#### THE UNIVERSITY OF CALGARY

Psychosocial Adaptation and Sibling Relationships in Siblings of Children with Autism

by

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#### A THESIS

# SUBMITTED TO THE FACULTY OF GRADUATE STUDIES IN PARTIAL FULFILMENT OF THE REQUIREMENTS FOR THE DEGREE OF MASTER OF SCIENCE PROGRAMME IN CLINICAL PSYCHOLOGY

CALGARY, ALBERTA

AUGUST, 1998

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#### **ABSTRACT**

This study investigated the adaptation, feelings of loneliness, social support resources, and sibling relationships in siblings of children and adolescents with autism, compared to siblings of children with Down syndrome and siblings of normally developing children. In addition, it examined siblings' perceptions and understanding of their siblings disability. Ninety siblings (30 per group) between the ages of 8 and 18 participated in this study. Results indicated that siblings of children with autism were well-adjusted and do not report greater feelings of loneliness than siblings of children with Down syndrome or siblings of normally developing children. Siblings of children with autism, like the two comparison groups, reported high levels of social support from individuals in their lives. Sibling relationships in children with autism and their sibling were characterized by less intimacy, pro-social behavior, and less nurturance by the child with autism relative to those of the two comparison groups.

#### **ACKNOWLEDGEMENTS**

I would like to express my gratitude to the numerous organizations and individuals who assisted with this research study. The supportiveness of many organizations that helped me to recruit families to participate in this research is greatly appreciated. I would like to thank the Autism Calgary Association, the Edmonton Autism Society, Autism Manitoba, the Society for the Treatment of Autism, the Ups and Downs Parent Support Group, Winnipeg Down Syndrome Society, the PREP Program, and the Calgary Catholic School Board for their invaluable assistance in this regard.

Special thanks to the individuals from these organizations who went to extra effort to assist me with this project especially, Nancy Belanger, Marie Henessey, Barbara Olsen, and Phyllis Kalmanovitch. My appreciation is also extended to the many families who volunteered to participate in this study. I am thankful for your openness and generosity with your time.

I am grateful to the staff at the Behavioral Research Unit for their assistance with this research. I would particularly like to express my sincere appreciation to my supervisor, Dr. Deborah Dewey, for her ongoing input, guidance and support.

On a more personal level, my thanks also go out to Kyla and Naomi for their encouragement. Also especially to Steve, for all your support during a busy time. Finally, my greatest thanks goes to my family for all their love and moral support.

This project was supported by an Alberta Heritage Foundation for Medical Research (AHFMR) studentship to the author.

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#### INTRODUCTION

Autism is a severe developmental disorder that is characterized by deficits in social interactions and communication (DSM-IV, 1994). The presence of a child with autism in the family has been found to add increased stress to the family unit (Bouma & Schweitzer, 1990; Gray & Holden, 1992; Wolf, Noh, Fisman & Speechly, 1989). Very few studies have specifically investigated how having a child with autism influences non-disabled children in the family. Some studies have indicated that having a child with autism in the family places non-disabled siblings at increased risk for maladjustment and difficulties such as loneliness and problems with peers (Bagenholm & Gillberg, 1991; Crinic, Friedrich & Greenberg, 1983). However, other studies have found that siblings of children with autism are quite well adjusted (Ferrari, 1984; Mates, 1990). In addition, limited research has been conducted on how autism influences relationships between siblings.

Social support resources of siblings may be important in buffering the stressful effects of having a child with a disability in the family (Wolf. et. al, 1989). Studies have indicated that social support plays an important role in reducing stress and facilitating healthy adjustment in parents of children with autism (Gray & Holden, 1992; Wolf, et. al, 1989). However, research has not specifically investigated the importance of social support in the adaptation of siblings of children with autism.

#### Definition of Autistic Disorder

Autistic disorder is a relatively rare pervasive developmental disorder that occurs in between 2 and 5 individuals per 10,000 people (DSM-IV, 1994). Autism is characterized by the presence of significantly impaired or aberrant development in social interaction, communication, and a markedly restricted repertoire of interests and activities

(DSM-IV, 1994). Children with autism show deficits in social interactions, communication, and imaginative play. Use of language is often unusual. For example, many children with autism display echolalia, the repeating of words and phrases used by others (Schreibman, 1988). In approximately 75% of cases, individuals with autism function in the mentally retarded range of intelligence (DSM-IV, 1994). The prognosis for children who have autism is quite poor. Most individuals tend to remain dependent on others for all of their lives with only a small percentage being able to live and work independently (Wing, 1976).

A variety of abnormal behavioral patterns are associated with autism. Children, as well as adults with autism often have a strong desire for the maintenance of sameness (Wolf-Schein, 1996). Children with autism often show abnormalities in response to their physical environment (Schriebman, 1988). A child who does not respond to the sound of their own name or a loud noise may be extremely sensitive to other sounds such as a newspaper being turned (Wolf-Schein, 1996). They may seem unaware of the environment around them, yet be extremely interested in minuscule objects such as a piece of lint. Many children with autism display self-stimulatory behaviors such as rocking, hand flapping, hair twirling or tapping objects (Schreibman, 1988). Self-injurious behaviors are a significant problem for a portion of children with autism. These behaviors vary in intensity and include behaviors such as head banging, hair pulling and face scratching (Schreibman, 1988).

#### Sibling Relationships in Childhood and Adolescence

Research in child development has tended to emphasize parent-child relationships and relationships with peers (Stocker & Dunn, 1990; Stocker, 1994). However, the importance of sibling relationships in child development is beginning to be recognized.

Siblings share a unique and important relationship with one another within the family unit (Knott, Lewis & Williams, 1995).

Sibling relationships appear to be important for the development of social skills, particularly during early childhood (Dunn, 1988). Studies indicate that the behavior of older siblings is associated with differences in the socio-cognitive development of younger siblings. During the pre-school years, the development of teasing, reference to social rules, conciliation and participation in social role play in younger siblings appears to be related to the behaviors of their older brothers and sisters (Dunn & Munn, 1986). During middle childhood, 6-year-old's affective perspective taking and social reasoning abilities appear to be related to their older sibling's behavioral styles (Beardsall, 1987; as cited in Dunn, 1988). Cooperative play behaviors are more common in children who have older siblings who have been very pleasant to them (Dunn, 1988).

Research has found that the dynamics of sibling relationships appear to change as children develop. As children grow older, they begin to take on increasingly active roles in interactions with their siblings (Munn & Dunn, 1989). Communication with older siblings increases when younger children are between three and four years of age (Brown & Dunn, 1991). In middle childhood (ages 6-11) relationships become somewhat more egalitarian between siblings and increases in both conflict and cooperation are reported during this time period (Buhrmester & Furman, 1990; Dunn & Mcguire, 1992). As children begin to reach adolescence, there is generally a decline in companionship between siblings (Buhrmester & Furman, 1990).

