it was necessary to design a study in which the focus was on all family members, on its functioning (i.e. the relationships which develop within the family) and on the triangulation of these data. This is an attempt to add to the previous approaches used to study families of children with autism by focusing on an expanded conception of family (i.e. relationships within the family as well as relationships with various support networks).

Chapter III

METHOD

Research Design

The design of the present study is a descriptive multiple case study (Yin, 1994) involving ethnographic interview/data collection techniques. A key purpose of conducting a study, in which ethnographic methods have been incorporated, is to ask "What is this or that kind of experience like?". In this case, the researcher attempted to understand and interpret the experience of living with a child with autism. A multiple case study design was selected to identify common themes across families of children with autism.

Initial Contact with Participants

In Appendix A an example of the letter explaining the nature of the study and requesting the families' participation is provided. Interested participants initiated contact by telephoning the researcher at home and/or by returning the consent form (Appendix B) to the researcher. After gaining the families' informed consent, the researcher interviewed the parents and siblings at a mutually agreed upon time. All interviews were arranged within two weeks of the initial telephone call.

Initial contacts with these families were made through local associations such as the Ministry of Children and Families in Victoria, Nisika Community Services, Laurel Group Enterprises, and the Vancouver Island Society for Children with Autism (VISCA).

Participants

Six families of children with autism, in which there are two siblings (one with autism and one who is nonautistic), participated in this study. These families included 3 traditional families, 2 single parent families and 1 stepfamily. Data collected from 2 single parent families included only interviews with the mother and the nonautistic sibling because the father had minimal or no contact with the mother or children.

There were three criteria for inclusion of the participants in the present study: (a) a diagnosis of autism according to the criteria in the DSM-IV made by a team of professionals that included a registered psychologist; (b) the presence of two children in the home, one with autism and one without this diagnosis; and (c) a nonautistic sibling between the ages of 10 and 18 who displayed the skills necessary to answer the interview questions.

Five families were interviewed in Victoria; BC while 1 family was interviewed in Nanaimo, BC. Interviews with two of the fathers were conducted at their offices to accommodate their work schedules. The other interviews were conducted in the families' homes.

All of the children with autism had undergone rigorous psychological and physical assessments and were, therefore, accepted as participants. Registered psychologists and physicians made all diagnoses of the children with autism. In the case of 3 families, the diagnosis of autism was made by a team of professionals at Sunny Hill Hospital in Vancouver, BC and in the other 3 cases by qualified professionals at Queen Alexandra Hospital in Victoria, BC.

The nonautistic sibling was the older sibling in 3 families and the younger sibling in the remaining 3 families. The ages of nonautistic siblings ranged between 10 and 12 years of age. Therefore, all of the nonautistic siblings were able to offer their informed consent to an individual interview and displayed the verbal skills necessary to understand

and answer the interview questions.

All participants were assigned pseudonyms to protect their anonymity. Descriptions of the children with autism, including relevant details of the participants in this study, other family members and family environment, follow.

Carl

Carl (a pseudonym) was 10 years old and in a grade 5 class for students with special needs at the time of the study. The focus of this program was on teaching the students basic life skills such as safety in the home and in the community, cooking and grocery shopping. He had limited verbal communication. He is the younger of two children. He was diagnosed with autism in 1992 by a team of professionals at Sunny Hill Hospital in Vancouver, BC. His parents reported that they knew that something was different about Carl's development when he was approximately one year old. Initially medical professionals thought that his lack of speech at 2 years of age might be the result of hearing loss. Extensive hearing tests were conducted in Victoria. However, his mother stated that she knew that this was not the case, as he would display behaviors like screaming and hitting when they went out shopping. She now attributes these behaviors to him being over stimulated. Both parents described him as making eye contact, being very social and seemingly experiencing little or no physical pain when he was growing up.

His mother, Beth (a pseudonym) runs a home-based business and fulfills most of the care taking duties associated with raising 2 children. His father, Doug (a pseudonym), is employed outside of the home. Doug adopted Carl's half-brother, Tyler (a pseudonym), when Tyler was 3 years of age. Tyler was 12 years old and in grade 7 at the time of the study. Tyler was diagnosed with ADHD at 8 years of age and was being administered Ritalin at the time of the study. Beth shared Tyler's diagnosis only after Doug and Tyler had been interviewed. While he does have a diagnosis, this in no way impacted his ability to understand and answer the interview questions.

Alan

Alan (a pseudonym) was 13 years old at the time of the study. Alan is the firstborn child. He was placed in a modified educational environment on a temporary basis because his parents did not believe the high school in their district would provide sufficient support to Alan. His mother stated that, at the time of the study, he was not being educated or provided with life skills training at this school. Both parents described him as very verbally and physically aggressive. The primary targets of Alan's aggressive behaviors are his family members. As a result, Alan is cared for by the staff of a group home from the time that school lets out until bedtime 4 days per week. He also stays at this resource every weekend. In sum, he is home 1 night per week for dinner. His parents added that, at the time of the study, he was taking a mood stabilizer.

Alan's father reported that he thought that there was something unusual about his development when he was 3 years old. His mother shared that she had the same concerns when he was in kindergarten and that he did not look or behave autistic until that time. Both parents reported that he was diagnosed with autism when he was 7 years old by a team of professionals at Sunny Hill Hospital in Vancouver, BC.

Both of Alan's parents, Lynn and Robert (pseudonyms), are professionals who work outside of the home. Lynn returned to work 3 years ago. Prior to that she was the primary caregiver to both children. His brother, Roger (a pseudonym), was 11 years old and in grade 5 at the time of the study.

Tina

Tina (a pseudonym) was 5 years old at the time of the study. She is the younger of two children. She was enrolled at a Montessori school for a half-day in preschool and a half-day in kindergarten. At the time of the study, she was considered nonverbal. She was diagnosed with autism at 3 years of age by a pediatric psychiatrist from Alberta visiting Queen Alexandra Hospital in Victoria, BC.

Tina's mother reported that she knew that something was wrong with her daughter from the time that she was born. Tina did not eat, would not respond to people around her and slept more than an average baby. Her mother told me that the doctors and nurses told her not to worry. At 8 months of age Tina had a CAT scan that was reported to be normal. It was another 2 and half years before she was diagnosed. Her mother described her as nonverbal and happy.

Her mother, Ellen (a pseudonym), is a single parent and a professional who works outside of the home. She returned to work part-time a year ago after spending 4 years at home caring for her children. Tina's sister, Sonya (a pseudonym), was 10 years old and in grade 5 at the time of the study.

Andrew

Andrew (a pseudonym) was 12 years old and in a modified grade 6 program, that included a 1:1 classroom aide, at the time of the study. He is the oldest of three children. His mother placed him in a different school in September because he was no longer receiving supplementary educational support and supervision at the previous school. He was diagnosed at 3 years of age with a developmental delay and diagnosed with autism 5 years later by a psychiatrist in Victoria, BC. His mother stated that he is violent towards his family and has limited interpersonal skills. She also told me that he wants more than anything to be considered normal by his peers. He was, at the time of the study, prescribed anti-depressant medication to stabilize his mood and in respite care with a family 3 days of the week.

His mother, Lucy (a pseudonym), is a single parent who stays at home to care for her children. At the time of the study she was contemplating the possibility of returning to school. His sister, Sandra (a pseudonym), was 10 and in grade 4 at the time of the study. She agreed to be interviewed and participated in the study. His brother, Nathan (a pseudonym), was 8 and in grade 3 at the time of the study. Nathan did not participate in the present study.

Leanna

Leanna (a pseudonym) was 16 and in a program for students with special needs at the time of the study. She is the older of two children. She was diagnosed with autism when she was 11 years old by a team of professionals at Sunny Hill Hospital in Vancouver, BC. Her mother reported that she began to speak at 10 months of age and stopped talking at 1 year of age. Her parents were concerned about her lack of speech when she turned 18 months of age. At 2 years of age, she underwent tests to assess her hearing. Her hearing was reported to be normal. At 3 1/2 she began to speak. Her parents described her as physically active, bright, creative and mischievous.

Her mother, Nicole (a pseudonym), is a professional who stays at home to care for her children. Her father, Adam (a pseudonym), is a professional who works outside of the home. Her brother, Christopher (a pseudonym), was 12 and in grade 6 at the time of the study.

John

John (a pseudonym) was 9 and in a modified grade 4 program, that included a 1:1 classroom aide, at the time of the study. He is the younger of two children. He was diagnosed with autism when he was 4 years old by a team of professionals at Queen Alexandra Hospital in Victoria, BC. His father reported that John was observed for a year by the staff at Queen Alexandra prior to receiving the diagnosis. Both parents reported noticing signs that something was different about his development when he was 18 months old. He would sit in his crib and rock for extended periods of time. He also had not developed speech by the time that he was 3 years of age. At this time he was sent to an ear specialist to have his hearing assessed. His hearing was reported to be normal. His parents described him as physically aggressive, demanding, sensitive and gifted at taking apart and reassembling electronic equipment.

Both of John's parents, Mary and Charles (pseudonyms), are professionals who stay at home to care for their children. Charles retired 5 years prior to the study to support Mary in caring for John. John's sister, Victoria (a pseudonym), was 12 and in grade 6 at the time of the study.

Parent and Sibling Interviews

Each family member was interviewed individually at a mutually agreed upon time. The interviews were between 30 minutes and two hours in length. The length of each interview was considered appropriate for each participant by the principal investigator.

As suggested by Kvale (1996), the context of the interview was introduced to the participant with a *briefing,* in which the interviewer described the interview process, the purpose of the study and the use of the tape recorder. The participant was asked whether he/she had any questions prior to initiating the interview.

Following the briefing, the tape recorder was started. Spradley (1979) established some guidelines for conducting an ethnographic interview. The steps outlined in this method include building rapport, introducing a "grand tour" question, and following up with more specific questions. This format was adopted for both parent and sibling interviews.

The first stage of the interview was to establish rapport. Friendly conversation about the surroundings and personal interests were introduced. The goal of establishing rapport was to increase the participant's level of ease (Spradley, 1979). This was considered a critical part of the interview process.

After rapport was established, a "grand tour" question was introduced. A grand tour question is a general, open-ended question that is posed to allow the participant to provide a detailed description of their experience (Spradley, 1979). Participants in the present study were asked "Tell me about the experience of living with a child with autism".

The interview was then focused around the open-ended, semi-structured questions in Appendix C. Minor modifications of the questions were made based on the age of the participant and the nature of the rapport that developed in the course of the interview.

Finally, each interview was followed up with a *debriefing* (Kvale, 1996). At this time, the principal investigator addressed any questions the participant might have had and provided the participant with the opportunity to share any feelings or ask any questions that the interview process might have raised. For the most part, the participants asked who might read this research paper. All of the debriefing took place after the tape recorder was turned off in order to ensure that any remaining questions or concerns were addressed in a comfortable atmosphere.

A telephone interview was arranged within 1 month of the initial interview(s) to review and confirm the themes that emerged and to ensure that the participants' responses were interpreted accurately. This also offered an additional opportunity to address any questions or concerns raised by their participation in the first interview(s). This interview required no more than 20 minutes.

Data Collection and Analysis

Demographic data (i.e., ages of children and parent(s), employment of parent(s), education of parent(s), marital status, and diagnosis of the child) were collected from the parents.

To ensure that the basic criteria for trustworthiness were met (Lincoln & Guba, 1985) the length and number of interviews were modified in each case to allow the principal investigator to build sufficient trust with each participant and enough time to feel confident that the principal investigator understood each participant's experience. Further, all themes were confirmed by the participants to ensure the accuracy of what they intended to say (Ely et al., 1991; Merriman, 1988).

All interviews were audiotaped and transcribed verbatim within 2 weeks of the initial interview. The interviews were analyzed for themes that were verified by the participants in a telephone interview scheduled within 1 month of the initial interview. As part of the verification process, each participant was presented with the potential themes and the related statements that they made during the initial interview. Each theme was addressed in turn. The participants were asked to verify these themes and to elaborate on any of the information they had provided during the initial interview. These themes were coded and continuously compared to the interview data for verification. Categories were developed from these themes in an effort to organize the themes that emerged from the data. The data were reported using guidelines proposed by Bachor (2000; Davis & Bachor, 1999). In general, a ratio was computed for each theme as a way of illustrating the representativeness of the evidence collected during the interviews, specifically the typicality of the evidence being discussed. This process is described in more detail in the subsequent chapter.

Chapter IV

RESULTS

The results from this study are organized into 4 parts. Demographic and background information of the participants are presented in the first part. Themes, identified from the analysis of the interviews with the mothers, are presented in the second part. Next, results of the analysis of data collected from the nonautistic siblings will be presented. Finally, results from the analysis of the data collected from the fathers will be reported.

Part I: Demographic and Background Information

All demographic information was obtained at the beginning of each parent interview. Parents were asked about the ages of all household residents, their educational background, their occupations, and details about the diagnosis of the child with autism (i.e., when the diagnosis was made and by whom).

Family backgrounds. All parents in the sample had completed at least 12 years of formal education. Most of the parents had received a degree at the post secondary level (4 mothers and 3 fathers). The mothers' ages ranged between 35 and 41 years with a mean age of 36.7 years. The fathers' ages ranged between 36 and 56 years with a mean age of 45 years.

In 4 families the mothers stayed at home to care for the children. One of these mothers started a home-based business to be at home for her children. In the other two cases the mothers had returned to work within 3 years prior to the study. In one family both the mother and father stayed at home to care for their child with autism.

The nonautistic sibling was the older sibling in 3 families and the younger sibling in the remaining 3 families. The ages of nonautistic siblings ranged between 10 and 12 years with a mean age of 11.2 years. All of the nonautistic posed the verbal skills necessary to understand and answer the interview questions.

Evidence groupings. Interview data reported in the following sections were grouped into themes following the procedures recommended by Strauss and Corbin (1990). Initial interview data were verified with all participants in the second interview and themes were constantly compared to the original data. The evidence was then quantified into ratios for reporting purposes according to the guidelines suggested by Bachor (2000; Davis & Bachor, 1999). Theme names are italicized to differentiate them from the descriptive text and are reported with the ratio indicating the number of responding participants: For example, *Appreciation* (5/6) means the theme of appreciation was reported by 5 out of 6 participants. Themes in each part are organized conceptually into categories. In each section the categories are identified, then the themes in each category are presented and finally examples are taken from each participant to elucidate each theme. Appendices E, F and G are complete lists of categories and reported themes for mothers, nonautistic siblings and fathers respectively.

Part II: Mothers

In reporting the results of interviews with mothers, themes were organized into 7 categories: unpredictability, coping mechanisms, impact on siblings, social issues, want versus need service expectations, impacts on mothers and problems with the children with autism falling asleep or staying asleep. Unpredictability includes verbal aggression and physical aggression. The coping mechanisms, reported by the mothers, include making sense of the physical/verbal aggression, removal of child with autism/respite, reactive solutions, drug administration, control over the environment, and avoidance of unpredictable situations. The impacts on the siblings include siblings being at risk for violent outbursts from the child with autism, additional responsibilities for siblings, neglect of siblings, and compensation for the siblings. The social issues identified by the mothers include acceptance/rejection in public and acceptance/rejection at home. Want versus need expectations include unmet expectations and getting the wanted support. Impacts on the mothers include concerns for the child with autism's physical health, mothers' emotional reaction, long-term care for the child with autism, mothers' feeling of isolation, mothers' role(s), diagnostic issues and mothers' reports of changes to their perceptions of life. Each of these will be examined in detail in the following sections.

Unpredictability

Themes that emerged from unpredictability are *verbal aggression* (5/6) and *physical aggression* (3/6). These themes will be discussed in order of frequency of appearance.

Verbal Aggression

Most of the mothers identified that the child with autism is verbally aggressive (*verbal aggression*, 5/6). Three mothers described this verbal aggression as screaming. Carl's mother, Beth, commented that Carl uses verbal aggression to get Tyler to give him things or spend time with him, "If Tyler has something that Carl wants he'll usually give it to him. It's just not worth hearing the screaming." She added, "Sometimes Tyler wants to be alone and Carl wants to be with him. That's hard. We ask him to put up with him or else he'll scream and make life miserable for everyone for an hour." By contrast Tina's mother, Ellen, said that Tina uses verbal aggression to communicate with others, "Then she got older and she was tantruming for attention. Mostly out of frustration. But you didn't know what she wanted, if she wanted a drink or to eat." Similarly, Nicole, Leanna's mother, said that her daughter's verbal aggression is related to how she expresses herself; "She expresses her frustration by screaming and clenching her fist and shaking."

In two cases the mothers described their children's verbal aggression as threats and commands. For example, Alan's mother, Lynn, described a recent, specific instance of verbal aggression displayed by Alan, "He screamed at me for 45 minutes…He started telling me that he would stop threatening me if I take it back." When asked about dinnertime in her home Lynn said, "At dinner Alan would be rude and aggressive verbally." Similarly, Mary described John by saying; "He is always commanding and threatening. We don't ask him things anymore. He speaks in a commanding way. Sometimes for no reason he has a tantrum."

Physical Aggression

Four mothers described how their child with autism displays physical aggression (*physical aggression*, 4/6). Three mothers illustrated how they live with ongoing displays of physical aggression directed at other people. When Lynn, Alan's mother, was asked about living with a child with autism she said that she'd experienced, "Hell. Continuous, repeated outbursts of physical aggression." Andrew's mother, Lucy, reported a similar pattern; "Up until the behavior consultant's intervention, we couldn't go through a week without him having a violent episode, sometimes 2 or 3 times a week." Mary provided accounts of a similar pattern and provided a description of what happens when John is physically aggressive,

> [During a tantrum John will] grab your hair and bang his forehead against your chin and chest. Aggressive. He would try to punch you. Sometimes you can protect

> yourself. He knows that. Then he'll spit at you... On a good day maybe once. That's what's happened lately.