The birth order of siblings also impacts on interactions between siblings. The older sibling is generally an important model and teacher for the younger child (Knott, et. al, 1995). At two years of age, younger children frequently imitate their older siblings, while the converse is less common (Dunn & Kendrick, 1979; Peplar, Abramowitz &

Corter, 1981). Imitative behavior has been associated with the development of social behavior in younger siblings (Dunn, 1988). Older siblings are more likely to initiate both positive and antagonistic interactions with their younger siblings, while younger children tend to reinforce the leadership role of older brothers or sisters by responding positively to pro-social behavior and submitting to the demands of the older child (Peplar et. al, 1981)

Sibling interactions also serve as important sources of social support to children. Jenkin & Smith's (1990) study indicated that positive sibling relationships appeared to be particularly important in buffering the negative influence of stressful experiences such as family discord. Children who had close relationships with their siblings were found to show fewer problems behaviors than children who had less positive relationships with their siblings. Warmth in sibling relationships has also been associated with lower levels of loneliness and conduct problems in children and higher feelings of self-worth (Stocker, 1994).

# Sibling Relationships of Children with Disabilities

#### Interactions Among Siblings of Children with Disabilities

Only a few studies have investigated how disability in children influences their interactions with siblings. The studies which have been completed have included children with varying types of disability. Observations of sibling interactions have been used to identify how disability influences sibling relationships. Although some differences in interactions among siblings have been identified, in general children with disabilities and their siblings show marked similarities in their interactions to normally developing sibling pairs. However, additional research is needed in this area.

Abramovitch and colleagues assessed the influence of Down syndrome on sibling interaction (Abramovitch, Stanhope, Peplar & Corter, 1987). In this study, 31 children with Down syndrome and a non-disabled sibling were observed in their homes by the researchers. These children were between 1 and 11 years of age. Although some group variability was identified, drastic differences in interactions were not found when comparing children with Down syndrome and their siblings with normally developing sibling dyads. Results of this study indicated that levels of interaction were similar between children with Down syndrome and their siblings and non-disabled sibling pairs. Children with Down syndrome (regardless of birth order) tended to show interactions with their siblings that were similar to younger normally developing children. As compared to their siblings, children with Down syndrome displayed more imitative behaviors, and initiated less pro-social and less antagonistic behavior. One group difference that was reported was that siblings of children with Down syndrome showed more pro-social behavior towards their sibling than did older siblings of children who were developing normally.

Stoneman, Brody, Davis & Crapps (1987), assessed the interactions between children with mental disabilities (due to a variety of causes) and an older sibling of the same gender. In this study, children with mental disabilities ranged in age from 4 to 8-years of age, while siblings ranged in age from 6 to 12 years. As with Abramovitch et. al. (1987), children with mental disabilities interacted with their siblings as often as non-disabled sibling pairs. No differences were found in the proportions of positive versus negative interactions in disabled and control sibling pairs. Siblings of children with disabilities tended to accommodate to the skill levels of their sibling in the activities that they chose. Greater role asymmetries were found between children with disabilities and their older siblings as compared to normally developing dyads, with siblings of children

with disabilities engaging in more frequent management of their sibling. Sisters of children with disabilities tended to assume managing and helping roles with their sibling more often compared to brothers with siblings with disabilities. Children who had less severe disabilities tended to exhibit more interactions with their siblings, and greater symmetry in their role relations with siblings. The severity of disability had more influence on sibling interactions than the child's ability to communicate.

A study of pre-school children's interactions with their sibling with a disability also found few differences compared to normally developing sibling dyads (Lobato, 1991). Siblings of children with disabilities engaged in more social and parallel play and were more nurturing of their sibling than normally developing controls, but were no more likely than controls to be aggressive or controlling with their sibling.

Knott et. al, (1995), investigated sibling interaction in 15 children with autism in comparison to 15 children with Down syndrome. Children with disabilities ranged in age from 3 to 9 years of age, while their normally developing siblings were between 1 and 12 years of age. Children with autism and Down syndrome both participated in frequent interactions with their siblings, with the non-disabled sibling usually initiating play. The general pattern of interaction in children with Down syndrome and their siblings was similar to those identified in previous research. Children with Down syndrome in this study tended to make fewer initiations than their siblings but engaged in more imitative behavior than their siblings. A number of differences were noted between the sibling interactions of children with autism as compared to children with Down syndrome. First, children with autism tended to spend less time with their sibling than children with Down syndrome. Second, children with autism used a smaller number and less variety of both pro-social and antagonistic initiations towards their sibling as compared to children with Down syndrome. Third, children with autism and their siblings also imitated each other

less often and responded less frequently to each others initiations. Despite these differences, however, Knott and colleagues (1995) noted that children with autism did demonstrate some social skills in their play and did spontaneously initiate some of the interactions with their sibling. Although children with autism and their dyads interacted less often than children with Down syndrome, they showed similar patterns of interactions and a similar levels of initiations and responding as seen in pairs of normally developing siblings. However, the results of this study are limited by the relative small proportion of participants in each of the sibling groups.

#### Siblings of Children with Disability's Perspectives on Sibling Relationships

Very few researchers have investigated non-disabled children's perspectives on their relationship with a sibling with autism. Additional studies are needed to explore other aspects of sibling relationships which have yet to be addressed in the research. For example, research is needed on how having a sibling with a disability influences intimacy, conflict and rivalry between siblings.

McHale, Sloan & Simeonsson (1986) conducted a well controlled study of the sibling relationships of groups of children who had siblings with autism, intellectual disabilities and no known handicap. Three groups of thirty children between the ages of 6 and 15 were interviewed about their relationship with their sibling, their sibling's place in their family, and their sibling's role in relation to the non-disabled child's friendships. Siblings of children with autism or mental disability were also asked about their ability to cope with their sibling's disability, their understanding of their sibling's disability, feelings of rejection towards their sibling, reactions of parents and peers, parental favoritism, feelings of burden, responsibility, and self-doubt and future concerns. Mothers

were also interviewed about how accepting, supportive, hostile and embarrassed the nondisabled child acted in relation to their sibling with a disability.