By contrast, one mother indicated that her daughter's physical aggression is most often directed at inanimate objects and rarely directed at other people. Nicole said, "Sometimes [Leanna] will have violent outbursts because she is really frustrated and doesn't know what to do…It's very rare but sometimes she will actually grab at someone in this state."

Coping Mechanisms

The mothers in this sample identified six strategies they use to cope with the child with autism's unpredictable behavior. These are *avoidance of unpredictable situations: going out in public* (5/6), *making sense of the physical/verbal aggression* (4/6), *removal of child with autism/respite* (4/6), *reactive solutions* (3/6), *drug administration* (3/6), *avoidance of unpredictable situations: dinnertime* (3/6), and *control over the environment* (2/6). Each of these will be discussed in the following sections.

Avoidance of Unpredictable Situations: Going out in Public

All participants were asked to describe what happens during family outings. Most mothers said that they limit family outings, or do not go out as a family, because of the child with autism's unpredictable behavior (*avoidance of unpredictable situations: going out in public*, 5/6). In all cases, concern about others' reactions when the child with autism is behaving in an unpredictable manner in public was identified as the reason for this decision. Lynn, for example, depicted the last time her family went out for dinner together,

> We sat down in the restaurant. And Roger wanted chocolate milk. We said no and

> Alan demanded that Roger be allowed to have chocolate milk. He threatened to kill us right there in the restaurant...We were completely still for 20 minutes while he continued to threaten us and escalated. People heard it and it was awful. And we've never gone anywhere again [as a family].

Ellen identified that she is concerned about what she imagines other people are thinking when Tina is behaving unpredictably,

> It is easier [not to go out] and if we go out it's a pain sometimes. If she is having a good day it's fine...If she feels that today is a loud singing day, everybody turns around...They stare at you like 'Control your child'. Like you're not a good parent. I don't pay too much attention to it but it does bother me. It adds stress to the situation.

This theme was echoed in statements made by Lucy and Nicole. Lucy said, "I might take them out to the park or to the corner store...if Andrew gets upset I can't have him screaming on the floor of a restaurant." Nicole illustrated how challenging it is to be in public with her daughter sometimes,

> Sometimes it is a little tricky when she is screaming really loudly and attention is drawn to us. I guess you kind of get used to having people stare at us. We're able to ignore it for the most part.

Mary specifically described feeling embarrassed during her family's most recent outing,

> The last time we went out was fine. It was somewhere he likes. Mind you he tried to run into the kitchen to see the food being cooked. He wouldn't sit quietly. It was embarrassing. We don't go out that often.

Nicole identified an additional stress for members of her family during family outings. She talked about how her daughter would attempt to run away on family outings; "One problem is that she will run away which can get a little frustrating and scary. Sometimes the three of us feel a little exhausted after we've been on an outing."

Making Sense of the Physical/Verbal Aggression

Many mothers made statements that appeared to be attempts to make sense of the child with autism's verbal/physical aggression (*making sense of the verbal/physical aggression*, 4/6). All of the mothers said that their child's aggression is an attempt to communicate. For example, Beth said, "...Carl's frustrated. He's hitting himself more lately...The only thing you can do is let him deal with it. Eventually he'll stop. Even if you soothe him...he tries so hard to say something." Ellen described how Tina's tantrums are one of her only forms of communication,

> You would talk to her and she would not respond. Then she got older and she was tantruming for attention. But you didn't know what she wanted, if she wanted a drink or to eat. She wasn't able to communicate at all.

Both Lucy and Nicole said that their children don't know how to communicate any other way when they are frustrated. Lucy said,

> Well, when he gets anxious and he gets wound up to the point of no return, we can have extreme violence...People often forget that he doesn't want to be that way...When he does things, he is trying to tell you something but he doesn't know how to tell you. He explodes. That's his way of telling you.

Nicole described a similar experience, "Sometimes we have violent outbursts because she is really frustrated and doesn't know what to do...We feel like it's not that person, she's almost reaching out to them to say, 'Help me'."

Removal of Child with Autism/Respite

Four mothers said that their family was receiving some form of respite (*removal of child with autism/respite*, 4/6). All of these mothers suggested that this respite was a necessary support for the family. Lynn explained the family's need for safety from Alan's physical aggression,

> And up until a while ago he'd come home. But he'd come home and was so violent that the Ministry upped the hours and [the group home] picks him up from school and brings him home at 8:30…It's been dangerous for a very long time.

Ellen described needing respite to initiate a specialized program for Tina; "I have a university student. A fourth year psychology student. I like the way she deals with Tina…She was doing 6 hours of therapy. One on one…Tina needs that kind of learning and stimulation." Similarly, Mary shared that her family has required increasing support through the years, "[Our respite] started with just a few hours per month and then in grade 2 or 3 it went up to 19 hours per week…Before that there was nothing for home. We needed some kind of help."

Two mothers indicated that they were willing to have the child with autism live in their home, currently or in the future, under the condition that respite is provided. For example, Lucy decided that she would not have her son live at home full time, following an extended absence of the child with autism from the home, without considerable support. "…I placed him for 4 months. And then things became different at home. Better. I made the decision that I would not have him back full time. My respite magically went from 6 to 15 days per month." When Nicole was asked about planning for transition when her daughter, Leanna, turns 19, she said, "For me [transition] is not a big priority as long as I continue to get some respite."

Avoidance of Unpredictable Situations: Dinnertime

Four mothers talked about how their families do not sit down together for dinner because the child with autism can be disruptive before and during dinner (*avoidance of unpredictable situations: dinner time*, 4/6). For example, Lucy suggested that what happens at dinnertime is often the result of events leading up to dinnertime.

> ...I will make dinner and it doesn't really matter where we eat...If it's been a really bad day, I might feed them cereal for supper. As long as they get something in their stomachs, I don't care. We don't sit around the dinner table and talk about our day. Usually by then if there is something that will happen it will be by then.

Mary described what happens in her home, "We don't sit down together. It would be too difficult with John and his behaviors. We eat at different times...I have to eat when I supervise him eating."

Two of these mothers described having made attempts to have their families sit down for dinner together and their decision to avoid the challenges associated with having the family sit down together. Beth said,

> Carl doesn't sit down for very long at all. He's always on the go...We tried to have him sit with us [for dinner] and it just didn't work...He wouldn't eat and he'd scream. It just wasn't worth it...We were brought up to appreciate dinner and family time. But, it's just too difficult.

Lynn established that dinnertime was when Alan would become verbally and physically aggressive. This pattern contributed to the family's need for increased respite.

> We used to try [to sit down for dinner together] but that was just disaster. So, that's

> why they gave us extra funding…He would be rude and aggressive verbally. It would escalate into violence. If there wasn't anything important to get angry about he'd find something.

Reactive Solutions

Most of the mothers indicated that they have developed ways to manage, or cope with, the child with autism's unpredictable behavior (*reactive solutions*, 4/6). Two of the mothers shared what they do when the child with autism becomes physically aggressive. Lynn, for example, said, "Roger (the nonautistic sibling) and I have spent more than one night hiding in the attic with the deadbolt". In the second case, Lucy described her plan when similar situations arise, "When Andrew is off the wall these days we will leave and go for a drive. If we can't get out quickly enough I have locked them or me in the bathroom. I have sent them out of the house."

Two mothers shared that they have developed solutions to deal with problems their children have falling asleep and staying asleep at night. For example, Nicole shared that she has put a lock on Leanna's bedroom light to discourage her from turning it on to read or play in her room. By contrast, Mary shared that her family has devised a different solution to a similar issue, "[John] used to be up all night screaming…Now Charles sleeps in John's room. If he wakes up Charles is there to calm him and get him back to sleep."

Drug Administration

Half of the mothers interviewed in this sample said that the child with autism was prescribed medication (*drug administration*, 3/6). Two of the mothers described the medication as necessary to manage the child with autism's behavior/mood. Lynn said,

> He's been put on a mood stabilizer and his behavior has improved, but he's still not being educated and given life skills training because there might be aggressive fallout initially, at least when he hears the word 'no'. He's barely tolerable.

Lucy described a similar experience; "He is on significant doses of anti-depressants just to get him through the day."

One mother described how her daughter was prescribed medication specifically to help her sleep. Nicole said; "About a year ago [Leanna] was staying awake until 3 or 4 in the morning or couldn't fall asleep at all…The psychiatrist prescribed some drugs and they seem to have helped."

Control Over the Environment

Two of the mothers reported that they have implemented control over the child with autism's environment (*control over the environment*, 2/6). Lynn shared that she was concerned about what might happen if the police were called to her house because Alan was being physically aggressive. Her main concern was that the police might mistake him for an intruder or that they might use unusual force to subdue him. She said, "I phoned the police a year ago. I told them that if they get a call that it's my mentally ill son trying to hurt me. They were very good and supportive." In the second case, Mary shared that one of her challenges in supporting John has been hiring experienced staff, "[we hire only people who are] not afraid to get physical. He can get physical. Someone who understands behavioral challenges and is not afraid of that."

Impact on Siblings

The mothers in this sample identified 5 ways that the siblings are affected by the presence of a child with autism. The impacts on siblings are *additional responsibilities* *for siblings* (6/6), *unusual maturity or display of adult-like behaviors by siblings* (6/6), *neglect of sibling/differential treatment* (3/6), *compensation for siblings* (3/6) and *siblings at risk of aggressive outbursts from child with autism* (3/6). Each of these themes will be discussed in the following sections.

Additional Responsibilities for Siblings

All of the mothers highlighted how the siblings have responsibilities that are not typical of children their age (*additional responsibilities for siblings*, 6/6). For example, three mothers described how the sibling is extremely sensitive to how others view them. Beth said, "He tries to please everybody. It's annoying because he tries to please too much." Lynn provided a similar description, "When his brother is here, Roger is the good child, the sweet child, the wise child, the mature child. And he is all those things." Lucy described Sandra as not only being sensitive to how others view her but also vigilant about monitoring the outward expression of her feelings,

> She tries to be a very good little soldier. She tries really hard to be nice to Andrew when he gets off respite…Her role in this is she tries. She is having a lot of difficulty keeping it together but she tries to make it look like it's not hard.

Two mothers were more specific about the additional responsibilities for the siblings. Nicole said that Christopher's role is 'cheap entertainer'. In this role he is responsible for livening things up and lightening things up. Similarly, Mary described how Victoria has adopted a more adult role for her mother, "She gives me emotional support."

Finally, two mothers indicated that the siblings have to cope with the destruction of their belongings. Beth said, "If Tyler has something that Carl wants he'll usually give it to him. It's just not worth hearing the screaming…He often wrecks his stuff and doesn't give it back." Similarly, Lucy stated, "She lives a life where she is…having her things in her room trashed all the time. She has to try to put up with it. She has to live that way."

Unusual Maturity or Display of Adult-like Behaviors by Siblings

All of the mothers made statements about the sibling's unusual maturity or reported that the siblings display adult-like behaviors (*unusual maturity or display of adult-like behaviors by siblings*, 6/6). Four mothers specifically stated that the sibling is very mature for his or her age. For example Beth said, "But he's really so grown up in so many ways." Similarly, Lynn shared that Roger is aware that he is mature for his age; "He told me that he feels like he's 10 going on 40…Roger has clear opinions about how other kids treat other children…He's wise beyond his years." Lucy expressed concern about how mature Sandra has to be to cope with her living environment; "She tries to be brave, be the leader and take some responsibility but she has no choice that she has to deal with no social life and when [Andrew] destroys her belongings. It's too much for a 10-year-old." By contrast, Mary expressed that she needs Victoria to be mature and requires her support; "I am depressed. She is older than her age. She would comfort me."

Two mothers highlighted how the siblings adopt adult roles. Ellen described how Sonya participates in a behavioral therapy program, based on single case design principles (Kazdin, 1982), for Tina; "She is able to do ABA therapy. She knows the techniques so well and uses them all the time. The prompting, the direct instruction." She also indicated that she needs Sonya to monitor her sister at bedtime,

> I say goodnight and I think it helps Tina knowing that her sister is there as well. She had difficulty going to bed if she is by herself. I am happy that Sonya is willing to be

> there with her or I would be the one in there with her.

Nicole described Christopher by talking about his sensitivity to others and his interest in caring for them; "I think he is so aware of others' feelings and he is very polite to other people. He almost has a nurturing personality. He is helpful to little kids. He is careful not to criticize people."

Neglect of Sibling/Differential Treatment

Three of the mothers expressed concern about how the mothers don't have enough energy to give to the sibling or how the children are treated differently (*neglect of sibling/differential treatment*, 3/6). Two mothers described how they are aware that they give more to the child with autism at the expense of the sibling. Lucy said,

> She needs more comfort and understanding than I'm capable of giving her right now…And because I'm so consumed with the boys and it feels like I'm on red alert all the time I don't seem to be able to be sympathetic enough…I have very little energy left over for her.

Mary described a similar experience,

> I realize how I neglect Victoria because I focus on John…Sometimes when Victoria has a bad week I have to consciously make time for her. Many times she is blamed for things that John has done. She's told me that she thinks that it's unfair.

Beth said that there are often different expectations for Tyler than there are for Carl,

> Yes, because Carl gets away with so much. You try to explain it and kids just don't understand…[He gets away with] eating while he's running around and he gets to stay up later. General things…If Tyler has something that Carl wants he'll usually give it to him. It's just not worth hearing the screaming…Try to explain it to Tyler.

> But it's hard for a kid to give up his toys.

Compensation for Siblings

Three of the mothers mentioned specific ways that the siblings are compensated for the challenges of living with a child with autism (*compensation for siblings*, 3/6). Beth said, "We try to compensate. Like Doug taking him over to see the Monster Trucks." Similarly, Lynn said that she makes herself available to spend time with Roger,

> I put my work aside to be with him. I don't think that he sees it. We watched Nova the other night. We go for walks. I pick him up after school 3 times a week just to talk. I focus, and have always focused, on making time for Roger.

Ellen described a similar pattern; "We go out on dates every once in a while to spend time alone together."

Siblings at Risk of Aggressive Outbursts from Child with Autism

Three mothers said that the siblings were at risk of aggressive outbursts by the child with autism (*siblings at risk of violent outbursts from the child with autism*, 3/6). While discussing her family's need for respite Lynn said, "Here is a child who is a danger to a 10-year-old in his own home." She also described how she and Roger have taken measures to protect themselves from Alan when he is being physically aggressive; "Roger and I have spent more than one night hiding in the attic with the deadbolt." The second mother to identify this concerns was Lucy who described feeling helpless to protect Sandra; "And Sandra was wrapped up in a blanket on the couch, and I thought 'I can't do it anymore. I can't even protect her'...She's getting pounded." When asked about the relationship between Sandra and Andrew she said, "...Sandra is the main target of Andrew's anger. He goes after her more than his brother." In the third case, Mary described how she allows Victoria to defend herself when John is being physically and verbally aggressive,

> The person he targets is mostly Victoria. He pulls her hair. He teases her. She hits him back and we don't stop her. It would be unjust for us to make her stop and not be able to stop him.

Social Issues

The mothers identified two social issues faced by families of children with autism. These themes are *acceptance/rejection in public* (5/6) and *acceptance/rejection at home* (4/6). Both of these themes will be discussed in the following sections.

Acceptance/Rejection in Public

Most of the mothers discussed concerns about how people in public view them and their child with autism (*acceptance/rejection in public*, 5/6). For example, Lynn made this statement, "There's a dark side to this life. We're afraid that people will hate us or judge us." Similarly, Ellen described how she carefully chooses activities outside the home that involve the child with autism,

> We go swimming at [a recreation center in Victoria]. There is an integration swim. It is so comfortable to be there. Everyone, who is there, is or has been associated with someone who has a mental disability. I never go when it is a regular swim because I can't stand how people look at you or her. I don't need that.

This theme was echoed in Nicole's words when she talked about being aware that other people stare when Leanna is displaying verbally aggressive behaviors and expressed concern that Christopher might feel embarrassed at these times,

> I guess you kind of get used to having people stare at us. We're able to ignore it for

> the most part but I do wonder especially for Christopher. He seems like he's handling it but sometimes for a kid that age it might be embarrassing.

Mary talked about feeling embarrassed during their last family outing; "He wouldn't sit quietly. It was embarrassing." Like Nicole, she also talked about Victoria feeling embarrassed by John; "His condition puts her in a very uncomfortable situation…He embarrasses her more than anything."

One mother implied that she was concerned about how others will react if her child with autism behaves unpredictably in public. Lucy said, "…if Andrew gets upset, I can't have him screaming on the floor of the restaurant."

Acceptance/Rejection at Home

Four mothers mentioned that they do not entertain in their home because of the child with autism's unpredictable behaviors (*acceptance/rejection at home*, 4/6). Lynn said that Alan enjoys having visitors over, however, "…he's more of a terror. And as his world grows smaller, and people become more afraid of the aggression, we don't have visitors to our home." Ellen described a similar experience, "We don't have anyone over like you would if you had a typical child. Only people who are really concerned, they will stick around. The other ones won't." In another case, Lucy shared that they haven't had many guests to their home and said, "We can't have anyone over to the house. How would they react?" Similarly, Mary expressed concern about how John would act while visitors are in the house, "We can't have people over to our house. We don't know how he will act while they are here." She added that there are guidelines for Victoria having her friends over to visit. "[She can have friends over] but not whenever she wants. We can't have sleepovers. He would want to bug them or he'd run around the house naked…She's more shy and afraid of what people say."

Want Versus Need Service Expectations

Two want versus need service expectations were identified from the interviews with mothers in this sample. These themes are the *unmet expectations* (5/6) mentioned by these mothers and reports of challenges in getting the wanted support which were *waiting for services* (5/6) and *reactive versus proactive service delivery* (4/6). These themes will be discussed in the following sections.

Unmet Expectations

Most of the mothers identified that their experience of support for the child with autism did not meet their expectations (*unmet expectations*, 5/6). For example, Beth discussed how there had been funding cutbacks at her son's school and described one consequence of those cutbacks at home,

> He's asking me to do more for him that I know he can do. I brought it up at school and they said that it's because of teacher cutbacks. Now they have 2:1. Now the kids aren't allowed to go into the fridge. He's brought that home.

She added,

> They cut back on the budget for special needs, teacher aides. He doesn't go to McDonald's anymore. They don't have shopping. Instead of a lunch I'd send money. They'd go shopping, make a list and do that. There's no more integration at lunch.

In another case, Lucy described the consequences of not receiving support when she identified a need for it; "Nobody did anything all the time when he nearly killed me. The school knew, [professionals] knew, anybody I talked to…They all knew the other children were in danger and did and offered nothing."

Two mothers talked about concerns for the child with autism's health and their unmet expectations of support. For example, Lynn said,

> I wanted him taken off his meds. They wouldn't do it. So I brought him home and took him off them. Everyone thought that I couldn't do it, that it wasn't safe, but no one offered to do it in a safe setting. So, we had no choice. I said these medications are making him worse and we have to help him. The system wouldn't do it so we had to. And it was really bad. He was 190 and aggressive and going through drug withdrawal.

Ellen shared a similar experience,

> Most of the times that I initiate, it's not the system saying that perhaps the child needs this or that. Let's see how she's doing. She has a big problem breathing at night. I'm always fighting the system to see what can be done.

Three of the mothers said that they'd been told that there was no funding to support the child with autism and their family. Lucy said, "They will often use the excuse that 'we have no funding'." Similarly, Nicole stated, "First of all whenever you have someone new working with her you have to spend so much time training them and often it doesn't work out. Or you get told that there isn't any funding to help us out." In another case, Mary had help at school, believed that she needed help at home and was told the same thing as Lucy and Nicole, "Before that there was nothing for home. We needed some kind of help. They told us there was no funding."

Getting the Wanted Support

Two themes were identified as mothers talked about the challenges of getting the wanted support. These themes are *waiting for services* (5/6) and *reactive versus proactive support* (4/6).

Waiting for services. Almost all of the mothers described having to wait for some kind of support for the child with autism or their family (*waiting for services*, 5/6). Lynn described how she and her husband made the decision to place their child in care and then had to wait for a vacancy in the appropriate placement; "At that time I was so upset. And then of course the universe always does this. The bureaucracy says that we have to wait 6 months. Finally, after making a hard decision that this is what your child needs." Mary also said that there was a delay for support after she and her husband identified a need for this support; "It took 2 years to get any support. It's been 4 years, since he was in grade 1…Before that there was nothing for home. We needed some kind of help. They told us there was no funding."

Two mothers talked about wait lists that they'd been placed on. Ellen said, "We made an appointment with my social worker because I had been on the wait list for a long time. I was number 8 on the list. I wasn't counting on [the support]." Similarly, Nicole said that she was waiting for services; "We are registered with [with an agency for respite services] but are still on their wait list."

In two cases, the mothers said that they could not wait for support from the government and began using their family's financial resources and time. Nicole described how they'd had difficulty finding a child and family worker for Leanna; "We had some difficulty finding a good match for her. We were without a worker for a year and a half. I hired privately for that time." Ellen also said that she went ahead and implemented a program for Tina on her own; "I find the system so bureaucratic. I'm not here to wait for them to help me. I couldn't wait. I went ahead and started Tina's program."

Reactive versus proactive service delivery. Four mothers said that they felt that they had to devote considerable time and energy to advocating for the child with autism, educating themselves or enduring unusual challenges before they received any support (*reactive versus proactive support*, 4/6). Lynn said, "It's been dangerous for a very long time. But the Ministry finally did something because Robert called our MLA and talked to our District Manager and went over a few people's heads." Similarly, Lucy described how she had lived with physical aggression from her son and only received support after he physically threatened a behavior consultant in the home,

> They knew that there were severe behavioral problems. But even with that, it was only when things got so bad that there was a risk of someone else getting hurt or dead...When he went after the behavior consultant and we had to keep him from leaving the house, I was offered the opportunity to place him for 4 months.

She added, "I am probably lucky to have the services I have because other families don't. I still find the whole system reactive not proactive."

Two of the mothers indicated that they needed to educate themselves about the available support services for families of children with autism before receiving any support. Ellen said that she was encouraged to get some help by a community support agency; "She thought I was stressed...I find the system so bureaucratic." Nicole described a similar experience; "When Leanna was really little we should have asked for things but I didn't know what was available. We had to tell them that we needed help before we got any services."

Impacts on Mothers

The mothers identified several ways they are affected by the presence of a child with autism in their family. These themes are mothers' *emotional reaction* (4/6), *feeling of isolation* (4/6), and *concerns about the child with autism's physical well-being/health-related concerns* (3/6). Four additional categories are used to describe the ways that the children with autism affect the mothers. These categories are long-term care for the child with autism, mothers' role(s), diagnostic issues and changes to mothers' perceptions life.

Emotional Reaction

Four of the mothers described their love for their child with autism in a very emotional way (*emotional reaction*, 4/6). For example, Beth said, "There is so much love. With handicapped children there's not more love by a different kind of love…A mother's love is more than I knew." Similarly, Lynn described the love she has for Alan in this way,

> I really, really love him and it's really, really difficult…It's the mother's love that aches to the bones. I am really blessed but it is a bittersweet thing…Never getting sleep or rest. I think that I have plummeted the depths and soared the heights of maternal love.

This theme was echoed in Lucy's words when she described the range of emotions she has for Andrew,

> There are times when I don't hate him I just hate what it does to all of us. I hate what it does to me…I feel very protective and then very, very angry and resentful of all the things that have gone on in this house. And at other times, there are moments that you can just see the nice side of him. He says something so sweet.

Similarly, Mary said, "And I love him. Only a mother can do what I do...That you realize that in spite of everything that you love that child. A mother's love is so strong."

By contrast, two mothers talked about feeling like the challenges of raising a child with autism are more than they can bear. Lynn said, "I can understand the Latimer story. I know what it's like to be asked to do something that is beyond what is reasonable for a person to do." In the second case, Mary specifically talked about murder and suicide; "It's been absolute hell. I've thought about killing myself and John. It's too much. I would never hurt him. But there are times when I want it to end."

Feeling of Isolation

Most of the mothers expressed that they feel isolated or have felt isolated since having a child with autism (*feeling of isolation*, 4/6). For example, Beth shared her experience during the first 7 years of Carl's life; "The first 7 years of his life were sheer hell. I couldn't go out anywhere...I felt like I was caged...I really didn't have a life." By contrast, Ellen talked about how her feeling of isolation is related to judgments other people have made about Alan's behavior and her as a mother; "Not only did the family not get the support they needed but we got ostracized and blamed. So, while you're grieving, you're coping with a special needs child and you're coping with societal judgments. It's hell." Ellen added that her family's social network is limited,

> It is a limiting factor. Because we can't really associate with anybody. We just end up dealing with people who are more open-minded and sensitive to something that is not so common. We don't have anyone over like you would if you had a typical child.

In the third case, Mary shared that she feels isolated because other people don't understand her experience, "Now I make a regular habit of taking a walk or visiting people…But I don't feel much like socializing. I don't think that people understand how I feel or what I endure."

Concerns for the Child with Autism's Physical Well-Being/Health-Related Concerns

Three mothers talked about their concerns for the child with autism's physical well-being or about health-related concerns faced by the child with autism and his/her family (*concerns for the child with autism's physical well-being/health-related concerns*, 3/6). Lynn described her experience when she wanted to take Alan off of the medication he was on,

> I said these medications are making him worse and we have to help him…He was 190 and aggressive and going through drug withdrawal. But once we got through that, one new med and one old med at a lower dose and it made a difference…And Alan would have been 190 pounds and full of suicidal thoughts and violent and full of remorse.

Similarly, Ellen talked about Tina's breathing difficulties during the night, and digestive concerns, and some of the strategies she'd explored to alleviate these health concerns,

> She had an oxymeter to see how much oxygen she was getting in and to see how much her body is absorbing during the night while she is at home. Now we are trying to see if she has allergies. The inside of her sinuses are swelling up and she can't breathe properly. And then her bowel movements. That's why I'm looking into Secretin.

By contrast, Mary described her concerns around caring for John's physical well-being in a more general way, "His hands get dry. We have to make sure that he puts cream on his skin. It's a big job just to look after his body. It's not just his mental condition but also his physical condition."

Long-Term Care for the Child with Autism

All of the mothers were asked about long-term care for their child with autism. Two themes were identified from these discussions. These themes are *care within the family home* (4/6) and *concern about what will happen to the child with autism* (2/6). Each of these will be discussed in the following sections.

Care within family home. Four of the mothers said that they would care for their child with autism in their home when their child with autism turns 19 (*care within family home*, 4/6). Two of the mothers said that they have a suite that the child with autism could occupy after he/she turns 19 years of age. Beth said, "We talked about it and we decided that if he's still with us at 25 that he could live in a suite in our house." Similarly, Mary clearly said that she wants John to live at home; "We definitely want him to stay home. This is the ideal situation…We would like to be able to provide for him when he's 19. We have accommodation for him. We can supervise him. It's here at our house."

Two mothers identified that they would be responsible for their child's care, even when they turn 19 years old, and that it is possible that the child with autism would live with them when they become an adult. These mothers reported different experiences of transition in part because of their children's ages. Ellen, who's daughter was 5 at the time of the interview, said,

> I thought about transition and I really don't see any clear picture where she is going to be or where I will be…I don't know what she is going to do or be when she gets

> older. Definitely, I will always be the person responsible for her care.

Nicole, who's daughter was 16 at the time of the interview, said that her priority was making sure that a day program is firmly in place before they examine alternatives for Leanna's living arrangements,

> The way I imagine things happening, we're first going to work on finding things for her during the day…We are going to be moving forward soon and trying out some places. My thought it that I want to get that firmly into place before we look at another placement…I think she is better off living here. She is very comfortable her right now and transitions are hard for her.

Concern about what will happen to the child with autism. Two mothers expressed concern about what will happen to the child with autism when the child turns 19 years of age (*concern about what will happen to the child with autism*, 2/6). Both of the children with autism were already spending considerable time in respite care. Lynn declared that Alan might end up in jail because of his unpredictable behavior,

> Because his IQ is above 70, he'll get nothing. We've thought of little else. He's not eligible for any support…There's nothing for him except for our home or the criminal justice system. We've got 6 years to change that. We're going to fight it.

Similarly, Lucy expressed concern about Andrew's ability to function on his own at 19,

> I try really hard not to [think about transition]. I sometimes stay awake wondering what is going to happen to him. I guess it would be semi-independent living…He can talk about a lot of things but when it comes to getting up in the morning, he doesn't remember to take his meds, to put on his clothes, or what he needs to take to school. No life skills.

Mothers' Role(s)

Most of the mothers in this sample identified that they are torn between what they believe their role, as a mother should be and their desire to have a job (*role conflict*, 5/6). Additionally, three of the mothers indicated that the family, and the child with autism in particular, depends on them for much of the day-to-day support and responsibilities in the family (*dependence on mothers*, 3/6).

Role conflict. All six of the mothers stayed home after the child with autism was born. Two of the mothers had returned to work within 2 years of being interviewed for this study and 1 mother had started a home business to be at home to support her child with autism. Five of these mothers indicated that they were unable to work because of the child with autism and were interested in working (*role conflict*, 5/6). Beth said, "I felt like I was caged…I was working two days per week. That was my escape. It really was. But, I decided that I needed to be at home for Carl. Now, I need the time I spend working." Ellen shared a similar experience; "I wasn't working…I had to be at home with her…Now that she's in school most of the day I can go to work."

In two cases the mothers talked about the sacrifices they've made to be at home with the child with autism. Lynn, for example, talked about the financial sacrifices her family made for her to be home with Alan, "But the reality is I stayed at home for 5 years to raise my child instead of earning money. I had to or he wouldn't get the support he needed. And we lived on 1 income." Similarly, Lucy is interested in going to college and pursuing a career to offer her kids more than she has been able to and how she has been unable to do this because she needs to be at home to support Andrew,

> Because I have more support now I am thinking about going in and getting retraining.

> To go to college. I'm unsure of what I want to do…I guess I would go into office work again. But if Andrew breaks down again, I guess I will put it on hold. I need to work. I need to have him out of here so there is room for him and the kids won't be bothering him.

Finally, Mary specified that she has been unable to work because of John's sleep patterns; "Usually he's up at 4 or 5 everyday. That's why I can't work…He used to be up all night screaming."

Dependence on mothers. Three of the mothers identified that their family, and specifically the child with autism, is dependent on them (*dependence on mother*, 3/6). Lynn described feeling responsible for ensuring that everything runs smoothly,

> I'm the overachiever who does too much and tries to keep the family together. I have to fix everything…The consequences are dire if anyone makes a wrong step that I feel like I have to police everything in order to keep things on the straight and narrow.

Similarly, Ellen characterized how she will be Tina's primary support into adulthood,

> I see myself as the role model mainly for my older daughter…I want her to be as self-sufficient as possible. With Tina it is a different story. I don't know what she is going to do or be when she gets older. Definitely I will always be the person responsible for her.

Similarly, Lucy described how Andrew, and her other children, are dependent on her despite living in a challenging situation,

> I do everything. I think a psychologist hit it on the head. He said Andrew is very dependent on his mother and she is also his safety net. They are very dependent on me to do things for them and protect them and I'm also a safe place for them to let

> loose. I think they can't stand the situation but they are still dependent on me…If I get upset, they get upset. There are a lot of bad feelings and there is a lot of dependence.

Diagnostic Issues

All of the mothers were asked about circumstances surrounding the diagnosis of the child with autism. Three themes were identified as diagnostic issues from these discussions. These themes included descriptions of their initial reaction to the diagnosis, *misdiagnosis/lack of diagnosis* (6/6) and the *length of time to get a diagnosis* (5/6). The mothers had three initial reactions to the diagnosis of their child: *denial* (3/6), *mixed emotions* (2/6) and *relief* (1/6).

Misdiagnosis/lack of diagnosis. All of the mothers recounted that the child with autism was initially misdiagnosed or that they did not have a diagnosis after they expressed concern about their child's development (*misdiagnosis/lack of diagnosis*, 6/6). Three mothers said that their child had been tested for hearing difficulties. Beth stated, "First it was his speech…Then they thought it was his hearing and had that tested." A similar experience was shared by Mary; "He wouldn't speak…He sent us to an ear specialist to test his hearing. He was fine. I suspected that there was something more serious." Nicole stated that Leanna had also had her hearing tested; "At first we thought that she was going through a phase where she didn't want to talk…But then by 18 months we started feeling uncomfortable with that. We had her hearing tested around 2."

Two mothers reported that they had received an initial diagnosis of developmental delay. For example, Nicole shared, "They said she had autistic tendencies but no one would say she had autism. Before that they said she was developmentally delayed."

Lucy made a similar report; "When he was young he was diagnosed with a developmental delay and was not looked at as autistic."

Two mothers were concerned by a lack of diagnosis. Lynn reported, "[Specialists] thought in November of kindergarten that he was autistic but wouldn't make a diagnosis. It took us another 2 years to get an official diagnosis." Similarly, Ellen expressed feeling confused by the lack of diagnosis,

> I noticed the day she was born…I remember telling the nurses there is something wrong with her. But they just told me not to worry about it…She was getting older but things didn't appear to change…There were some clear signs. That's why it amazes me still that we know so much about autism and they don't get it until the children are older.

Length of time to get a diagnosis. Most of the mothers reported that there was a lengthy delay in getting a diagnosis (*length of time to get a diagnosis*, 5/6). This delay included having to wait for the child with autism to be observed by professionals. For example, Beth said,

> And it took almost 2 years to see them. When we got in the door they said that they would test him but that he was definitely autistic. They didn't need to test him. It took us that long to get there…That's how long the wait was.

The delays were also the result of professionals wanting to accurately diagnose the child. Often the children were observed for lengthy periods of time and underwent multiple tests. For example, Ellen said,

> She was about 6 months old when they did tests. She had a CAT scan when she was 8 months old. She just got the diagnosis when she was three after seeing the

> psychiatrist. It was a long 3 years.

Similarly, Nicole related that Leanna was diagnosed at 11 after having her hearing tested and being diagnosed as developmentally delayed. She shared that they had given up on pursuing an accurate diagnosis but then learned that they were not receiving support without a diagnosis of autism; "We gave up on it for a while but then realized that we weren't getting the services such as a worker with her because of the lack of an autistic label."

Two mothers said that they were told by professionals not to be concerned by their child's development. Mary, for example, reported that they were asked by their family physician to wait 3 years before considering an in depth examination of John's development,

> He would rock in his crib for hours and hours. We mentioned that to the doctor. The doctor dismissed it. He told us to wait until he was three. We waited and he told us that he thought that it was nothing.