McHale and colleagues (1986) found that both children and mothers in all three sibling groups reported positive relationships between siblings. Mothers of children with disabilities rated their children's sibling relationships more positively than mothers of normally developing sibling pairs. No group differences were found on the variables that assessed sibling relationships. Despite the lack of group differences, the authors noted that siblings of children with autism and Down syndrome tended to show a much wider range of responses than siblings of normally developing children. Some of the siblings of children with disabilities gave very positive reports of their relationship with their sibling, while others gave very negative reports. In contrast, siblings of normally developing children tended to have more average responses. This suggested that siblings of children with disabilities tend to have quite varied perceptions of their relationship with their handicapped sibling.

McHale et. al (1986) also reported that siblings viewed their relationship with their sibling with autism or Down syndrome more positively when they accepted the child's place in the family, perceived minimal parental favoritism, and were not worried about the future of the child with a disability (McHale et. al, 1986). Well developed coping abilities, understanding of their sibling's disability and positive responses from parents and peers towards the child with autism or mental disability also encouraged positive sibling relationships. Several demographic variables also influenced sibling perceptions. Children who were younger than the child with a disability tended to feel more rejecting towards their sibling than older siblings. Siblings also reported more concerns about the future and a less positive role of their sibling in the family when the

child was male. In addition larger family size was related to fewer feelings of embarrassment about the child with a disability and fewer feelings of burden.

Bagenholm & Gillberg (1991), conducted an extension of McHale and colleagues (1986) study with a sample of children and adolescents between the ages of 5 and 20-years-old in Sweden. Twenty of the participants were siblings of children with autism, 20 were siblings of children with mental disability and 20 were siblings of children with no known handicap. Greater differences were found between groups in this study. Although all groups reported quite positive relationships with siblings, siblings of children with autism reported less positive attitudes towards their sibling and less positive descriptions of their sibling's role in the family. In addition, a high proportion of siblings of children with autism (over 50%) and siblings of children with mental disabilities (67%) did not have a way of explaining what was different about their brother or sister, irrespective of the age of the non-disabled sibling. Additional results of Bagenholm & Gillberg's (1991) study are presented in the sections on loneliness and adjustment in siblings of children with autism.

#### Loneliness in Childhood and Adolescence

Research focusing on children and adolescents who feel lonely and socially isolated has increased over the last number of years (Crick & Ladd, 1993; Davis, 1990; Henwood and Solano, 1993; Luftig, 1987; Marcoen & Brumagne, 1985; Page, Scanlan & Deringer, 1994; Sanderson & Siegal, 1995; Renshaw & Brown, 1993; Quay, 1992). Loneliness has been described as a "vague, empty feeling that is both unpleasant and unwanted" (Davis, 1990). Lonely individuals often describe themselves as isolated, not part of a group, inadequate and unhappy (Horowitz, French & Anderson, 1982; as cited in Davis, 1990). Earlier researchers suggested that loneliness was not experienced by children, and thus focused on studies of adolescents and adults (Asher & Wheeler, 1985).

However, recent studies have indicated that feelings of loneliness are not uncommon in childhood and have been expressed by children as young as four years of age (Asher, Hymel & Renshaw, 1984; Luftig, 1987; Sanderson & Siegal, 1995).

Early research related to loneliness in children focused on external measures of loneliness, such as reports by teachers, peers or unfamiliar adult observers (Asher et. al, 1984). More recently, self-report instruments have been developed that identify children's feelings of loneliness and social dissatisfaction. These self-reports indicate that a significant portion of children feel lonely (Asher et. al, 1984; Luftig, 1987).

#### Prevalence of Loneliness in Childhood and Adolescence

Most recent studies of loneliness in youth have investigated feelings of loneliness in middle childhood. Asher & colleagues (1984) administered the "Loneliness and Social Dissatisfaction Questionnaire" to 506 third through sixth grade children. More than 10% of children in this sample reported feelings of loneliness and social dissatisfaction. Children who had few friends and were rated as undesirable play mates by their peers, were more likely to report loneliness.

Similar overall rates of loneliness in middle childhood have been confirmed by additional studies. Asher & Wheeler (1985) found that 8.4% of 3rd through 6th graders reported experiencing loneliness. Similar overall rates of loneliness (7% of all children) were found in Luftig's (1987) study of 364 children in grades 2, 4, and 6. However, an even higher percentage of children in Luftig's study endorsed particular loneliness items in this sample. For example, 22% of second graders, 20% of fourth graders and 12% of sixth graders indicated that they "felt alone". These studies indicate that loneliness is a relatively common experience in middle childhood.

A few studies have indicated that early elementary school children may be particularly vulnerable to feelings of loneliness. Quay (1992), administered a loneliness scale to 876 kindergarten through fourth grade children. In this study, older children (in grades 2-4) reported more loneliness than younger children (kindergarten and grade 1). Quay suggested that the results of this study indicated that although some children in the younger age group did report loneliness, loneliness appeared to be more common during the early elementary years of school.

More research is needed to distinguish how developmental age influences reports of loneliness in middle childhood. However, these initial studies suggest that children are particularly likely to report loneliness during their early years in school. Possible explanations for this finding are that young children may be more "in touch" or more candid about their feelings, or that they may have less mobility to seek friendships outside of school (Luftig, 1987). These hypotheses remain to be tested.

A relatively high proportion of adolescents also report that they are lonely. Research on loneliness in high school students indicates that between 8% and 16% of adolescents report that they are lonely (Moore & Schultz, 1983). While several studies have indicated that loneliness becomes more prevalent during adolescence, other studies have failed to confirm this hypothesis (Parkhurst & Asher, 1992; Marcoen & Brumagne, 1985).

One study which did not provide evidence that loneliness increases during adolescence investigated loneliness in 393 pre-adolescents and adolescents in grades 5, 7 and 9 (Marcoen & Brumagne, 1985). Participant's reports of peer related loneliness were not influenced by their grade in school. Indicating that rates of reported loneliness were similar in preadolescent and adolescent youth.

#### Loneliness, Isolation from Peers and Adjustment

Much of the increased interest in children's experiences of loneliness is a result of recent evidence that children and adolescents who experience poor peer relationships and social isolation are at risk for adjustment problems later in life (Coie & Dodge, 1983; Hymel, Rubin, Rowden & LeMare, 1990; Rubin & Mills, 1988; Vargo, 1987). Children who are isolated from their peers are missing out on important opportunities to learn about the social world (Davis, 1990). Social isolation has been associated with a variety of adjustment difficulties such as anxiety, depression, suicide, and school drop-out (Davis, 1990; Parker & Asher, 1987).