Ellen also mentioned that her concerns were dismissed; "I remember telling the nurses there is something wrong with her, but they just told me not to worry about it."

Initial reaction. Three of the mothers reported that they denied the initial diagnosis of their child with autism (*denial*, 3/6). Beth said, "When I found out I was devastated. I didn't want to believe that I have a handicapped child." Lucy shared that she looked for an alternative explanation, "The first time they diagnosed him when he was 3. I thought they might be wrong. He was just a little slower that other kids." Mary expressed feeling devastated, " Awful. I wanted to die."

Two mothers expressed feeling mixed emotions when they received the diagnosis (*mixed emotions*, 2/6). Ellen described her reaction this way, "Great and awful at the same time. I was hoping it was something she's grow out of. And on the other hand I felt acknowledged." Nicole shared a similar experience, "When we got the official diagnosis we weren't totally surprised. Relief on one hand and denial on the other hand."

One mother felt relieved to have a diagnosis (*relief*, 1/6). In particular, she was relieved to know that she was not responsible for Alan's behavior, "It was a huge relief. It was an enemy we could fight…It wasn't just a crappy mother doing a crappy job with a crappy child."

Changes to mothers' perceptions of life

The mothers in this sample said that their perceptions of life had changed as a result of having a child with autism. Themes that were identified were mothers' expressions of appreciation (*appreciation*, 6/6) and reports of how their social network is different as a result of having a child with autism (*social network*, 3/6).

Appreciation. All the mothers talked about how the child with autism has enriched their lives (*appreciation*, 6/6). This appreciation includes recognizing the small achievements made by others and an appreciation for someone else's experience of life. For example, Beth said, "It teaches you things in life you might otherwise take for granted. Things that are otherwise routine but when Carl does them it's like, 'Wow'. You know, you just can't believe it." Nicole made a similar observation, "The way it opens your mind up to a whole world of possibilities. Looking at the world through someone else's eyes. Seeing the joy she gets."

This appreciation also included a shift in what the mothers believe is important. For example, Lynn believed that academic achievement was critical. She now believes something entirely different,

> I would not have realized how lucky I am. I would have been expecting perfection from my kids so that I could feel good about myself...I don't see a lot of happiness of love out there. We've been hurt so much that we're not scared anymore to really live.

Lucy described a similar experience,

> Having everything changed...To be more patient and look at things differently. I never would have looked at things that way. Or I wouldn't have had those moments when everything is going well and all it takes is going outside and the sun is out for me to smile about everything.

Finally, this appreciation also included recognizing the power of the mother-child bond. For example, Mary said, "That you realize that in spite of everything that you love that child. A mother's love is so strong."

Social network. Three mothers described how their social network is better because of the presence of the child with autism. Lynn commented,

> We're also lucky that Alan keeps away the yucky people. After they see what can go on only special people stick around. We only have the best people in our lives. The top people in the world are my social network.

Ellen made a similar observation,

> Because we can't really associate with anybody [because of Tina] we just end up dealing with people who are more open-minded and sensitive to something that is not so common...Only people who are really concerned will stick around. The other ones won't. I think it's great. I don't want people who are not there for my well-being or my children's.

Nicole described how Leanna has provided her family with opportunities to connect with people they might not otherwise meet; "We've met so many good people who have children and are in the field."

Sleep Disturbances

Four of the mothers reported the child with autism has difficulty falling asleep or staying asleep (*sleep disturbances*, 4/6). Three of these mothers reported that the child with autism was administered medication to help him/her fall asleep. Lynn said, "When [Alan] wasn't on the meds he wasn't sleeping at all. So, he wouldn't go to bed. He'd be jumping and screaming…This new med makes him sleepy." Lucy made similar observations of Andrew, "With the medication he sleeps. Without medication, once he got to sleep it was fine but he had a lot of trouble getting to sleep…We started the medication and it has really helped." In the third case, Nicole described the impact of Leanna's sleep disturbance on her ability to function during the day,

> The main reason for this is because of her sleep patterns. About a year ago she was staying awake 'til 3 or 4 in the morning or couldn't fall asleep at all which resulted in not being able to wake her up in the morning and her missing school…The psychiatrist prescribed some drugs and they seem to have helped.

In one case, the family did not administer medication to manage the child with autism's behavior. Mary depicted the long-term effects of John's sleep pattern and the solution adopted by the parents,

> He can sleep some nights. Usually he's up at 4 or 5 everyday. That's why I can't work. When Charles worked I'd be up all night to keep him quiet so that Charles can get some sleep. He used to be up all night screaming. When he was a baby he

wouldn't sleep much. Now Charles sleeps in John's room. If he wakes up Charles is there to calm him and get him back to sleep.

Part III: Nonautistic Siblings

In reporting the results in this section, themes were organized into 4 categories: unpredictability, coping mechanisms, impact on siblings and social issues. Unpredictability includes verbal aggression and physical aggression. The coping mechanisms reported by the siblings include making sense of the physical/verbal aggression, removal of child with autism/respite, drug administration and avoidance of unpredictable situations. The impacts on the siblings include siblings being at risk for violent outbursts from the child with autism, additional responsibilities for siblings, neglect of siblings, compensation for the siblings and sleep disturbance. The category social issues include acceptance/rejection in public in the first case and at home in the second instance. Each of these will be examined in detail in subsequent sections.

Unpredictability

Themes that emerged from unpredictability were *physical aggression* (5/6) and *verbal aggression* (4/6). These themes are presented in order of frequency of appearance.

Physical Aggression

When siblings were asked to talk about the child with autism most of them talked about physical aggression displayed by the child with autism (*physical aggression*, 5/6). Four of the siblings talked about the child with autism being physically aggressive with them/others. Roger shared that his brother "...can get really angry and be real mean. He hits people and grabs their hair." Similarly, Sonya focused on the details of the physical aggression as she's experienced it; "Sometimes when [Tina] gets mad she hits me and bites me at the same time." In the third case, Sandra stated, "Sometimes if something goes wrong at school, he doesn't get mad at school, he gets really mad here. Sometimes he tries to beat us up because he can't help it." Finally, Victoria commented, "When he gets a little too excited he starts to tease people and that's when he hurts them sometimes."

Physical aggression also included witnessing the child with autism hurting his or her own body in some way. Tyler provided this example, "If I get a new game or toy and he wants it he'll start screaming and smack himself and stuff." Similarly, Sonya said that Tina does not like certain sounds and provided the sound of the dishwasher as an example. When asked what happens when the dishwasher is on Sonya said, "She would sit down on the floor and hit the dishwasher and bite herself on the thumb."

Physical aggression was also described as damage, or potential damage, to inanimate objects by 3 siblings. Sonya talked about witnessing her sister picking something up and throwing it across the room when her sister is angry. Tyler described an ongoing pattern with his brother "And we've been having trouble with sweatshirts. He rips so many of them. That's just the way he is when he gets mad." He further provided a specific instance of this pattern "Like last night, he wanted my pop, so I gave him half. He wanted more. My mom told him no and he ripped his sweatshirt." Finally, Sandra talked about her brother displaying some self-control by focusing his aggression on inanimate objects; "He tries to control himself. Now sometimes instead of hurting people, he pushes things over. He's pushed over shelves and broken Christmas bulbs. He also pushed over the television."

Verbal Aggression

Four siblings included some description of *verbal aggression* (4/6) in their description of the child with autism. Three of these siblings used 'scream' or 'shriek' to describe the verbal aggression. Tyler said, "If he doesn't get what he wants he shrieks. One time he shrieked so much he lost his voice." Similarly, Christopher said, "She screams a lot. And sometimes she has temper tantrums. She'll usually cry and scream in a temper tantrum." Sonya discussed her sister's tantrums and commented, "If she wants a special dress and you don't give it to her she will scream and keep on screaming until she gets the dress she wants to wear."

One sibling described a different form of verbal aggression. Victoria talked about how John teases her and other people "When he gets a little too excited he starts to tease people and that's when he hurts them sometimes." When asked to describe her relationship with her brother, she said, "He's usually teasing me and going into my room. He wants me to get angry at him so that he can make a scene."

Coping Mechanisms

As mentioned, all of the siblings identified patterns of unpredictable behavior in the child with autism. As might be anticipated, the siblings presented several ways that they, and other family members, cope with these behaviors. Coping mechanisms that emerged as themes are *making sense of the physical/verbal aggression* (5/6), *removal of child with autism* (5/6), *avoidance of unpredictable situations: going out in public* (4/6), *avoidance of unpredictable situations: dinnertime* (3/6), *reactive solutions* (2/6), and *drug administration* (2/6). Each theme will be discussed in detail in the following sections.

Making Sense of the Physical/Verbal Aggression

Most of the siblings highlighted strategies they use to make sense of the physical/verbal aggression (*making sense of the physical/verbal aggression*, 5/6). Three of the siblings accepted the child with autism's behaviors and described these behaviors as out of the child with autism's control. For example, Tyler said, "And we've been having trouble with sweatshirts. He rips so many of them. That's just the way he is when he gets mad." Likewise, Sandra explained, "Sometimes he tries to beat us up because he can't help it." Finally, Victoria reported a similar experience "While at an assembly at school John began to have a tantrum and was yelling. And my friends said I guess John's not having a good day. I think they understand about John. He can't help it."

Two of the siblings provided explanations for the child with autism's behaviors. Sonya suggested that her sister only has tantrums when she is having a bad day. Similarly, Christopher stated that, although his sister screams everyday, it is "…mostly because she is excited or wants to do something."

Removal of Child with Autism/Respite

Most of the siblings talked about the *removal of child with autism/respite* (5/6) as a way to cope with the challenges of living with a child with autism. In fact, three siblings talked about how it is easier when the child with autism is not around. Sonya commented that she enjoys this time because "It's time not to be bothered by Tina, my mom being distracted by Tina. So I can talk to her without interruption." Christopher said, "It's quite a relief because we get to relax for a weekend. It's not relaxing when she is home because she would be screaming and getting into the food." Similarly, Victoria emphasized the benefits of respite for her and her parents. "We have workers who take John out on the weekend…It gives my parents a break…It's nice because we get a break and you can do your own thing."

By contrast, two siblings characterized respite as a necessity for the family. Roger said "I think it's a shame that he has to [be in respite] because we have a hard time with him. He can't live with us." Similarly, Sandra shared that her brother "…needs to go [into respite] so that he won't hurt us."

Avoidance of Unpredictable Situations: Going out in public

Four siblings reported that their families do not go out as a result of the child with autism's behavior (*avoidance of unpredictable situations: going out in public*, 4/6). Roger shared that he and his parents don't tell Alan when they go out. "He's not allowed to go for dinner with us. We sneak out now…We don't tell him. Sometimes we leave him alone and other times we go when he's [in respite]." In the second case, Sonya said, "Sometimes she has tantrums, so we don't go out that often. It's too hard and embarrassing." Sandra shared a similar experience. "We don't really go out as a family. It's too hard on my mom. Not knowing how Andrew will be." Finally, Victoria reported, "We can't do lots of things or go out because of John."

Avoidance of Unpredictable Situations: Dinnertime

Four siblings identified dinnertime as a time when the child with autism is likely to exhibit unpredictable behaviors. They also shared that, because of this pattern, their family does not sit down together for dinner (*avoidance of unpredictable situations: dinnertime*, (4/6). Tyler said, "We've tried to get him to [sit down for dinner] but he usually eats in front of the t.v. or in front of the Sony [Playstation]…If [my parents ask him to and] he doesn't want to he'll scream." Roger stated that respite has been arranged so that the child with autism is not home at dinnertime. When asked what happened in the past he said, "He'd freak out sometimes before dinner. Sometimes after dinner. Mostly at dinner…He'd yell, maybe throw a fork. Get really mad." Similarly, Sandra said,

> We don't eat together. There is no routine. Things can get really crazy around here before dinner with Andrew. Sometimes my mom is tired and we make our own dinner, like ham sandwiches or spaghetti if she lets us use the stove.

Finally, Victoria stated, "We [eat dinner] at different times. It's too much trouble with John."

Reactive Solutions

Three siblings reported that their families have implemented ways to manage the child with autism's behavior or protect themselves from the child with autism (*reactive solutions*, 3/6). All of these strategies were implemented in direct response to the child with autism's unpredictable behavior. For example, two siblings identified the need for someone to be in the child with autism's bedroom in order for them to fall asleep or stay asleep at night. Sonya said, "When my mom has to put Tina to bed my mom says I have to go to bed too otherwise Tina won't go to bed. I have to read in bed and watch her." Similarly, Victoria shared,

> Sometimes he sleeps through the night now. My brother has a bunk bed and my dad sleeps on the bottom now and he hears him and they quietly talk in the middle of the night and John goes back to sleep.

In one case, the sibling shared how precautions have been taken to remain physically safe from the child with autism's physical aggression. Roger shared, "My mom called from the attic 'Lock out' just as Alan came bursting out the door. 'Cause we have a lock on the attic door to protect ourselves. I ran up to the attic."

Drug Administration

Two siblings reported that the child with autism was prescribed medication to manage his/her behavior (*drug administration*, 2/6). For example, Roger shared some of the challenges faced by his parents and professionals to find a medication that would be successful in managing his brother's behavior; "He's on new medication. The old stuff made him bigger so he was a lot harder to handle when he did freak out. And the medicine didn't help much. The new stuff is better." In the second case, Sandra shared that Andrew has identified a need to remain on medication to manage his behavior,

> He takes medication but I'm not sure what it is but he takes one tablet a day because they are strong. One time he was really starting to beat people up because he was really tired. He called my mom up to tell her that he thought he was starting to get that again because he wasn't getting his medication.

Impacts on the Siblings

As expected, the siblings reported that the child with autism affects them. The impacts on the siblings, reported as themes, were *siblings being at risk of violent outbursts from the child with autism* (4/6), *additional responsibilities for the siblings* (3/6), *display of adult-like behaviors* (3/6), *sleep disturbance* (3/6), *neglect of sibling* (3/6), *compensation for the sibling* (1/6). Each theme will be discussed in the following sections.

Siblings Being at Risk of Violent Outbursts from the Child with Autism

Most of the siblings reported that the child with autism had hurt them or ascertained the need to protect themselves from the child with autism (*siblings at risk of violent outbursts from child with autism*, 4/6). For example, when Roger was asked about his brother's physical aggression he said, "You're all panicky. You worry about your safety. I hide in my room sometimes. Mostly in my parents' room…He can get frustrated all of a sudden. You never know what will happen." Sonya described her experience this way, "Sometimes when she gets mad she hits me and bites at the same time. Then picks something up and throws it across the room." In one case the nonautistic sibling was being removed from the home as a safety measure. Sandra shared that she was going to spend the summer at her grandmother's because of the physical aggression displayed by her brother. "[I'm going] because it's hard around home and my mom says I'm not safe here from Andrew." Finally, Victoria said,

> Sometimes he gets a little over-excited and hyper…When he gets a little too excited he starts to tease people and that's when he hurts them…When I try to get away from him in my room he's always slamming the door open. He's usually teasing me and going into my room.

Additional Responsibilities for the Siblings

Three siblings reported having to hide their belongings from the child with autism (*additional responsibilities for siblings*, 3/6). Tyler said, "I have to hide my special stuff or else he wrecks it. If he knows that it's hidden he'll trash the place." Similarly, Roger identified this pattern with respect to video games,

> I hide my Game Boy. Because he'll save his games over my games. So, I usually

> turn off the sound and go and play in my room. Or I bring it to school to play it. I keep it a secret.

Christopher recounted how his sister damaged a science project he worked hard to develop. "Sometimes I get along with her except when she tries to eat my science project. I guess it looked like candy. I have to hide my stuff from her."

Display of Adult-Like Behaviors

Three siblings described situations in which they adopt adult-like roles and responsibilities (*display of adult-like behaviors*, 3/6). Roger stated that he is the person responsible for getting help when Alan is attacking his parents, "I often have to call [for help] for my mom when Alan is freaking out. He grabs [my mom] by the hair." Sonya shared that she is responsible for monitoring her sister's behavior at bedtime; "When my mom has to put Tina to bed my mom says that I have to go to bed otherwise Tina won't go to bed. I have to read in bed and watch her." Finally, Sandra described helping her mother out financially; "I gave her $10.00 to help her out. I offered it because I knew that she would probably need it and I've never had that much in my life and so I thought she might need it."

Neglect of Siblings

Half of the siblings shared that they felt neglected in some way (*neglect of siblings*, 3/6). Tyler said, "I used to think that my parents loved Carl more than me. And I'd be really upset." Two siblings referred specifically to how much their parents' focus is on the child with autism. For example, when asked what the hardest part of having a brother or sister with autism is, Sonya said, "That your parent is spending time to take care of her and trying to listen to me but can't because they have to do this or that." When Victoria was asked the same question, she stated, "He gets more attention from my parents."

Sleep Disturbance

Three siblings described how the child with autism disrupts their sleep (*sleep disturbance*, 3/6). Roger said, "Like at night I don't get very much sleep because he talks to me. We share a room and he keeps telling me the same things over and over again…He keeps me up." Christopher described a similar experience,

> …she stays up really late at night and she jumps on her bed and makes noise when she's supposed to be sleeping. She will stay up until midnight or 1am and then fall asleep. I hear her at night and it sometimes keeps me up.

When asked about the hardest part of having a sister with autism he added, "She keeps me up at night so it makes it hard for me to wake up in the morning." Finally, when Victoria was asked to talk about what it's like to have a brother with autism she said, "He bothers you a lot. He wakes up at night talking and humming or getting upset."