A considerable amount of research has been conducted on children and adolescents who are socially isolated from their peers. Most of these studies use peer socio-metric ratings to identify children who are isolated from others. Four main social status distinction groups are derived from peers nominations of who they like and dislike or would and wouldn't like to play with (Coie et. al, 1982). Children's relative number of positive (e.g. "liked most") votes minus their negative (e.g. "liked least) votes are calculated to yield a social status score (Coie et. al, 1982). Children who receive high numbers of positive nominations and low numbers of negative nominations are labeled 1) popular children. Those who receive many votes on both positive and negative dimensions are labeled 2) controversial. Children who receive low numbers of both positive and negative nominations are called 3) neglected children. While children who receive low scores on the positive dimension, yet high scores on the negative one are considered 4) rejected children. Significant correlations have been found between peer ratings of other children and teacher's ratings of children's loneliness, as well as children's self-reports of feelings of loneliness (Asher, et. al, 1984; Asher & Wheeler, 1985; Dunstan & Nieuwoudt, 1994).

Studies have indicated that children who tend be actively rejected, rather than neglected by their peers, tend to be at particularly high risk for adjustment difficulties. Children tend to be rejected by their peers when they are either extremely withdrawn or aggressive (Kupersmidt & Patterson, 1991; Parkhurst & Asher, 1992; Rubin, Chen & Hymel, 1993; Rubin & Mills, 1988; Younger & Daniels, 1992). Rejected-aggressive and rejected-withdrawn children are vulnerable to different types of maladjustment and are not equally as likely to report feeling lonely. Individuals who are rejected by their peers because they are extremely withdrawn are particularly vulnerable to feelings of loneliness, tend to report distress about their relationships with others, and are at risk for developing internalizing disorders, such as depression and anxiety (Kupersmidt & Patterson, 1991; Parkhurst & Asher, 1992; Rubin, Chen, & Hymel, 1993; Rubin, Hymel & Mills, 1989; Vargo, 1991; Younger & Daniels, 1992). In contrast, children who are excluded from others due to behaviors such as excessive aggression or impulsivity, are less likely to report loneliness and distress about their relationships with others, and are at increased risk of developing externalizing disorders, such as conduct disorder (Hymel, et. al, 1990; Parker & Asher, 1992; Rubin & Mills, 1988).

#### The Complexity of Loneliness in Childhood

The experience of loneliness is a subjective experience that appears to be influenced by a variety of factors in a young person's life. Studies have indicated that children and adolescents who experience loneliness vary in the number of friends that they have and the degree to which they are accepted by their peers. Parker and Asher (1993) indicated that having a close friend, the quality of friendships, and group acceptance appear to make independent contributions to feelings of loneliness of children in the fifth grade. Research has indicated that having one close friend can help to buffer

feelings of loneliness in both pre-school and 5th grade children who are otherwise quite isolated by their peers (Parker & Asher, 1993; Sanderson & Siegal, 1995). Of interest is the finding that some children and adolescents who are well liked and popular with their peers also report high levels of loneliness (Asher et. al, 1984). These results highlight the complexity of loneliness in childhood and adolescence. The vast majority of studies that have investigated loneliness in childhood and adolescence have emphasized individual's loneliness in relation to peer acceptance. Investigating other aspects that influence loneliness in youth may offer interesting and important information about feelings of loneliness and isolation in children and adolescents.

A few studies have investigated the influence of family on feelings of loneliness in children and adolescents. One recent study found that loneliness in early childhood correlated with insecure-ambivalent attachment to caregivers in infancy (Berlin, Cassidy & Belsky, 1995). A relationship has also been reported between children's feelings of loneliness and reports of loneliness in their mothers (Henwood & Solano, 1994). Henwood & Solano (1994) proposed several explanations to explain this correlation such as genetic influences, parenting styles in lonely mothers, and familial stresses that influence both mother and child. Other familial circumstances have also been associated with loneliness in childhood, such as being a "latchkey child" and family living arrangements such as living in a foster home or with a relative rather than with a parent (Quay, 1992).

#### Loneliness in Siblings of Children with Autism

Children and adolescents who have siblings with a variety of special needs have also been found to have inflated levels of self-reported loneliness (Bagenholm & Gillberg, 1991; Bendor, 1990; Cairns, Clark, Smith & Lansky, 1979; Steiner, 1984).

Several studies have indicated that siblings of chronically ill or hospitalized children feel lonely and isolated from others (Bendor, 1990; Cairns et. al, 1979; Steiner, 1984). The aforementioned studies however, were lacking in adequate control groups. There is a paucity of research on feelings of loneliness in siblings of children with autism or other intellectual disabilities. One exception is Bagenholm & Gillberg's (1991) study that compared feelings of loneliness in siblings of children with autism, siblings of children with developmental delays and normally developing children. This study found that a significantly greater proportion of siblings of children with autism reported that they were lonely and had difficulties with peers. However, further research is needed on loneliness and social functioning of siblings of children with autism.

#### The Impact of Autism on the Family

Researchers have noted that autism is a disorder that presents a particularly difficult challenge for the family unit (Gray & Holden, 1992; Wolf et. al, 1989).

Individuals with autism frequently engage in a variety of behaviors that are potentially disruptive to family life, such as aggression, self-injury, impulsivity, hyperactivity, temper tantrums and obsessional ritualistic behaviors (DSM-IV, 1994; Gray & Holden, 1992).

Difficulties with communication may also present challenges in interactions with children with autism. The public may also be insensitive to the seemingly odd behavior of children with autism. This may be due to a lack of knowledge of autism and the fact that children with autism are generally normal in appearance (Bouma & Scweitzer, 1990; Gray & Holden, 1992; Howlin, 1988). Thus, public contact and family outings may be challenging for parents and siblings of children with autism (Bouma & Schweitzer, 1990).

Many families also go through a considerable period of time before a formal diagnosis of autism is given (Norton & Drew, 1994). Parents of children with autism describe the period of pre-diagnosis as a particularly stressful and difficult time for their family (Norton & Drew, 1994). Furthermore, although interventions can assist in improving the functioning of children with autism, there is essentially no cure for the disorder. Families realize that they will be caring for a child with autism for many years (Bouma & Schweitzer, 1990).

Inconsistent results have been found on the adaptation of families of children with autism. Most studies of family functioning have focused on the perspectives of mothers rather than of fathers or siblings in the family. Some studies indicate that parents of children with autism tend to report inflated levels of family disruption in comparison to both normal and developmentally delayed controls (Holroyd & McArthur, 1976; Leyser & Dekel, 1990; Bristol, Galagher & Schopler, 1988; Rodrigue, Morgan & Geffken, 1992). One of the few studies which assessed sibling's perceptions of family relationships found that siblings of children with autism and siblings of children with Down syndrome report that their family was slightly less cohesive than siblings of children who were developing normally (McHale, et. al, 1986). In contrast, other studies indicate that overall families of children with autism adapt well (Bristol, 1984; as cited in Morgan, 1988). Families of children who had high levels of expressiveness, cohesiveness and whom participated regularly in social and recreational activities appeared to be the most well adapted in this study. Researchers have also found that aspects such as coping abilities, social support and family stresses have an important impact on the functioning of families of children with disabilities (Failla, & Jones, 1991).

#### Adaptation of Parents of Children with Autism

Much of the research on families of children with autism has focused on the adjustment and support of parents. A brief review of the adaptation of parents of children with autism and other developmental disabilities is warranted given that parental mental health problems have been found to have a negative influence on the adaptation of children in families in the general population (Barker, 1988). The majority of the research has emphasized the effects of children's disabilities on mothers rather than fathers (Bailey, Blasco & Simeonsson, 1992). Studies that have compared the adjustment of both parents have found that mothers are especially likely to experience ill effects such as dysphoria and high stress levels compared to fathers (Bouma & Scweitzer, 1990; Gray & Holden, 1992; Wolf et. al, 1989). Researchers have suggested that the greater influence of having a child with a disability on the adjustment of mothers is likely due to the greater parenting responsibilities of many mothers (Bristol, Gallagher & Schopler, 1988; Wolf et. al, 1989). Bristol and colleagues (1988) reported that mothers assumed more responsibility for caring for a child with a disability regardless of whether they were or were not employed outside the home.

Several studies have evaluated stress levels of parents of children with autism (Beckman, 1983; Kazak, 1987; Konstantareas & Homatidis, 1989; Rodrigue, et. al, 1992; Wolf et. al, 1989). Some studies report that both mothers and fathers of children with autism report higher levels of parenting stress than parents of children with Down syndrome or normally developing children (Wolf et. al, 1989). However, other research has indicated that fathers of children with autism do not experience significantly higher stress levels relative to controls (Rodrigue, Morgan & Geffken, 1992). Mothers of children with autism have been found to report more stress in relation to their child's behavior and greater levels of aggravation and stresses in their lives than fathers and

control parents (Bagenholm & Gillberg, 1991; Bouma & Schweitzer, 1990; Freeman, Perry, & Factor, 1991; Factor, Perry & Freeman, 1990; Konstantareas & Homatidis, 1989; Moes, Koegal, Schreibman & Loos, 1992).

Particular characteristics of the child with a disability have also been found to influence parental stress levels. In a sample of mothers of children with a variety of disabilities, child responsiveness, temperament, repetitive behaviors and unusual care giving demands were associated with higher levels of stress in mothers (Beckman, 1983). Self-abusive behaviors and hyperactivity have been found to be particularly stressful for mothers and fathers of children with autism (Freeman, et. al, 1991). Conflicting results have been found as to whether more severe levels of autism cause greater stress in parents (Bouma & Schweitzer, 1990; Konstantareas & Homatidis, 1989). Higher levels of stress in parents have also been reported when the child with autism was male rather than female (Gray & Holden, 1992).

Recently, researchers have begun to investigate the psychological adjustment of parents of children with autism. One study indicated that mothers of children with autism had significantly elevated average scores for dysphoria compared to parents of normally developing children (Wolf et. al, 1989). Fathers in this study did not show significantly higher levels of dysphoria relative to controls. Dysphoria in parents appeared to be associated with high levels of parenting stress (Wolf et. al). Other studies have supported the notion that mothers of children with autism report higher levels of depressive illnesses as compared to fathers (Bristol et. al, 1988; Gray & Holden, 1992; Moes et. al, 1992). Higher levels of anxiety in mothers relative to fathers of children with autism have also been reported (Gray & Holden, 1992). However, not all studies, have found higher levels of psychological disorder in parents of children with autism relative to controls (Bristol et. al, 1988; Morgan, 1988).

#### Adaptation of Siblings of Children with Autism

Little research has investigated the impact of the child with autism on other children in the family. Studies have reported mixed results about whether siblings of children with disabilities, especially girls have greater responsibility for household chores than siblings of normally developing children (Cuskelly & Gunn, 1993; Stoneman, Brody, Davis, Crapps, Malone, 1991). Some siblings of children with autism have expressed that they feel overburdened with the duties of supervising their sibling (Howlin, 1988; Bagenholm & Gillberg, 1991). Furthermore, a large proportion of siblings of individuals with disabilities tended to feel a life long sense of responsibility towards their sibling (Wilson, McGillivray & Zetlin, 1992). Siblings of children with autism have also been found to express more concern for the future than siblings of children with other disabilities or siblings of normally developing children (Bagenholm & Gillberg, 1991)

Anecdotal reports have also provided suggestions as to some of the potential stress experienced by siblings of children with a variety of types of disabilities. Some siblings of children with mental retardation reported feelings of anger and resentment because they feel that their sibling with a disability received more attention and time from their parents (Howlin, 1988; Lobato, 1983). Siblings also reported feelings of guilt and fear that they were in some way responsible for their siblings disability (Howlin, 1988). Research has also found that the non-disabled sibling feels the need to over-achieve or compensate for the limitations of the child with a disability (Lobato, 1983).

However, positive influences of having a sibling with a disability have also been mentioned in anecdotal reports and research studies. Siblings of children with disabilities have been described as having increased sensitivity and tolerance of others (Seligman &

Darling, 1989; as cited in Norton & Drew, 1994). Many siblings of children with disabilities appeared to show greater maturity and were more responsible than siblings of normally developing children (Howlin, 1988). Also siblings of children with disabilities have been reported to be more altruistic than other children and were more likely to have careers in "helping" professions as adults (Cantwell & Baker, 1984; as cited in Howlin, 1988).

Several studies have evaluated the adjustment of siblings of children with a variety of types of disabilities. Early studies, that frequently lacked adequate control groups have generally indicated the greater levels of maladjustment in siblings of children with a variety of types of disabilities (Ferrari, 1984). In these studies, siblings of children with a variety of developmental delays were reported to have a greater frequency of behavioral problems and academic difficulties (Gath & Gumley, 1987). Several studies indicated that siblings of children with Down syndrome, particularly sisters were more likely to have conduct disorders than brothers of children with Down syndrome and siblings of normally developing controls (Cuskelly & Dadds, 1992; Cuskelly & Gunn, 1993; Gath, 1973).

Further, very few studies have investigated the adaptation of siblings of children with autism in particular. Studies of the adaptation of siblings of children with autism tend to be limited by issues such as small sample sizes and a lack of adequate control groups. Additional research, using more robust research designs is needed in this area.