Compensation for the Siblings

One sibling talked about how her parents tried to compensate her for having a brother with autism (*compensation for sibling*, 1/6). Victoria commented, "My parents get me stuff, like the computer, because if he didn't have autism they would give me more attention rather than a computer."

Social Issues

Two social issues were identified as themes: *acceptance/rejection at home* (4/6) and *acceptance/rejection in public* (2/6). These themes will be discussed in the following sections.

Acceptance/Rejection in Public

Four siblings suggested that they feel uneasy in public when the child with autism displays unpredictable behavior (*acceptance/rejection in public*, 4/6). When Roger was asked to describe the last time that his family went out together he said, "The last time we went [out] Alan got really angry. We were eating dinner. He's not allowed to go out with us. We sneak out now...He just sort of got angry. We were embarrassed." Similarly, Sonya said, "Sometimes she has tantrums so we don't go out that often. I worry about what people will think." In the third case Sandra reported, "We don't get to go places because [my mother] has to stay home and handle things with Andrew. He often can't control himself in public." Finally, Victoria shared, "He talks to strangers and sometimes I am uncomfortable with that."

Acceptance/Rejection at Home

Two siblings talked about feeling uncomfortable having their friends over to their homes or not being allowed to have their friends over (*acceptance/rejection at home*, 2/6). Roger described his fear that Alan would become physically aggressive in front of his friends; "...most of the time they come over when he's not here or when he's not freaking out. Sometimes we have to go play outside." He later added,

> I don't think it's a very good idea [to have my friends over when Alan is home]. We can't play on the computer. He'll freak out and say that we're doing it all wrong...My friends don't really want to come over either when Alan's here.

Sandra explained her mother's concerns about her having friends over to their house; "Andrew doesn't play with my friends any more because my mom doesn't let them come over unless he is away in case anything goes wrong."

Part IV: Fathers

In reporting the results of interviews with fathers, themes were organized into 7 categories: unpredictability, coping mechanisms, impact on siblings, social issues, want versus need service expectations, impacts on fathers and problems with the children with autism falling asleep or staying asleep. Unpredictability includes verbal aggression and physical aggression. The coping mechanisms, reported by the fathers, include making sense of the physical/verbal aggression, removal of child with autism/respite, reactive solutions, drug administration, control over the environment, and avoidance of unpredictable situations. The impacts on the siblings include siblings being at risk for violent outbursts from the child with autism, additional responsibilities for siblings, gender specific role expectations of siblings, expecting more of the siblings, neglect of siblings, and compensation for the siblings. The social issues identified by the fathers include acceptance/rejection in public and acceptance/rejection at home. Want versus need expectations were identified as unmet expectations. Impacts on the fathers include concerns for the child with autism's physical health, concerns for the mothers' emotional/psychological well-being, long-term care for the child with autism, fathers' feeling of isolation, diagnostic issues, fathers' need to manage child with autism's behavior, and fathers' reports of changes to their perceptions of life. Each of these categories and themes will be examined in detail in the following sections.

Unpredictability

Themes that were identified in this category are *physical aggression* (4/4) and *verbal aggression* (3/4). These themes have been presented in order of frequency of appearance.

Physical Aggression

All of the fathers reported that the child with autism could be physically aggressive (*physical aggression*, 4/4). The physical aggression described by the fathers included aggression directed at other people. For example, Robert said, "It's not safe. If he gets upset he'll start hitting you. Now it's not safe for anyone involved." In other cases the physical aggression directed at other people is not consistent. Charles depicted his experience of Leanna; "She may hit someone to get their attention when she's in an active state. This is an on again, off again problem with her." Charles, John's father, reported a similar pattern, "He does have tantrums but he usually does not hurt people. He has hit and spit at people but that it not very frequent."

In other cases, the physical aggression was directed at inanimate objects. Doug said, "Right now we're going through a process of him ripping his sweatshirts. About one a day." Similarly, Charles related, "He could be drawing and suddenly everything that is on the table is tossed across the room. He may not be able to tell you why he tossed it, he just had to. He does have some violent outbursts."

Verbal Aggression

Most of the fathers reported that the child with autism could be verbally aggressive (*verbal aggression*, 3/4). Descriptions of this verbal aggression included the child with autism screaming. For example, Doug reported, "A lot of times, Tyler can just walk into a room and Carl will scream pure hell…Then we walked in and Carl would scream and stuff because Carl was doing something he shouldn't be doing." Similarly, Charles implied that John's screaming was part of more general aggression, "You can't predict with John. He could start with throwing himself on the floor and kick and scream…"

In the other case, the child with autism was reported to verbally threaten other people. Robert said, "If you don't agree with him he will require it or he will make you agree by first being threatening verbally."

Coping Mechanisms

The fathers talked about strategies they use to cope with the child with autism's unpredictable behaviors. The themes that emerged in this category are *making sense of the physical/verbal aggression* (4/4), *avoidance of unpredictable situations: going out in public* (4/4), *removal of the child with autism/respite* (3/4), *avoidance of unpredictable situations: dinnertime* (3/4), and *drug administration* (2/4).

Making Sense of the Physical/Verbal Aggression

All of the fathers provided explanations for the child with autism's verbal/physical aggression (*making sense of the physical/verbal aggression*, 4/4). In all cases, the fathers reported that the child's intention is not to hurt other people or intentionally damage anything. Doug explained Carl's pattern of ripping sweatshirts, "[He rips his sweatshirts because of] his frustration I think. Because [the teachers] said that he knows that he can do stuff but he might not do it the first time." In the second case Robert described his recent insights into Alan's physical aggression, "Trying to be a little more accepting and trying not to personalize his behavior. I think that I've finally realized that he's not doing it on purpose. If he could stop doing it, he would." In the second case Adam observed that Leanna wants contact with people when she hits them; "She may hit someone to get their attention…But again, it's not an attempt to harm but rather the objective is to get someone's attention or engage them in some interaction." Finally, Charles explained that John's aggression is the result of what John's learned from his peers; "He doesn't try to hurt people. He is just trying to replicate what he sees on the playground. John will try to reproduce what he sees in play."

Avoidance of Unpredictable Situations: Going out in public

All of the fathers described how they limit going out in public as a family because of the child with autism's unpredictable behavior (*avoidance of unpredictable situations: going out in public*, 4/4). Doug said that they limit their family outings and described how any family outings were not possible 2 years ago,

> Basically, we couldn't go out of this house as a family. We could maybe go for a walk through the park…But, if we went to any malls, shopping, he would just drop, kick, scream…right up to probably the age of 6 or 7.

By contrast, Robert recounted how family outings were a common occurrence in the past; "We used to do everything with him. We took him to Disneyland…We had a huge scene at Universal Studios. They called the cops…We took him everywhere. Now, we don't go out with him." In the third case Adam described how he carefully plans each family outing,

> If we're invited somewhere, one of the first questions is not only do we take the kids but also do we take Leanna…We would be more selective about [some activities]. We're careful not to place other people in situation that might be extremely awkward for them.

Finally, Charles reported that family outings are not frequent because he is sensitive to how Victoria reacts at these times, "Victoria doesn't like to come out with us because it is too embarrassing. The way [John] talks and acts. He makes himself noticeable. It makes her want to disappear. We try to avoid putting her through that."

Removal of the Child with Autism/Respite

Three fathers in this sample said that the family receives some form of respite (*removal of the child with autism/respite*, 3/4). For example, Roger acknowledged that Alan needs to spend considerable time away from home because of his unpredictable behavior; "He's there now a lot of the time because he has such trouble at home…We don't see much of him." The other two fathers stated that the respite gives them a break. Adam admitted, "There is respite for one weekend a month for Leanna to stay overnight...That's just to give us a break because that's important." Similarly, Charles said, "We have someone come 2 times a week on the weekend. It gives us a bit of a break."

Avoidance of Unpredictable Situations: Dinnertime

Three fathers reported that their family does not sit down together for dinner because of the child with autism's unpredictable behavior (*avoidance of unpredictable situations: dinnertime*, 3/4). Doug acknowledged that he's made attempts to have Carl sit down at the dinner table. He added, "We don't force him to eat dinner at the table if he doesn't want to because it's just too upsetting. And then it makes dinnertime more stressful…It's not worth it." Similarly, Charles described how family members eat at different times; "We don't have dinnertime. We eat separately. It's too difficult with John…Who wants to eat when someone's going to have a tantrum? It takes too much work to get him to sit down for dinner." By contrast, Robert described making attempts to have dinner as a family; "When he's here [dinner] doesn't work so well. It's very disruptive with him there." This family's solution is to have Alan home for dinner only once a week.

Drug Administration

Two fathers reported that the child with autism was receiving medication to manage his or her unpredictable behavior (*drug administration*, 2/4). For example, Robert described his experience of Alan without medication,

> He sleeps well only because of the medication that he's on. About three months ago we weaned him. He had a huge array of medications...He was overmedicated and ate like a horse...So, we took him off all medication and then he was just a wild man. He never slept and never stopped moving...We never slept.

Similarly, Adam said that Leanna receives medication to help her sleep; "[Her sleep patterns have] changed somewhat with the drugs she's on. But ordinarily, she's capable of staying awake later than is ideal."

Control Over the Environment

One father stated that their family has implemented control over the child with autism's environment (*control over the environment*, 1/4). Charles highlighted the need to carefully select and train people who work with John,

> He could start with throwing himself on the floor and kick and scream or throw things across the room. It can be quite scary if you don't know the child. That's why you need trained people who can mediate and keep it from happening. When he does that he's got to be removed for the environment if there are people.

Impact on Siblings

The fathers in this sample identified several ways that the child with autism has affected his/her sibling. The themes in this category are *compensation for siblings* (4/4), *additional responsibilities for siblings* (3/4), *neglect of siblings* (3/4), *fathers'* *expectations of the siblings* (3/4), *siblings' unusual maturity* (2/4), *fathers' gender specific role expectations of siblings* (2/4) and *siblings at risk of violent outbursts from the child with autism* (1/4). Each of these will be discussed in the following sections.

Compensation for Siblings

All of the fathers said that they did things to compensate the siblings for the challenges of having a sister or brother with autism (*compensation for siblings*, 4/4). Three fathers said that they plan special outings with the sibling, often when the child with autism is in respite. For example, Doug said,

> Carl does not do the fishing trip stuff. Going for bike rides. This is something Tyler and I do together. We're going to Vancouver to see a concert this weekend. I do lots with Tyler because he does suffer...Tyler gets lots of treats.

Robert stated that he wants to offer Roger a sense of normalcy and uses time alone with Roger to do this; "We are determined to keep his life as normal as possible. We went camping this last summer. We went to a friend's cabin. Stuff like that." Similarly, Adam shared,

> We also try to do certain things when Leanna is [in respite]. One example is that last summer the three of us went on a brief camping trip...Or we might go to a movie...So, there outings like that when Leanna is away.

Two fathers said that they compensate the siblings by buying them things. Doug said, "And it's just, he's got his own room downstairs and his own waterbed and his own computer." Charles described the same experience; "We compensate her for the other lacks by getting her things like computer stuff and sports things that she wants."

Additional Responsibilities for Siblings

Three fathers stated that the siblings have responsibilities that other children their age do not have (*additional responsibilities for siblings*, 3/4). Robert recognized that Roger is sensitive to the conflict and tension that Alan's behavior brings to the family environment,

> He's often the person who tries to be the peacemaker. If you can imagine, Lynn and I have often have some serious conflicts about Alan. And Roger is there trying to make everyone happy when they're sad. Or when we're having a bad time act like the clown to make us laugh.

Adam stated that these responsibilities include looking after the child with autism; "Christopher is in a tricky situation. He has to face responsibilities that lots of other kids don't. Like looking after Leanna. And he does that well. He's really developed that sensitivity well."

Two fathers said that the siblings' additional responsibilities often include monitoring their personal belongings so that the child with autism does not damage them or take them. Adam described his experience,

> [Christopher] also has to be more responsible for his own actions. It's not safe for him, for example, to leave things unattended because they can be tampered with by Leanna. Most importantly, he's had to learn to be accommodating when something like that does happen.

Like Adam, Doug suggested Tyler should be more vigilant about monitoring his belongings,

> You see Carl gets into everything that Tyler has. Stuff Tyler wants to keep in good

shape, Carl gets into and wrecks it, half the time because he leaves it out. We tell him that he's got to hide it."

Neglect of Siblings

Most of the fathers in this sample mentioned that the sibling was often neglected in some way because of the child with autism's presence in the family (*neglect of siblings*, 3/4). Doug expressed concern that Tyler suffers because the two children are treated differently,

> Carl comes first in a lot of areas. That makes it hard for Tyler. Because Tyler understands and Carl doesn't…When Carl doesn't want to do something, or we want everyone to do something, Carl doesn't want to do it. Then we bend to please Carl. It's just easier to please Carl. Tyler suffers there.

Robert expressed concern about Alan's needs being put before Roger's; "He may have some big issue to talk about. But we're dealing with Alan and bigger issues. We ask him to be quiet at those times. It's hard on him." Finally, Charles expressed concern about Victoria's emotional health,

> The other concern is our other child. This is another thorn in our side because we know that our daughter is paying the price for John. An emotional cost, in terms of time we invest in her. We can't give her as much time as we give to John…She is still very deprived of a normal childhood after her brother was born. The worse he gets, the more she falls into the background.

He added, "Victoria thinks that I love John more than I love her. I can understand how she can get that impression because I spend more time with him than I spend with her."

Fathers' Expectations of the Siblings

Three fathers mentioned that they expect more of the sibling of the child with autism (*fathers expectations of the siblings*, 3/4). Doug said, "An outsider would probably say that we are too critical of him or something. That we expect more of him and that we're harder on him." Robert made a very similar observation, "I think that I've been a little hard on him. I've demanded more of him." Finally, Adam shared that he sees Christopher as a reflection of his parenting abilities,

> I think that Nicole and I see Christopher as propensitory tool to show us that we are not the worst parents in the world. We can produce one kid who's good. In that way, perhaps, we expect more of him.

Siblings' Unusual Maturity

Two fathers specifically said that the sibling is unusually mature for their age (*siblings' unusual maturity*, 2/4). Robert described Roger by saying, "A lot of the time he has to be way older than he is." Similarly, Adam observed that Christopher displayed "...a certain amount of maturity and responsibility. I think that he has that to a greater extent than other kids his age...He's older than his peers...but there is a difference from his peers."

Fathers' Gender Specific Role Expectations of Siblings

Two fathers indicated that they have gender specific role expectations of the siblings (*fathers' gender specific gender role expectations of siblings*, 2/4). For example, Doug said, "I have no reason to expect that he can't do what he wants to do. I just want him to get a good job, have a family and be happy." In the second case, Charles expressed concern that Victoria is not helping out with the cooking, traditionally considered a woman's responsibility; "Poor thing. She is a growing girl and she wants to do well in school and make her parents proud of her. She is helping her mom with the cleaning but not the cooking as much."

Siblings at Risk of Violent Outbursts from the Child with Autism

One father acknowledged that the sibling is the target of the child with autism's physical/verbal aggression (*siblings at risk of violent outbursts from the child with autism*, 1/4). Robert said, "And since Alan has gotten so much bigger, we're more careful and protective of Roger and the potential that he might hurt him."

Social Issues

Two social issues were identified in the fathers' interview transcripts. The fathers reported concerns related to acceptance/rejection by others in public (*acceptance/rejection in public*, 4/4) and acceptance/rejection by visitors in their home (*acceptance/rejection at home*, 2/4). Each of these themes will be discussed in the following sections.

Acceptance/Rejection in Public

All of the fathers expressed concern about judgments by others while in public with the child with autism (*acceptance/rejection in public*, 4/4). Doug shared that his concerns have meant that the family does what Carl wants when they are out in public,

> But if we went to any malls, shopping, he would just drop, kick, cry, scream…It's just easier to please Carl. Tyler suffers there…Then we remind him why things happen the way that they do. Why we bend to Carl's ways in some situations, especially when we're in public.

Robert described how Alan is no longer invited on family outings because of his behavior; "We took him to Disneyland…We had a huge scene at Universal Studios. They called the cops. It was really special. We took him everywhere. Now, we don't go out with him." He later added, "But, about half the time it turned into a scene if something didn't happen the way he wanted it to. We stopped taking him out." In the third case Adam stated how sensitive the family is to how others react to Leanna; "If we're invited somewhere, one of the first questions is not only do we take the kids but do we take Leanna…It's to do with us being defensive about how we're viewed." He later shared, "So, living in a family that's affected this way is tied up with how people outside the family then react with members of the family…I think that there is a psychological impact when others react." Finally, Charles expressed concern for Victoria when the family is out together; "Victoria doesn't like to come out with us because it is too embarrassing. The way he talks and acts. He makes himself noticeable. It makes her want to disappear. We try to avoid putting her through that."

Acceptance/Rejection at Home

Two fathers said that they have a limited social network because of the child with autism's presence in the family (*acceptance/rejection at home*, 2/4). Robert said, "The only friends that we have really, and we don't have that many, are another couple who has a son with autism…People don't call us. They're scared of Alan." Likewise Adam stated that he is sensitive to others' reactions to Leanna; "For example, if I have colleagues to visit, I can't have them to our home. We would be more selective about these activities. We're careful not to place other people in situations that might be extremely awkward for them."