Ferrari (1984), found that siblings of children with pervasive developmental disorders (largely autistic type) did not have higher levels of adjustment problems or lower self-concepts than siblings of children with diabetes or normally developing children. Siblings of children with autism had the highest levels of social competence and the lowest mean for externalizing behavioral problems as reported by parents and

teachers. No differences were found between sibling's self-reports of their self-concept. However, parents rated the influence of children with pervasive developmental disorders as more negative than the influence of children with diabetes or normally developing children on siblings. Positive adjustment of siblings of children with autism and intellectual disabilities was associated with positive self-concept, mothers perceived social support and early diagnosis of disability. This study was limited by a rather small sample size (16 participants per group).

Similarly, Mates (1990), reported that their sample of older siblings of children with autism had high self-concepts and healthy academic and behavioral adjustment as rated by parents and teachers. Siblings of children with autism had rates of behavioral difficulties that were within the average range. Mates (1990) study, however, did not include a control group of siblings of normally developing children. Other research has also indicated that siblings of children with autism were no more likely than siblings of normally developing children to have academic or language related difficulties (Gillberg, Gillberg & Steffenburg, 1992).

Bagenholm and Gillberg (1991), found a greater percentage of peer related concerns in siblings of children with autism as compared to siblings of children with intellectual disabilities and siblings of normally developing children. Higher rates of attention and conduct problems were found in both siblings of children with autism and siblings of children with intellectual disabilities relative to normal controls. A moderate sample size of 20 participants per group was utilized in this study.

Family demographic factors have been found to have an influence on the adjustment of siblings of children with disabilities. While Ferrari (1984) and Mates (1990), reported no influence of family size on the adjustment of siblings of children with autism, other studies have suggested that siblings of children with a intellectual

disabilities who come from two-child families are more at risk for maladjustment than those from multi-child families (Gath, 1973; McKeever, 1983, as cited in Correa, Silberman & Trusty, 1986). Researchers have noted that families of children with autism tend to have fewer children, than families with normally developing children (Gillberg, Gillberg & Steffenburg, 1992). Studies have also been inconclusive as to whether siblings that are younger or older than the child with a disability are at greater risk for adjustment problems (Breslau, 1982; Gath, 1974). Additional research is needed on how birth order and family size influences siblings of children with autism.

Gender is also a factor that influences the adjustment of siblings of children with disabilities. Numerous researchers have indicated that female siblings of children with disabilities and siblings of same sexed children with disabilities are more likely to have greater adaptation difficulties than opposite sexed siblings (Gath, 1974; Cuskelly & Dadds, 1992; Ferrari, 1984). One study found that same sexed siblings of children with autism were more likely to have higher levels of maladjustment than opposite sexed pairs (Ferrari, 1984). However, contrary to previous findings, females in Ferrari's (1984) study were found to have higher self-concept, and higher academic and social competence than males in this study. The influence of gender in this study, must be viewed with caution, however, as only siblings of children with boys were included in this research. Other research on siblings of children with autism has did not find a significant difference in adjustment in relation to gender (Mates, 1990) Additional studies are needed to ascertain the influence of gender on the adjustment of siblings of children with autism.

# Social Support and Families of Children with Autism Social Support and Parents of Children with Autism

Social support is defined as "the informational, instrumental, psychological, material, and physical resources provided by members of an individual's personal network that buffers one from negative reactions to stressful events and promotes and enhances both growth and well-being" (Dunst, Trivette, Hamby & Pollock, 1990). The only available research on social support in families of children with autism has focused on parents. Research has indicated that social support plays an important role in reducing stress and encouraging healthy adjustment in parents of children with autism (Gray & Holden, 1992; Wolf et. al, 1989). Social support from a variety of sources in parent's lives such as immediate and extended family, friends, neighbors, medical personnel and parents groups has been found to reduce stress and facilitate mental health in parents of children with autism and other disabilities. Parents with high levels of social support have been found to have lower scores on measures of depression, anxiety and anger, and greater life satisfaction, marital adjustment and family functioning (Failla & Jones, 1991; Gray & Holden, 1992). Inconsistent results have been reported as to whether parent's social support needs are most often met through professional services or informal networks such as friends and family (Levy, Rimmerman, Botuck, Ardito, Freeman & Levy, 1996).

Research has indicated that mothers of children with disabilities are more likely to express the need for increased social support than fathers (Bailey, Blasco & Simeonsson, 1992). Mothers have also expressed needs for increased support from family members and professionals, opportunities to meet with parents of disabled children and assistance with child care (Bailey et. al, 1992). Perceived social support from one's spouse has been found to be particularly important in facilitating healthy adjustment in mothers of

children with disabilities (Bristol, et. al, 1988; Konstantareas & Homatidis, 1989). Mothers who feel supported tend to have better parenting skills and have children with disabilities who have fewer behavioral problems (Barakat & Linney, 1992; Bristol et. al, 1988; Dunst, et. al, 1990).

#### Social Support and Siblings of Children with Autism

The availability of social support is one of the factors that may influence the adjustment of siblings of children with autism. Given the importance of social support to parents of children with autism, it is possible that siblings may also benefit from supportive relationships with others. Bagenholm & Gillberg's (1991) study suggested the importance of studying the social support resources of siblings of children with autism. As has been previously discussed, Bagenholm & Gillberg (1991) found that siblings of children with autism felt particularly concerned about the future and reported more peer problems and greater feelings of loneliness than siblings of children with developmental disabilities or siblings of normally developing children. It appears that siblings in this sample may have experienced a lack of social support, at least from their peers. However, research has not specifically investigated the availability and importance of social support in siblings of children with autism, or siblings of children with other types of disabilities.

#### Siblings of Children with Autism-Conclusions

Based on the above review of the literature, it is evident that there have been a paucity of studies that have investigated the psychosocial adjustment, loneliness and sibling relationships of siblings of children with autism. Many of the studies which have been conducted are hampered by methodological difficulties such as small sample sizes and a lack of adequate control groups. Studies have yielded conflicting results as to the

influence of a child with autism on sibling adjustment and sibling relationships.

Additional research is needed on factors such as social support, which may be an important aspect in the healthy adjustment of siblings of children with autism. The lack of research on siblings of children with autism in general, and on their psychosocial functioning and sibling relationships in particular suggests the need for further research in this area.

#### Hypotheses

The present study investigated child adjustment, feelings of loneliness, social support resources and sibling relationships in siblings of children with autism. Self-reports of loneliness in siblings of children with autism were compared with self-reports of loneliness in siblings of children with Down syndrome and siblings of normally developing children. Given the results of Bagenholm & Gillberg's (1991), study, it was hypothesized that siblings of children with autism would report higher levels of loneliness compared to siblings of children with Down syndrome and siblings of normally developing children. Research has suggested that children and adolescents who report being lonely are more likely to have a variety of adjustment difficulties. Therefore, it was hypothesized that sibling's who reported higher levels of loneliness were more likely to have adjustment difficulties.

The social support resources of siblings of children with autism were also investigated in this study. Perceived social support in siblings of children with autism has been ignored in the literature. Having a child with autism in the family appears to expose non-disabled siblings to a unique set of challenges and stresses. Given, these findings, it was hypothesized that the persons who provide social support to siblings of children with autism may differ compared to siblings of children with Down syndrome or siblings of

normally developing children. Given that past research has found that social support helps to encourage healthy adjustment in individuals, it was also hypothesized that siblings who reported high levels of social support would be more likely to be well adjusted than siblings who reported low levels of social support. In addition, since social support can help to buffer against feelings of loneliness, it was hypothesized that there would be a relationship between perceptions of social support resources and feelings of loneliness. It was expected that siblings who reported feeling lonely would also report receiving low levels of social support, particularly from classmates and close friends.

Contradictory results have been found regarding the adjustment of siblings of children with autism. Thus, exploratory analyses were conducted to ascertain, how having a sibling with autism influenced adjustment.

Similarly, very few studies have investigated sibling's perceptions of their relationship with their sibling with autism. The two studies which evaluated siblings views on their relationship with the child with autism, covered only some of the many aspects involved in sibling relationships (McHale, et. al, 1986; Bagenholm & Gillberg, 1991). The present study investigated qualities of sibling relationships which have not been previously assessed in the literature. Thus, no specific hypotheses were made about how sibling relationships would differ among the three groups of siblings. However, it was expected that some group differences in relationships would be found.

Little research has investigated the influence of the severity of autism on the psychosocial functioning of non-disabled children in the family. Given that more severe autism may be associated with greater stress and disruption in the family, it was expected that siblings of children with more severe autism would experience greater feelings of loneliness and greater adjustment difficulties in comparison to siblings of children with less severe autism.

Although, no specific hypotheses were made in these areas, this study also investigated sibling's of children with disabilities understanding and perceptions of their brother or sisters autism or Down syndrome and the availability of services for families of children with a child with autism or Down syndrome.

### **METHOD**

### **Participants**

Participants were 90 children and adolescents between the ages of 8 and 18 years of age and one of their parents. Three groups of thirty children and adolescents were included in the study: (1) individuals who had a sibling who has been diagnosed with autism, (2) those who had a sibling who had Down syndrome, and (3) individuals who had a sibling with no known disability. Participants in the three types of sibling groups were matched for gender, birth order (younger or older than child with a disability or control child) and approximate age. In families where there was more than one sibling who was willing to participate in the study, the child closest in age to the child with the disability or the normally developing control was selected as a participant. In cases where two siblings were equally close in age to a child with a disability, both children completed questionnaires, and the sibling who provided the best match with the other sibling groups was included as a participant. All participants were living in the same household as their sibling.

Families of children with autism were recruited through the Autism Calgary
Association (parent support group), Autism Manitoba (parent support group), Edmonton
Autism Society (parent support group), The Society for the Treatment of Autism (Early
Intervention Program), and Calgary Catholic School Board (special education). A total of
23 families (77%) were recruited through parent support groups, 4 families (13%) were
recruited through the Calgary Catholic School Board, and 3 families (10%) were
recruited through The Society for the Treatment of Autism.

Presentations were made to parents at Autism Calgary Association parent support group meetings, explaining the study and what involvement would entail. Parents who were interested in receiving more information about participating in the study provided their name and phone number to the experimenter. They were then contacted by

telephone to address any additional questions or concerns that and to arrange for an appointment if they wished to participate in the study. Parents obtained oral consent from the child who was participating in the study before an appointment was arranged to meet with the family. Before beginning their participation written parental and child consent was obtained (Appendices A and B).

Participants from Autism Manitoba, the Edmonton Autism Society, and the Society for the Treatment of Autism were recruited through the following procedure. Parents were sent letters outlining the purpose of the study and what their family's involvement would entail (Appendices C-E). They were also sent two copies of the parental consent form and an stamped envelope addressed to the experimenter. Families who were interested in participating returned one, signed copy of the consent form to the experimenter, which included a phone number where they could be reached. Interested families were then contacted by telephone to address any additional questions or concerns and to arrange for an appointment. Parents obtained oral consent from the child who would be participating in the study. While meeting with the family, and before participating in the study, a formal written child consent form was explained and signed by the participating child or children.

Advertisements were also placed in the Autism Calgary Association's and Edmonton Autism Society's monthly newsletters. The advertisement outlined the purpose of the study and indicated what involvement would entail (Appendix F). Participants recruited through advertisements contacted the experimenter by telephone or electronic mail. Formal written consent was obtained from both parents and children, prior to participation.

Participants obtained through the Calgary Catholic School board were recruited using the following procedure. A member of the school board contacted families of children with a diagnosis of autism who attended a Calgary Catholic school. Families

were informed about the purpose of the study and what involvement would entail. They were asked whether their name and telephone number could be released to the experimenter, but were not asked for any commitment to participate in the study. A list of families who were willing to be contacted was forwarded to the experimenter. Families were then telephoned by the experimenter who reviewed information about the study and the families involvement with a parent. Appointments were arranged with families who indicated that they would like to participate. Four of the six families (67%) whose names were provided by the Catholic School Board participated in the study. Formal written parental and child consent was obtained during the meeting with the family, prior to participation.

Thirty siblings of children with autism and thirty parents of children with autism were included as participants in this study. Siblings of children with autism ranged in age from 8 years and 1 month to 18 years and 3 months (average age of 11 years and 8 months). Equal numbers of male and female siblings (15 of each) participated in the study. Twenty-four of the siblings were older than the child with autism, one sibling was the fraternal twin of the child with autism, and the remaining five children were younger than the child with autism.

Seven siblings of children with autism completed the study, but were not included as participants, as they did not provide the most accurate match to the other groups of siblings in terms of age, gender and chronology (ie. being older or younger than the child with autism). Four of these siblings were from families where two siblings were interviewed because they were equally close in age to the child with autism.

All families included in the study had a child who had received a formal diagnosis of Autistic Disorder. Three families were excluded from the sample because their child had a diagnosis of Pervasive Developmental Disorder-Not Otherwise Specified. Three families were excluded from the sample because they did not have a non-disabled sibling

in their family in the specified age range. One additional family was not included in the study, because the sibling of the child with autism had a diagnosis of Pervasive Developmental Disorder.