Impact on Fathers

The fathers said that they were affected in several ways by the presence of a child with autism in their family. The themes that were identified are *feeling of isolation* (3/4) *concern about the mothers' emotional/psychological well-being* (3/4) *concern about the child with autism's health* (2/4), and *fathers' responsibilities* (2/4). Three additional categories were developed to discuss the child with autism's impact on the fathers: diagnostic issues, long-term care for the child with autism, and fathers' reports of changes to their perceptions of life. Themes related to diagnostic issues are initial reaction to the diagnosis (*initial reaction*, 4/4) and *misdiagnosis* (3/4). Themes related to the long-term care for the child with autism are *concern about what will happen to the child with autism* (3/4), *siblings' involvement in the long-term care of the child with autism* (3/4) and *care within the family home* (2/4). The fathers reported two ways in which their perceptions of life have been altered by the presence of a child with autism. These are *appreciation* (3/4) and *personal growth* (2/4).

Feeling of Isolation

Most of the fathers mentioned that they feel isolated because of the child with autism (*feeling of isolation*, 3/4). For example, Robert talked about how others react to Alan,

> You form relationships with people who are in a similar position that you are. The only friends that we really have, and we don't have that many, are another who has a son with autism. So, there is a sense of isolation that we experience. People don't call us. They're scared of Alan. So, you can feel very, very isolated.

Similarly, Adam expressed concern about judgments other people make about Leanna and the family; "We both experience more isolation. It's to do with us being defensive about how we're viewed by others." Finally, Charles talked about the sacrifices he's made and how these sacrifices contribute to the isolation he experiences; "It would be nice to go out and hang out with the guys, but that's the way it is. You can have a reasonably good life but it's not a normal life. There's a sense of isolation and helplessness."

Concerns about Mothers' Emotional/Psychological Well-Being

Three of the fathers in this sample stated concern about the mothers' emotional/psychological health (*concerns about mothers' emotional/psychological health*, 3/4). For example, Doug talked about how Beth copes with Carl's physical aggression,

> She's stressed…It's hard on Beth. She gets frustrated. She's stressed and tired. She does too much…She gets really upset with Carl ripping his shirts all the time and won't listen or is miserable. He can throw stuff and get angry.

Two fathers said that the mothers are depressed. For example, Robert said,

> [The diagnosis] knocked a lot of that fun out of her. It's so much work, so much heartache, so far to go. A lot of joy is gone from her life. It's very, very sad. I ask her sometimes if she's looking forward to something, anything, and she tells me that she doesn't look forward to anything anymore. Because if she does she feels that she is setting herself up for disappointment. Why do that? The other day she called me from work. She and I got into a fight about how I interacted with Alan. It's just awful. She is depressed. She calls me from work crying.

Charles expressed very similar concerns about Mary; "Mary had expectations that were shattered…Mary blames herself. She suffers from depression and this does not help her…She is suicidal."

Concern about the Child with Autism's Health

Two fathers mentioned concern about the child with autism's health because their child is unable to tell them if something is wrong or hurts (*concern about the child with autism's health*, 2/4). Doug said, "He never feels pain. If he hurts himself now we're really concerned about any infections on his skin and stuff like that." Adam shared a similar experience; "We're also more vigilant in her physical care because she is not always capable of telling us when there is something wrong. There is an ever pressing concern about that."

Fathers' Responsibilities

Two fathers said that they have to be in the home when the child with autism is at home (*fathers' responsibilities*, 2/4). In both cases this is because the child with autism is a threat to himself and to others. Robert described his situation, "Now he's gone every weekend, all weekend. This is good because I have to be there. Whenever Alan is home, I have to be there. I couldn't leave Lynn and Roger alone with him at all." Charles shared that he sleeps in John's room at night to help manage his behavior at night. He described this and talked about his experience during the day,

> My presence in his room at night also improves his mood during the day because he gets a better sleep. It does cause the problem of attachment and I can't go anywhere because I am the only one who can really control him. But it does make life easier for my daughter and my wife…It made our lives a lot easier that way. If you want to make your life easy there are things you have to do. Our family life is all organized around him.

Diagnostic issues

The themes were identified from fathers' discussion of the diagnosis of the child with autism. These themes are *initial reaction* (4/4) and *misdiagnosis* (3/4).

Initial reaction. All of the fathers reported that they remembered their initial reaction when the diagnosis of their child was made (*initial reaction*, 4/4). Three of the fathers said that they'd anticipated the diagnosis. For example, Doug said, "I kind of expected it. We were working in that direction. I wasn't shocked…It was a relief." In the second case Robert reported a similar experience, "We knew that something was amiss when we moved here. He was just three." Finally, Adam said, "For me the whole process was formality."

One father reported that he denied his son's diagnosis of autism. Robert said, "I just ignored [his diagnosis] for a long time. Big time avoidance. For like three years."

Misdiagnosis. Three of the fathers reported that they initially received a diagnosis other than autism. Two fathers indicated that professionals were concerned that their children might be deaf. Doug said, "They thought he might maybe deaf because there was no responding to eye contact…when you spoke to him like he would look at you or respond in any way." Robert described a similar experience, "And we had a speech pathologist because he wasn't listening so good. She's the one who first used the 'A' word with us."

In the third case the child was diagnosed with mental retardation. Charles said, "We told them that we thought it was autism but they initially told us it was mental retardation."

Long-term Care for the Child with Autism

The fathers in this sample discussed issues related to the long-term care of the child with autism. The themes in this category are *concern about what will happen to the child with autism* (3/4), *siblings' involvement in the long-term care of the child with autism* (3/4) and *care within the family home* (2/4). Each of these themes will be discussed in the following sections.

Concern about what will happen to the child with autism. Three fathers identified concerns about what support and services will be available for the child with autism when they turn 19 (*concern about what will happen to the child with autism*, 3/4). Robert said that he feels a need to be proactive about ensuring that Alan is cared for while recognizing that the family cannot support him,

> That's an emotional question. There's nothing for him. And we know that we have to try to plan something or he's going to end up in jail or dead on the street. At the same time we don't want to sacrifice our whole lives…We know when he's 19 everything he has now comes to an end. We're going to have to do something. If you can imagine, our plan was not for him to live with us at 19 and for the rest of our days. The way he is now it would be too hard.

Adam stated, "Once she turns 19 all support stops. It's not clear what ministry becomes responsible or what services will be available." Finally, Charles made a similar observation; "We see how kids do not exist when they turn 19…The funding disappears."

Two fathers mentioned making arrangements for the child with autism when the parents die. Adam described his experience,

> One of them is trying to be a little more resourceful or careful about ensuring some

> sort of stability and ability to maintain supervision and care for Leanna into the future. One of our biggest concerns is care for Leanna as we age.

Similarly, Charles said, "Parents with children with disabilities have to arrange for the child after they die...There has to be a team set up fighting for them. We are looking at people now who we can depend on."

Siblings' involvement in the long-term care of the child with autism. Three fathers mentioned the long-term involvement of the sibling in the care of the child with autism (*siblings' involvement in the long-term care of the child with autism*, 3/4). Two fathers said that they did not expect the sibling to take responsibility for the care of the child with autism. Robert said, "When we're no longer around we don't expect that Roger will care for Alan." Charles made a similar statement; "It's very easy to say, when we're not there, that Victoria will take of him. We can't do that...You cannot ask a sibling for life."

By contrast, Adam said that he wants Christopher to take part in Leanna's care,

> To the extent that Christopher moves along in his life he might be able to offer help with caring for Leanna. So, we would like to see him develop in a way that would leave him willing and able to take part in that.

Care within the family home. Two fathers indicated that they would be prepared to have the child with autism live in their home after they turn 19 (*care with the family home*, 2/4). Both fathers indicated that this might be a semi-independent living situation. Doug said, "I'm willing to keep Carl. There is a suite downstairs. If we're still in this home we will have Carl live with us...I don't plan on at 19 kicking him out the door." Charles described preparing for a similar living arrangement; "If he decides to stay home that would be fine with me. There is a suite downstairs that could work for him. A semi-independent. We have had someone stay there and we feel this could work for John."

Fathers' Reports of Changes to Their Perceptions of Life

The fathers in this sample mentioned that they've experienced changes to their perceptions of life. These changes were an appreciation for life they did not experience before having a child with autism (*appreciation*, 3/4) and the recognition that they experienced some personal changes following the birth of the child with autism (*personal growth*, 2/4).

Appreciation. Three fathers said that they appreciate life in a way that they did not before having a child with autism (*appreciation*, 3/4). Doug mentioned some of the things he sees differently,

> It makes you realize to be thankful for what you have. Little things in life are really big things. Like when Carl got toilet trained. We were partying and phoning everyone up…Stuff like that makes us so happy. It makes us aware of the big things and that there are no little things.

He added, "I think it makes you appreciate life more…Having any child with a disability makes others more alive. Disability is only what you make it." In the second case Adam expressed feeling the same way, "In Leanna's case we celebrate her minor accomplishments. All of the small things mean more." Charles talked about how his values have changed,

> I think it makes you appreciate the world in a different way. It puts things in a very different perspective. You don't take things for granted…It allows you to understand there are things that are important and things that aren't so important after all. Because you have to give up so much. Even things that are material because they get

> broken. Did we really need those things. You have different values.

Personal growth. Two fathers said that they believe the child with autism has provided them with an opportunity to grow as a person and learn about themselves (*personal growth*, 2/4). Robert said,

> He's helped me come to grips with some personal issues. From my upbringing, my personality, the way that I've handled life. He's changed me a lot. If I'd had a perfect child I'd have been insufferable...He knocked a lot of arrogance out of me. He's made me a better person.

Adam shared how his observations of Leanna have led him to think about who he is and what he does,

> A spin off of that is that it's highlighted certain personal characteristics that I had not observed in myself before. As I sort of watched Leanna and tried to figure out what might be motivating her or how she might be experiencing things. I begin to detect parallels between some of her behaviors and experiences and some of my own.

Sleep Disturbances

Three fathers said that the child with autism have difficulty falling asleep or staying asleep (*sleep disturbances*, 3/4). Two fathers reported that the child with autism receives medication to help them sleep. For example, Robert shared, "He sleeps well only because of the medication that he's on...He never slept and never stopped moving...We never slept." Similarly, Adam said that Leanna is sleeping better than she did in the past; "This has changed somewhat with the drugs she's on. But, ordinarily she's capable of staying awake later than is ideal."

In one case, the child with autism was not receiving medication to help him sleep at night. Charles described how now sleeps in John's room to help keep him quiet at night,

> I sleep on the bottom bunk and John sleeps on the top. When I feel the bed vibrate I use a low voice and ask if he is awake…It happens 3-4 times a night but we're only missing a few minutes of sleep.

Commonalities/Differences Across Participants

This section will provide a summary of common themes identified across participants and discuss some of the unique experiences reported by these participants. For example, all participants reported that the child with autism displayed verbal/physical aggression. This pattern of behaviors typically resulted in the development of coping mechanisms like respite care for the child with autism and the avoidance of family rituals (i.e. sitting down for dinner and engaging in family outings). Most of the participants commented that they had concerns about how others view the child with autism and them in public and at home, that the nonautistic sibling was neglected or treated differently, and that the nonautistic siblings appeared more mature than other children their age. The participants also identified that the children with autism's sleep patterns were disturbed. A surprising result, however, was that the children with autism disrupt the sleep of the nonautistic siblings, a theme that did not emerge from other data. Mothers and siblings remarked that the nonautistic sibling was at risk of violent outbursts from the child with autism. Only one father made a similar observation. Both parents said that they felt isolated and expressed concern about the child with autism's health and their long-term care. Only fathers discussed the role that the nonautistic sibling might play in the long-term care of the child with autism. Both parents talked about the misdiagnosis/lack of diagnosis of the child with autism. Mothers emphasized how their expectations of support services for the child with autism have not been met and talked about the emotional reactions they had in response to their experience. They also mentioned that they had conflict about being at home with the child with autism or going to work, and commented that other family members were dependent on them. Fathers stressed that they were concerned about the mothers' emotional and psychological health, that they were aware that they have high expectations of the nonautistic siblings, and that they had to be at home when the child with autism was at home. Both parents discussed how they've compensated the nonautistic sibling for the challenges that they've experienced. Only one sibling made a similar observation. Finally, both parents talked about the positive aspects of raising a child with autism including changes to their perceptions of life. For example, both parents expressed appreciation for the small things in life that they'd previously taken for granted. Mothers also recognized, however, that they had a stronger social network than they might otherwise have had. Fathers on the other hand commented that they've become more self-aware.

Chapter V

DISCUSSION

The purpose of this chapter is to interpret the results presented and discuss these results as they pertain to studies cited in this paper. Limitations of the completed investigation, suggestions for future research, and cautions that must be taken when interpreting the data will be integrated into this discussion. This chapter will conclude with a summary of the discussion and limitations of the present investigation.

Interpretations

This study was successful in providing some general descriptions of the experience of being a member of a family of a child with autism. Here, results pertaining to each family member of interest in this study (i.e. mothers, siblings and fathers) are interpreted and discussed in the context of previous research.

Mothers

Previous researchers have identified that mothers of children with autism experience more stress than comparison groups of mothers (DeMyer, 1979; Donovan, 1988; Kostantareas & Homatidis, 1992; Wadden, (1994). In fact, interest in the stress experienced by mothers of children with autism has guided examinations of the families of children with autism for more than two decades. Results of the present study are both consistent and inconsistent with previous examinations in this area.

Mothers in the present study identified that the children with autism can be verbally and/or physically aggressive. Some of the behaviors labeled verbal or physical aggression included screaming, threatening, punching, and spitting. As a result, the mothers reported that they are reluctant to go out in public or have people to their homes because of the child with autism's unpredictable behavior. They also identified how challenging it is to have dinner together as a family because the child with autism can be disruptive at these times. Half of these mothers described sleep disturbances in the children with autism. In general, the mothers in the present study identified that a number of the behaviors exhibited by the children with autism are a source of stress for them and said that these behaviors have required the implementation of strategies to manage them. These results are consistent with the findings of Holyroyd and McArthur (1976) and DeMyer (1979) who reported that mothers of children with autism identified more disruptive behaviors in their children with autism than a comparison group of mothers, that they experience greater interference with normal personal and family functioning than other mothers, and that they are adversely affected by the child with autism's disturbed sleep patterns.

In the present study the display of unpredictable aggressive behaviors by the children with autism and the mothers' sensitivity that other people may be uncomfortable with these behaviors, or have judgments about these behaviors, contributed to the development of some of the coping mechanisms and social issues reported by the mothers. Some of the coping mechanisms related to this issue included the mothers' need to make sense of the aggression observed in the child with autism, the implementation of action plans to keep them and other members of the family safe from the child with autism including locking themselves in the attic or leaving the home, the administration of drugs to the children with autism to manage their behavior, and, in the case of the more challenging children with autism, the placement of these children in respite. In fact, almost all of the mothers identified that some form of respite was necessary for them to be safe or to simply give them a break from the child with autism.

The social issues of interest here were specifically related to the mothers' concerns about how others react to them and the children with autism in public and at home. The mothers in this sample identified that they feel judged by others in public and felt embarrassed by the child with autism in public. They also said that they were concerned that the nonautistic sibling has felt embarrassed in public and described how they've carefully selected activities that involve taking the child with autism out in public. Finally they shared that they avoid having guests to their home because of the child with autism's behavior. These findings are again consistent with Holyroyd and McArthur (1976) who reported that mothers of children with autism experienced more embarrassment and disappointment in their children with autism and were more aware of the effects of their children's personality and behavioral problems than a comparison group of mothers.

Part of the challenge of raising a child with autism identified by the mothers in the present study was related to the expectation that the mothers had for support from community services or the government. Almost all of the mothers identified that the expectations they had of support for them, their children with autism, and their families had not been met. Further, they reported that there was what they consider significant delays in receiving the support they required, including being put on wait lists. These findings are, again, consistent with Holyroyd and McArthur (1976), who reported that mothers of children with autism experience a lack of community resources, and Wadden (1994), who reported more needs and unmet needs in mothers of children with autism than the comparison groups of mothers.

By contrast, others researchers have not identified that one source of stress for mothers of children with autism is the energy and time they devote to advocating for their children, the need to educate themselves about services available to families of children with autism, and the unusual challenges they occasionally endure before receiving support for them and their families. For example, some of the mothers in the present sample reported living with violent behavior from the children with autism for considerable periods of time and not being offered support from the government until they'd identified that they wanted support, what support was available in the community, and convinced the government to pay for this support. This is a significant contribution to our understanding of the 'experience' of being a mother of a child with autism. Following more in-depth investigation and some education this knowledge may allow social workers and community support services to more effectively support these families.

Most of the mothers in this study talked about feeling isolated from other people. This isolation was related to beliefs that others blame or judge them and/or their parenting abilities. This experience was also related to a lack of interest in being around other people or feeling different from other people. When this information is combined with the mothers' descriptions of how others are dependent on them, often for their physical safety, their conflict between wanting to work and feeling like they have to be at home to support the child with autism, and how the mothers talked about the love they have for their children with autism, including descriptions of anger, ambivalence, bittersweet blessings, and in at least two cases the challenges being more than the mothers believe they can bear, concerns about the mothers' psychological well being should be raised. These results are consistent with DeMyer (1979) who reported that mothers of children with autism experience more guilt, depression, anger and doubt in their parenting abilities and Bristol, Gallagher and Schopler (1988) who reported that mothers of children with autism are more at risk for depression than other mothers. It should be highlighted, however, that the mothers in this sample were not assessed for depression and so concluding that these mothers were depressed at the time of the study is not possible. What is clear is that five of the mothers reported conflict between wanting to work and supporting their family, four of six mothers made very similar statements about their emotional reaction to being the mother of a child with autism, four of the mothers reported a sense of isolation and half the mothers said that family members were entirely dependent on them. A more in-depth investigation, which includes both qualitative and quantitative investigative techniques, is warranted to more completely understand the complexities of the experience of mothers of children with autism.

Half of the mothers in this sample identified that they were concerned about the child with autism's physical well-being. These concerns were identified as ongoing and as requiring considerable time and energy to address. These results are both consistent and inconsistent with Bristol (1984) who stated that concern about the child with autism's health is a stressor experienced by parents of children with autism at some time in the child's development and implied that parents' focus then shifts to other issues (i.e. life skills training, education, and vocational development). Upon examination of the results of the present study it is clear that this is a stressor identified by mothers of children with autism, an ongoing issue, a concern identified by mothers of children with autism at different ages, and a concern that it is reported in addition to other stressors. Bristol's description of parental stress should be compared with mothers' reports in future examinations of these families.

Another stressor was concern about how and where the child with autism will be cared for in the future. All of the mothers identified this as a concern for them and their families. Unlike Bristol (1984), however, neither vocational concerns nor life skill development were identified as themes by the mothers in the present sample despite being asked about the educational and vocational dreams they had for the child with autism. In some cases these issues were touched on, but only as they related to the mothers' unmet service expectations. Clearly, other concerns were more pressing at the time of the interviews. Further examination of the experience of simultaneous stresses identified by the mothers of children with autism is required to provide effective and appropriate support to these families.

This is an important consideration in future research because the child with autism was not the mothers' only concern. A significant amount of stress was related to how they believed the child with autism affected the nonautistic sibling. For example, half of the mothers reported that the nonautistic sibling was at risk of aggressive outbursts from the child with autism. The mothers reported feeling helpless and having to protect the nonautistic sibling from the child with autism. Likewise, half of the mothers said that they didn't have enough energy to support the nonautistic sibling or reported that they were concerned about how the two children are treated differently. Some of these findings are consistent with DeMyer (1979) who identified mothers are concerned that the nonautistic sibling is neglected or treated differently. However, concerns about the physical safety of the nonautistic siblings and the helplessness expressed by some of the mothers have not previously been identified as a stressor for mothers of children with autism. Further investigation is warranted.

The mothers in the present study also identified that the nonautistic siblings have responsibilities that other children their age do not have and discussed how the siblings display unusually mature behaviors. For example, they talked about how the nonautistic siblings try to please other people, try really hard to keep it together, is the 'good child', makes others laugh in times of stress, and provides emotional support to their mother. These descriptions are consistent with findings reported by DeMyer (1979) and with the characteristics of siblings of children with autism provided by Siegel (1996). Siegel described the characteristics of nonautistic siblings in three ways: (a) the parentified child, used to describe siblings who act like a parent to the child with autism; (b) the withdrawn child, used to describe siblings who become overwhelmed by the demands placed on them by the behaviors of the child with autism or their parents; and (c) the family mascot, used to describe siblings who attempt to compensate for the perceived losses that the family is experiencing. All three of these descriptions were reflected in statements made by the mothers in the present sample. One extension of Siegel's descriptions of these children is the understanding that the nonautistic siblings in this sample displayed parentified patterns of behavior in response to the needs of their parents as well as those of the child with autism, including providing emotional support to their parent(s).

The mothers in this sample also recognized that the nonautistic siblings experience unusual challenges living with a child with autism. Half the mothers talked about the ways that they compensate the siblings, including trips to special events and arrangements to spend time alone with the siblings. Previous examinations of families of children with autism have not identified this as part of the experience of being a mother of a child with autism. However, it might be argued that this reflects the maternal guilt DeMyer (1979) reported in her study.

The stresses identified by the mothers in the present sample included issues related to the diagnosis of the child with autism. In all cases, the stress of parenting a child with autism started prior to receiving a diagnosis of autism. All of the children with autism were initially misdiagnosed or not diagnosed. The parents were typically told that their child was hard of hearing or that they were developmentally delayed. In other cases, the parents were told that there was nothing to be concerned about and to wait to have their child diagnosed. Related to this issue, almost all of the mothers in this sample talked about how long it took to get a diagnosis of autism. In some cases, this meant not receiving services to support the children with autism and their families, and, and in other cases, that their concerns about their child's development were minimized.

When asked about their reaction to the diagnosis of their child, the mothers reported inconsistent experiences. The experiences the mothers reported ranged from denial to relief to a mixture of both denial and relief. Clearly, there is no consistent reaction to the diagnosis and, therefore, no consistent way to support the mothers of children with autism when they receive the initial diagnosis. What seems appropriate to suggest is an examination of what mothers identify they need at the time that a diagnosis is made and implementation of appropriate support on an individual basis.

Although there were a number of stresses and challenges associated with parenting a child with autism identified by these mothers, they also talked about the positive aspects of their experience. All of the mothers said that the child with autism has enriched their lives in some way. This included an appreciation for the things they might have otherwise taken for granted and shifts in what they value in their lives. Further, half the mothers said that their social network is better as a result of the presence of the child with autism in the family. Clearly, the experience of being a mother of a child with autism is more complex than previously understood and can be described more fully when the mothers are asked about the positive aspects of the presence of a child with autism in the family.

In summary, the mothers of children with autism in the present study identified specific sources of stress including primarily the unpredictable verbal/physical aggression displayed by the child with autism. As a result of these behaviors the mothers said that they are reluctant to go out in public or have people to their home and that it is challenging to maintain normal family rituals. They also reported that they are concerned about the way that other people perceive them and the child with autism and identified a number of coping mechanisms they have adopted. They further reported that significant sources of stress are related to their expectations of support for the child with autism and the family provided by the provincial government and community support agencies, and their perceptions of how the child with autism affects the nonautistic sibling. Future research should focus on the examination of the mothers' experience using qualitative and quantitative investigative techniques, specifically related to the assessment of maternal depression and guilt. Careful consideration should also be paid to issues surrounding the diagnosis of the child with autism in an effort to provide the most appropriate support to families of children with autism. Finally, further investigation into the positive aspects of these mothers' experience should be made to more accurately describe the complexities of the experience of mothers of children with autism.

Nonautistic Siblings

What was previously understood about the experience of siblings of children with autism was almost entirely the result of what mothers have told researchers. The findings of the present study are both consistent and inconsistent with what mothers and siblings have reported elsewhere. Additionally, there are findings that have not previously been reported in the literature. All of these results will be discussed in this section.

The siblings in this sample all identified that the child with autism can be physically and/or verbally aggressive. These patterns of behavior meant that more traditional family rituals, like family outings and sitting down for dinner, were not possible or avoided by the parents. It also meant that respite was identified as necessary by these siblings to remain safe from the child with autism and to give the family a break from the day to day challenges imposed by the child with autism on the family. These results are consistent with Holl (1998) who found that siblings reported spending less time together as a family, and McHale et al. (1984) who reported less involvement in family activities families of children with autism.

As a result, the social development of these siblings may be different than siblings of other children. For example, most of the siblings described feeling embarrassed when they are out in public with the child with autism. Likewise, two of the siblings described feeling that they were not able to have their friends over to their house. These findings have not been reported elsewhere and warrant further investigation to identify if these themes are unique to this sample of nonautistic siblings.

The pattern of unpredictable behavior displayed by the child with autism also meant that the siblings were sometimes at risk of violent behavior from the child with autism and were required to adopt more adult roles and be more responsible with protecting their personal possessions from damage by the child with autism. These results have not been reported elsewhere in the literature and warrant further investigation.

However, some of the characteristics of siblings of children with autism provided by Siegel (1996), and specifically descriptions of the 'parentified' child, are represented in some of the statements made by the siblings in the present sample. For example, the siblings said that some of their responsibilities included calling for help when the child with autism is attacking their parent, taking care of the child with autism, and offering financial assistance to their mother. There is a need to collect more data from siblings of children with autism in order to understand the full range of the experience of being the sibling of a child with autism. Perhaps it might also be appropriate to implement a comparison group of siblings to ascertain how unique the experiences of these children are. For example, it is not unique for siblings to fight over toys and personal belongings. However, it seems plausible to suggest that there are unique dynamics present in these families. For example, there may be the challenge of teaching the child with autism to respect the property of others, hence the nonautistic siblings are asked to take responsibility for the safe keeping of their belongings. Further, it might be that monitoring the belongings of the nonautistic siblings comes secondary to more immediate concerns like protecting others from verbal/physical harm and the behavior management of the child with autism.

Clearly, the behaviors exhibited by the children with autism can be considered challenging for all members of the family. Two of the ways that these siblings reported that they cope with these behaviors were to describe these behaviors as out of the child with autism's control and provide explanations for these behaviors (i.e. these behaviors are the result of excitement or frustration). In addition, they were knowledgeable about the administration of medication to the child with autism, and talked about autism in a well-informed and respectful manner. These results are consistent with Holl (1998) who reported that nonautistic siblings openly discussed the special challenges of living with a child with autism, and were knowledgeable and empathetic about their brother or sister's disability.

Although there appeared to be an understanding of their siblings' disability and empathy for the child with autism, half of the siblings in the present study reported that they felt neglected and talked about how much time the parents spend supporting the child with autism. These findings are only partly consistent with DeMyer (1979) who suggested that, based solely on maternal reports, 30% of nonautistic siblings felt neglected. It is also consistent with McHale and Pawletko (1992) who reported more differential treatment of siblings in families of children with disabilities. It should be highlighted, however, that this might not accurately reflect what the siblings believe about this issue because siblings who did not report feeling this way may be concerned that this information will be shared with their parents. Conversely, this was a self-selected sample of siblings of children with autism. A second alternative might be that the children with autism in this sample exhibit unusually challenging behaviors that require an incredibly high level of support from their parent(s). This may be reflected in statements made by the siblings. As such, the siblings in this sample may not represent the more general population of siblings of children with autism. Careful consideration of these issues ought to be considered in the design of a similar investigation.

There are several variables that have been addressed in previous examinations of siblings of children with autism. For example, a number of researchers have examined nonautistic siblings' self-concept, level of depression and functioning at school and home. These were not examined in the present study. However, it seems plausible to suggest that a combination of qualitative and quantitative methods of investigation might yield a more complete and accurate understanding of the experience of siblings of children with autism. One specific recommendation for future research is that sibling interactions, and perhaps interactions between all family members, be observed and analyzed. Previous examinations of these types of interactions have yielded meaningful information (e.g. Dallas et al. 1993; McHale & Gamble, 1989). Therefore, one extension of another investigation might be a comparison between what siblings report in an interview and what an investigator observes while the nonautistic sibling and the child with autism are at play or engaged in some activity.

One surprising finding was that half the siblings reported that the child with autism disrupts their sleep. In fact, two of the siblings identified this as a concern in response to questions about what they find most challenging for them as the sibling of a child with autism. This finding has not been reported elsewhere in the literature and was not identified as a concern by the parents. Clearly, the fact that the siblings were occasionally kept up late, or awakened in the middle of the night, presents unique concerns about the overall development and health of these siblings. Further, it seems appropriate to suggest that the parents need to be aware that this is a concern for the siblings. Further investigation to replicate and extend these findings is warranted.

In summary, the nonautistic siblings identified that a significant source of stress for them and their family was the verbal/physical aggression displayed by the child with autism. As a result of these behaviors the siblings reported that respite care was necessary to ensure the safety of all family members and to give the family a break. The siblings also shared that their personal safety and the safe keeping of their belongings were at risk and that they've adopted adult roles within the family. Although they talked about the child with autism in a respectful and knowledgeable manner, they also said that they felt neglected. A surprising result was that half the siblings said that the child with autism disrupts their sleep. A number of suggestions were made for the design of future investigations.

Fathers

As previously discussed, the experience of fathers of children with autism has often been equated with the experience of mothers of children with autism. Previous researchers have also reported that fathers of children with autism experience more stress than fathers of other children. Additionally, this stress is experienced differently than the stress reported by mothers of children with autism. Results of the present study are both consistent and inconsistent with the results of previous research. These issues will be discussed in this section.

All of the fathers in the present study identified that the child with autism can be physically and/or verbally aggressive. Physical aggression included aggression directed at other people and inanimate objects. Verbal aggression included screaming and threatening people. Consistent with reports made by the mothers and nonautistic siblings, the fathers said that this meant that normal rituals like family outings and sitting down for dinner together were avoided. It also meant that respite care was used as a coping mechanism because the parents were having difficulty managing the child with autism's behavior or because the family needed a break. These results are inconsistent with Bristol, Gallagher and Schopler (1988) who identified that mothers of children with autism were more likely, than fathers, to report more disruption in daily life. They are, however, consistent with Rodrigue et al. (1992) who reported that fathers of children with autism identified more disruption in family planning than fathers of children with Down's syndrome.

In order to make sense of the aggression displayed by the children with autism, all of the fathers provided explanations for the child with autism's aggression. For example, this aggression was attributed to frustration and attempts at communication. They also described this behavior as out of the child with autism's control.

Although they could make sense of their children's behavior, the fathers in this sample identified that they were concerned about how others perceive the child with autism, and them, in public or in the home. All of the fathers identified that they have stopped taking the child with autism out or said that they avoided engaging in family outings because of how others react to them. Two fathers said that they avoided having people over to their home. Again, concerns focused on how others might view them. This meant that, like the mothers in this sample, the fathers felt isolated. These findings have not been reported elsewhere in the literature and warrant further investigation.

An additional result of the child with autism's unpredictable behavior is the fact that half the fathers said that they needed to be home when the child with autism is at home. In one case, this meant that the father had to retire at an early age to be at home to help manage the child with autism's behavior. These findings are inconsistent with the findings of previous researchers that fathers of children with disabilities or autism are less involved in caring for these children (Bristol, Gallagher & Schopler, 1988; DeMyer, 1979; and Erickson & Upshur, 1989). Further examination into the role that fathers play in families of children with autism is warranted.

The fathers also reported concerns about the mothers' emotional/psychological well-being and the child with autism's health. These results are in part consistent with DeMyer (1979). She reported that the several fathers were concerned about their wives' physical and emotional health. It should be highlighted, however, that three quarters of the fathers in this sample reported this concern, a rate that is substantially higher than DeMyer reported two decades ago.

DeMyer(1979) also reported that almost half of the fathers were concerned about their wives' preoccupation and concerns with the child with autism's condition. This theme was not identified in the present sample. In fact, the fathers shared the same concern for the child with autism's physical health as the mothers did. This pattern may reflect the more active role that fathers are playing in families more generally, and in families of children with autism more specifically.

With respect to the long-term care of the child with autism most of the fathers expressed concern about what would happen to the child with autism after they turn 19 years of age. This concern was specifically related to the fact that the support that the families of children with autism receive ends when the child with autism becomes an adult. The fathers also said that they were concerned about what would happen to the child with autism in the event that the parents could no longer care for the child with autism. These findings are consistent with Beckman (1991) who reported that, when mothers and fathers of children with autism were compared, only fathers indicated that decreases in their stress levels were related to increases in formal support. In this case, it might be argued that increases in fathers' stress were related to the knowledge that there are decreases in formal support when the child with autism turns 19.

Sleep disturbances in the child with autism were identified as another source of stress for the fathers in this sample. In one case this meant that the father had to sleep in the child with autism's bedroom to keep them calm should they become agitated during the night. In the other two cases this meant administering medication to help manage the child with autism's sleep patterns. These stresses have not previously been identified in the literature and warrant further investigation.

When the fathers were asked about their initial reaction to the diagnosis of their child almost all of them recalled that they'd anticipated the diagnosis. In fact, only one father said that he'd denied the diagnosis. Consistent with maternal reports, most of the fathers said that their child was initially misdiagnosed with a hearing loss or mental retardation. This is an area that requires further investigation. It remains unclear how the fathers in this sample came to anticipate a diagnosis of autism. For example, they might have interpreted information shared by professionals in a different way than the mothers in this sample did or they might have done some independent research that prepared them in some way. This hypothesis is consistent with Rodrigue et al. (1992) who suggested that fathers of children with autism use coping strategies such as information seeking more often than fathers of children with other disabilities. Questions specifically addressing this issue should be incorporated into future qualitative examinations of families of children with autism.

Secondly, it should be highlighted that both the mothers and fathers recalled receiving an initial diagnosis other than autism. Following further investigation, this information may provide important information about how professionals can best support the families of children with autism.

Like the mothers in this sample, the fathers identified that they were aware that the child with autism affects the nonautistic sibling. The fathers identified that the siblings have responsibilities that other children their age do not have (i.e. ensuring that the child with autism does not damage their belongings), that the nonautistic siblings are neglected because of the child with autism's behavior, and that the nonautistic sibling is unusually mature for their age. In contrast to mothers' and siblings' reports, only one father reported that the nonautistic sibling was at risk of violent outbursts from the child with autism.

Related to these patterns, the fathers expressed concern that they've expected more of the nonautistic sibling than the child with autism and identified that they have gender specific role expectations for the nonautistic sibling. By contrast, all of the fathers reported that they compensate the siblings for the challenges they experience. They shared that they plan special outings and buy them things. These themes have not previously been identified as part of the experience of being the father of a child with autism. With such a small sample it is difficult to draw meaningful conclusions about these reports. However, it appears that the fathers in this sample wanted to maintain a sense of normalcy in their families by raising at least one child who meets societal standards of success (i.e. as a housewife, father or student). In fact, their ability to feel good about themselves as parents may have been, in part, dependent on this. Further, their concerns about the expectations they've had for the nonautistic sibling may reflect a feeling of guilt that they experience. Further investigation of these issues and extensions of the present study are necessary to more completely describe the experience of fathers of children with autism.

Although there is considerable stress related to being the father of a child with autism, the fathers identified positive aspects of their experience. They reported an appreciation for life that they did not have before the birth of the child with autism. For example, they talked about developing new perspectives and appreciating the small things. Half the fathers also reported that their experience has provided them with the opportunity to learn about themselves and do things differently than they did in the past. These results have not been reported in previous research and warrant future replication and examination.

In summary, all of the fathers in this sample said the child with autism could be verbally/physically aggressive. This meant that there were disruptions to normal family rituals and that they were required to be home when the child with autism was home in order to manage the child with autism's behavior. The fathers identified several coping mechanisms they've adopted and social issues that have guided whether they go out in public with the child with autism or have people over to their house. Like the mothers, the fathers said that the child with autism had difficulty falling asleep and/or staying asleep. Further, they also said that they felt isolated and identified concerns related to the long-term care of the child with autism. Consistent with previous research, they identified that they were concerned about the emotional/psychological well being of the mothers. Specific issues related to how the child with autism affects the nonautistic sibling were discussed. Finally, fathers' perceptions of the positive aspects of their experience were highlighted and considerations for future research were identified.

Limitations

A significant limitation of my study was the voluntary nature of families' participation. The families who agreed to participate in this study may have felt relatively comfortable with disclosing information concerning their family environment. As such, this may result in a sample that is not representative of the populations of families of children with autism.

Secondly, this sample is small and the parents' educational level high relative to the general population of parents. As such, any generalizations of these results to the population of families of children with autism should be made cautiously.

A third limitation was the lack of quantitative and observational techniques in this study that might have provided richer and more accurate descriptions of the family members of interest. For example, it might be useful to observe the children at play or to examine various aspects of psychological/social adjustment and marital adjustment in conjunction with ethnographic interview techniques. Future examinations of families of children with autism using a variety of techniques are warranted.

Finally, the scope of my data collection was limited to interviews with the immediate family members. The role of significant others (Carpenter, 1998) and extended family members, most significantly grandparents (Gardner et al., 1994; Harris, Handleman & Palmer, 1985; Hastings, 1997), cannot be underestimated. Future research should continue to examine these relationships and supports as they relate to the experiences of families of children with autism.

Conclusions

Almost all of the participants in the present study identified that a significant challenge of living with a child with autism was verbal or physical aggression displayed by the child with autism. As a result, most of the participants said that they and their family have developed ways of coping with these behaviors. They also identified social issues related to the presence of the child with autism and shared how normal family rituals are avoided because of the child with autism's unpredictable behavior. Although mothers, nonautistic siblings and fathers all identified unique concerns and experiences, there seemed to be this more general experience that they all shared. In fact, it can be suggested that this study has provided important information about some of the specific challenges and stressors that all members of families of children with autism face.

Research conducted by Gray (1997) may be consistent with this conclusion. He examined the experience of parents of children with autism and reported that 'normal family life' for these parents meant engaging in family outings and maintaining family rituals like eating dinner together. He also identified that aggressive tendencies in the child with autism were associated with parents' perceptions that their family was abnormal. Although the participants in the present study did not label their experience as abnormal, they clearly identified that their experiences are different from those of other families and presented concerns about how other people view them.

In addition to this more general experience, there were unique concerns and stressors reported by the mothers, nonautistic siblings and fathers of children with autism. These have previously been discussed in this paper and will not be reiterated in this section. However, it should be mentioned that these results provide important information about how to appropriately and effectively support each member of a family of a child with autism in order to support the family as a whole. And although the present study has added to what is currently known about families of children with autism much remains to be examined using a variety of investigative techniques.

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APPENDIX A

Nonautistic Siblings' Letter of Informed Consent

April, 1999

Dear Sibling:

I am a graduate student presently completing my Master of Arts degree in Education at the University of Victoria. I am interested in studying families of children with autism (The Family Study). The purpose of this study is to describe families of children with autism by asking siblings of children with autism and their parents questions about such things as their knowledge of autism, the day-to day functioning of their family, and the supports/resources available to these families.

My research for *The Family Study* will involve two individual interviews with each family member. With your permission, these interviews will be audiotaped and later typed into a computer for me to analyze. I will be the only person to hear these interview tapes. The first interview will take approximately 1-2 hours and the second interview will take about 1 hour. These interviews will be conducted in your home at a time that is convenient for you and your parents.

All information gathered throughout *The Family Study* will be kept confidential. When writing or publishing my research findings, any identifying personal information will be altered to protect your anonymity and your family's anonymity; this means that you, your parents and anybody mentioned during the interviews will be assigned code names. Also, all collected information (including audiotapes, transcripts, master lists of participants' real names and code names, and other documents provided by you and your parents) will be kept confidential and stored in a secure, locked filing cabinet in my home. Other members of your family will not see the interview transcripts or hear the interview tapes. My professor, Dr. Dan Bachor, will be the only other person who will see the interview transcripts. There will be no public presentation of the interview tapes or any other collected information. Materials will be retained for a period of five years to allow for possible publication; after this time period, all collected information will be destroyed. Most importantly, you and your parents are completely free to withdraw from the study at any time and for any reason. You do not have to tell me why you are withdrawing from the study. Should you withdraw from *The Family Study*, all of the information that I have collected about your family will be destroyed immediately.

I would greatly appreciate your support for *The Family Study*, the results of which will form the basis for the final version of my master's thesis. This study will be conducted between "X date and Y date", 1999. If you have any questions or would like more information concerning this study or your participation in this study, please feel free to contact me, or have your parents contact me, at (250) 920-0307. My professor is Dr. Dan Bachor, Faculty of Education, University of Victoria. His office phone number is (250) 721-7788.

If you agree to participate in this study, please sign this form and return it in the enclosed self-addressed stamped envelope. Thank you for considering participating in *The Family Study* project.

Sincerely,

Tanya Marie Davis, B.A.

Approval.

I hereby volunteer myself to participate in *The Family Study*, which will be conducted in my home between "X date and Y date", 1999. I realize that my participation in this project is strictly voluntary and that I can withdraw my participation at any time and for any reason.

____

Sibling's signature

APPENDIX B

Mothers' Letter of Informed Consent

April, 1999

Dear Parent of Guardian:

I am a graduate student presently completing my Master of Arts degree in Education at the University of Victoria. I am interested in studying families of children with autism (The Family Study). The purpose of this study is to describe families of children with autism by asking mothers, fathers and siblings of children with autism questions about such things as their knowledge of autism, the day-to day functioning of their family, and the supports/resources available to these families.

My research for *The Family Study* will involve two individual interviews with each family member. With your permission, these interviews will be audiotaped and transcribed (following the interview) for me to analyze at a later time. I will be the only person to hear these interview tapes. The first interview will take 1-2 hours and the second interview will take approximately 1 hour. Interviews will be conducted in your home at a mutually agreed upon time.

All information gathered throughout *The Family Study* will be kept confidential. When writing or publishing my research findings, any identifying personal information will be altered to protect your anonymity and your family's anonymity; you, your child and anybody mentioned during the interviews will be assigned pseudonyms. Also, all data (including audiotapes, transcripts, master lists of participants' real names and pseudonyms and any other documents provided by you and your child) will be kept confidential and stored in a secure, locked filing cabinet in my home. Any information obtained in individual interviews will not be shared with other members of your family. My thesis supervisor, Dr. Dan Bachor, will be the only other person who will see the interview transcripts. There will be no public presentation of the audiotapes or any other collected information. All data will be retained for a period of five years to allow for possible publication; after this time period, all gathered information will be destroyed. Most importantly, you and your child are completely free to withdraw from the study at any time and for any reason. You do not have to tell me why you are withdrawing your participation. Should you withdraw from *The Family Study*, all of your family's collected data will be destroyed immediately. Your decision to withdraw from the study will not affect your child's status with your allocated service provider or your relationship with the Ministry of Children and Families in any way.

I would greatly appreciate your support for *The Family Study*, the results of which will form the basis for the final version of my master's thesis. This study will be conducted between "X date and Y date", 1999. If you have any questions or would like more information concerning this study or your participation in this study, please feel free to contact me at (250) 920-0307. My thesis supervisor is Dr. Dan Bachor, Faculty of Education, University of Victoria. His office phone number is (250) 721-7788.

If you agree to participate in this study, please sign this form and return it in the enclosed self-addressed stamped envelope. A signed letter of approval, indicating informed consent, is required from each parent and nonautistic sibling. Thank you for considering participating in *The Family Study* project.

Sincerely,

Tanya Marie Davis, B.A.

Approval.

I hereby volunteer myself to participate in *The Family Study*, which will be conducted in my home between "X date and Y date", 1999. I realize that my participation in this project is strictly voluntary and that I can withdraw my participation at any time.

____

Parent's signature

APPENDIX C

Fathers' Letter of Informed Consent

April, 1999

Dear Parent of Guardian:

I am a graduate student presently completing my Master of Arts degree in Education at the University of Victoria. I am interested in studying families of children with autism (The Family Study). The purpose of this study is to describe families of children with autism by asking fathers, mothers and siblings of children with autism questions about such things as their knowledge of autism, the day-to day functioning of their family, and the supports/resources available to these families.

My research for *The Family Study* will involve two individual interviews with each family member. With your permission, these interviews will be audiotaped and transcribed (following the interview) for me to analyze at a later time. I will be the only person to hear these interview tapes. The first interview will take 1-2 hours and the second interview will take approximately 1 hour. Interviews will be conducted in your home at a mutually agreed upon time.

All information gathered throughout *The Family Study* will be kept confidential. When writing or publishing my research findings, any identifying personal information will be altered to protect your anonymity and your family's anonymity; you, your child and anybody mentioned during the interviews will be assigned pseudonyms. Also, all data (including audiotapes, transcripts, master lists of participants' real names and pseudonyms and any other documents provided by you and your child) will be kept confidential and stored in a secure, locked filing cabinet in my home. Any information obtained in individual interviews will not be shared with other members of your family. My thesis supervisor, Dr. Dan Bachor, will be the only other person who will see the interview transcripts. There will be no public presentation of the audiotapes or any other collected information. All data will be retained for a period of five years to allow for possible publication; after this time period, all gathered information will be destroyed. Most importantly, you and your child are completely free to withdraw from the study at any time and for any reason. You do not have to tell me why you are withdrawing your participation. Should you withdraw from *The Family Study*, all of your family's collected data will be destroyed immediately. Your decision to withdraw from the study will not affect your child's status with your allocated service provider or your relationship with the Ministry of Children and Families in any way.

I would greatly appreciate your support for *The Family Study*, the results of which will form the basis for the final version of my master's thesis. This study will be conducted between "X date and Y date", 1999. If you have any questions or would like more information concerning this study or your participation in this study, please feel free to contact me at (250) 920-0307. My thesis supervisor is Dr. Dan Bachor, Faculty of Education, University of Victoria. His office phone number is (250) 721-7788.

If you agree to participate in this study, please sign this form and return it in the enclosed self-addressed stamped envelope. A signed letter of approval, indicating informed consent, is required from each parent and nonautistic sibling. Thank you for considering participating in *The Family Study* project.

Sincerely,

Tanya Marie Davis, B.A.

Approval.

I hereby volunteer myself to participate in *The Family Study*, which will be conducted in my home between "X date and Y date", 1999. I realize that my participation in this project is strictly voluntary and that I can withdraw my participation at any time.

____

Parent's signature

APPENDIX D

Interview Format

A. Introduction and Briefing

B. Collection of Demographics from Parents

1. Names of all family members
2. Ages of all family members
3. Occupations of parents
4. Highest level of education attained by parents
5. Grade levels of target children
6. Approximate date of diagnosis of child with autism and by whom

C. The 'Experience'

"Tell me about the experience of living with a child with autism."

1. Tell me about autism.
2. Tell me about your family.
3. Tell me about a typical day for you.
4. Tell me about a typical day in your family.
5. What happens at mealtime?
6. What happens when you go on a family outing? What happens on the weekend?
7. What is your role in the family? What is your mother's/father's/child's role in the family?
8. What are your chores/responsibilities? What are the chores/responsibilities of the other members of your family?
9. What makes your family different from other families? How is your family similar to other families?
10. What impact has your child/sibling had on your life?
11. Tell me about the resources/supports accessed by your family. What is your experience of the support offered by these services?
12. Tell me about the hardest part of living with a child with autism.
13. What positive impacts has your child/sibling had on you? And your family?

D. Debriefing

E. Follow-up Interviews (within one month of the initial interview)

APPENDIX E

Mothers' Themes

Unpredictability

- Verbal Aggression (5/6)
- Physical Aggression (4/6)

Coping Mechanisms

- Avoidance of Unpredictable Situations: Going out in public (5/6)
- Making Sense of the Physical/Verbal Aggression (4/6)
- Removal of Child with Autism/Respite (4/6)
- Avoidance of Unpredictable Situations: Dinnertime (4/6)
- Reactive Solutions (4/6)
- Drug Administration (3/6)
- Control over the Environment (2/6)

Impact on Siblings

- Additional Responsibilities for Siblings (6/6)
- Unusual Maturity or Display of Adult-like Behaviors (6/6)
- Neglect of Sibling/Differential Treatment (3/6)
- Compensation for Siblings (3/6)
- Siblings at Risk of Aggressive Outbursts from the Child with Autism (3/6)

Social Issues

- Acceptance/Rejection in Public (5/6)
- Acceptance/Rejection at Home (4/6)
- Want Versus Need Service Expectations
  - Unmet expectations (5/6)
  - Getting the wanted support
    - Waiting for services (5/6)
    - Reactive versus proactive service delivery (4/6)

Impact on Mothers

- Emotional Reaction (4/6)
- Feeling of Isolation (4/6)
- Concerns about the Child with Autism's Physical Well-being/Health-related Concerns (3/6)
- Long-term care for Child with Autism
  - Care within family home (4/6)
  - Concern about what will happen to the child with autism (2/6)
- Mothers' Role(s)
  - Role conflict (5/6)
  - Dependence on mothers (3/6)
- Diagnostic Issues
  - Misdiagnosis/lack of diagnosis (6/6)
  - Length of time to get a diagnosis (5/6)
  - Initial reaction to the diagnosis
    - Denial (3/6)
    - Mixed emotions (2/6)
    - Relief (1/6)
- Changes to Mothers' Perceptions of Life
  - Appreciation (6/6)
  - Social network (3/6)

Sleep Disturbances (4/6)

APPENDIX F

Nonautistic Siblings' Themes

Unpredictability
-Physical Aggression (4/6)
-Verbal Aggression (4/6)

Coping Mechanisms
-Making Sense of the Physical/Verbal Aggression (5/6)
-Removal of Child with Autism/Respite (5/6)
-Avoidance of Unpredictable Situations: Going out in public (4/6)
-Avoidance of Unpredictable Situations: Dinnertime (4/6)
-Reactive Solutions (3/6)
-Drug Administration (2/6)

Impact on Siblings
-Siblings at Risk of Violent Outbursts from the Child with Autism (4/6)
-Additional Responsibilities for Siblings (3/6)
-Display of Adult-Like Behaviors (3/6)
-Neglect of Siblings (3/6)
-Sleep Disturbance (3/6)
-Compensation for Siblings (1/6)

Social Issues
-Acceptance/Rejection in Public (4/6)
-Acceptance/Rejection at Home (2/6)

APPENDIX G

Fathers' Themes

Unpredictability
- -Physical Aggression (4/4)
- -Verbal Aggression (4/4)

Coping Mechanisms
- -Making Sense of the Physical/Verbal Aggression (4/4)
- -Avoidance of Unpredictable Situations: Going out in public (4/4)
- -Removal of the Child with Autism/Respite (3/4)
- -Avoidance of Unpredictable Situations: Dinnertime (3/4)
- -Drug Administration (2/4)
- -Control Over the Environment (1/4)

Impact on Siblings
- -Compensation for Siblings (4/4)
- -Additional Responsibilities for Siblings (3/4)
- -Neglect of Siblings (3/4)
- -Fathers' Expectations of the Siblings (3/4)
- -Siblings' Unusual Maturity (2/4)
- -Fathers' Gender Specific Role Expectations of Siblings (2/4)
- -Siblings at Risk of Violent Outbursts from the Child with Autism (1/4)

Social Issues
- -Acceptance/Rejection in Public (4/4)
- -Acceptance/Rejection at Home (2/4)

Impact on Fathers
- -Feeling of Isolation (3/4)
- -Concerns about Mothers' Emotional/Psychological Well-being
- -Concern about the Child with Autism's Health (2/4)
- -Fathers' Responsibilities (2/4)
- -Long-term Care for the Child with Autism
  - -Concern about what will happen to the child with autism (3/4)
  - -Siblings' involvement in the long-term care of the child with autism (3/4)
  - -Care within the family home (2/4)
- -Fathers' Reports of Changes to their Perceptions of Life
  - -Appreciation (3/4)
  - -Personal growth (2/4)

Sleep Disturbances (3/4)

VITA

Surname: Davis-Jones Given Names: Tanya Marie

Place of Birth: Fort Collins, Colorado, USA

Educational Institutions Attended:

University of Victoria	1996 to 2001
University of Victoria	1988 to 1992

Degrees Awarded:

B.A. (Honours)	University of Victoria	1992

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Title of Thesis: The Family of a Child with Autism: A case study examination of mothers, fathers and siblings

Author: [redacted]

TANYA MARIE DAVIS-JONES

Dated: Aug. 15/01.