Families of children with Down syndrome were recruited from the Ups and Downs Parent Support Group, The Winnipeg Down Syndrome Association, The Edmonton Down Syndrome Society, the PREP program and the Calgary Catholic School Board. A total of 23 families (77%) were recruited through parent support groups, 6 (20%) were recruited through the PREP program and one family (3%) was recruited through the Calgary Catholic School Board.

Presentations were made to parents at Ups and Downs monthly support group meetings, explaining the study and participants involvement. Interested parents provided their name and telephone number to the researcher. Families were then contacted to set up an appointment. Due to the small number of families attending many of the support group meetings, families who were members of the Ups and Downs groups were also recruited through "warm contacts". Two of the members of Ups and Downs were very active in the organization contacted other members and provided them with basic information about the study. If families were interested their names and phone numbers were provided to the researcher and they were telephoned to address any questions. Appointments were arranged with interested families. Before participating in the study, written consent was obtained from parents and siblings (Appendices B and G).

Participants were recruited from the Winnipeg Down Syndrome Association and the Edmonton Down Syndrome Society through the following procedure. The president of each of these associations was contacted to identify families of children with Down syndrome who had siblings within the specified age range. The president telephoned parents who were members of the support group, provided them information about the study, and asked if they were interested in being contacted by the researcher. Parents who

consented were contacted by the researcher and were given thorough information regarding the study and what their participation would entail. Appointments were made with families who were interested in the study. Written consent was obtained from both parents and children before participation.

Families were also recruited through the Ups and Downs monthly newsletter (Appendix H). The same procedure used for recruiting families of children with autism through advertisements was utilized. An advertisement was placed in the Ups and Down newsletter that outlined the purpose of the study and what involvement would entail. Interested families contacted the researcher by telephone. Formal written consent was obtained from both parents and children prior to participation.

Families of children with Down syndrome were also recruited though Calgary Catholic schools, following the same procedure used to recruit families of children with autism. Two families of children with Down syndrome were contacted by the researcher. One of the families was rejected because they did not have a non-disabled sibling in the specified age range.

Families of children with Down syndrome were also recruited through the PREP program, which offers services such as early childhood education and speech therapy to children with Down syndrome. Letters to the families were placed in the child's locker at the PREP program school (Appendix I). Families who were interested in participating in the study returned a signed copy of the consent form in a stamped envelop addressed to the researcher. Parents were then contacted by telephone to arrange for an appointment. Written consent from the participating child was obtained before participation.

Thirty siblings of children with Down syndrome and their parents were selected as participants. These children were matched with participants in the other sibling groups for approximate age, gender and birth order in relation to their sibling with Down syndrome. Siblings of children with Down syndrome ranged in age from 8 years, 0 months to 16

years and 4 months (average age 11 years and 11 months). The gender distribution of the group was 16 males and 14 females. Twenty-four of the siblings were older than their brother or sister with Down syndrome and 6 were younger. One sibling was excluded from the study because of inadequate matching with the other sibling groups. Two additional families were rejected as participants because the siblings of children with Down syndrome were not in the specified age range.

Siblings of normally developing children were recruited through advertisements placed in the community, the University of Calgary subject pool, the Calgary Catholic School Board and through acquaintances and "warm contacts" in the community. Advertisements were posted at the University of Calgary (Appendix J). The same procedure was followed for recruiting siblings of children with autism through advertisements. Ten percent of the sample was recruited through community advertisements.

One participant (3%) was recruited through a psychology class at the University of Calgary. The instructor of the course presented an overview of the study and what participation would entail. The interested participant provided her name and phone number and was then contacted by the researcher to arrange for an appointment.

Siblings of normally developing children were also recruited through the Calgary Catholic School Board. Parents of children attending St. John School were sent letters outlining the study and consent forms (Appendices K-L). In total, eighty-eight children in grades 4 through six were sent letters. Four families (13%) returned letters to their classroom teacher. These letters were collected from the school by the researcher. Families were contacted by telephone to arrange for a time to meet with them in their home.

Three families (10%) were friends or acquaintances of the experimenter. These families were asked verbally if they would like to participate in the research study.

Families who were interested provided written consent before participating in the study.

The remaining 19 siblings of normally developing children (63%) were recruited through other families who participated in the research study. Participants were recruited through families in all three of the sibling groups. Families who indicated that they knew of friends or neighbors who they felt would be interested in the study, and whom they were willing to contact telephoned these families. These families were given information about the study and asked if the researcher could contact them. Families that consented were contacted by telephone and were given a thorough description of the study.

Arrangements were made to meet with families who were interested in participating.

Thirty siblings of children who were developing normally and their parents were included in the study. These children ranged in age from 8 years and 7 months to 16 years and 11 months (average age, 11 years and 6 months). The gender distribution was equal with 15 males and 15 females being included as participants. Twenty-four (80%) of the siblings were older than the control normally developing siblings and the remaining 6 (20%) participants were younger than their sibling. Siblings were interviewed about the sibling to whom they were next in birth order. In many families more than one child was interviewed per family. The child whom provided the closest match to the groups of disabled siblings was then selected as the participant. A total of 13 children completed the study, but were not included as participants due to inadequate matching.

### Measures

Social Support Scale for Children (Harter, 1985). This is a 24-item self-report scale assessing children's perceptions of support from their parents, teachers, classmates, and a close friend (see Appendix M). Six items are included in the scale for each of the

four sources of social support. Children are asked to choose which of two opposing statements are true for them and then identify whether the chosen statement is "sort of true" or "really true" for them. Scores range from 1 to 4 for each item and from 24 to 96 for the entire scale. Higher scores are indicative of greater perceived levels of social support.

Harter reports internal consistency reliabilities ranging from .72 to .88 across subscales of children who were in grades 3 through 8. Children's overall scores on the Social Support Scale for Children correlate moderately with children's reports of self-worth. Harter also offers evidence as to the validity of the various subscales. Classmate support was found to correlate at .62 with self-rated acceptance, and close friend support was found to correlate at .46 with the child's self-rated ability to disclose thoughts and feelings to friends. Parental support correlated .48 with congruence of values between children and their parents.

Loneliness and Social Dissatisfaction Questionnaire (Asher, Hymel and Renshaw, 1984). This self-report scale consists of 16 core items that assess feelings of loneliness and social dissatisfaction (e.g. "I feel left out of things") as well as eight filler items that focus on hobbies and interests (see Appendix N). Children and adolescents respond by indicating how true an item is for them on a five point Likert scale ranging from "always true" to "not true at all". Scores range from 1 to five for each item. Scores for the entire scale range from a low of 16 to a high of 80, with higher scores indicating greater feelings of loneliness and social dissatisfaction. The Loneliness and Social Dissatisfaction questionnaire has been found to be internally consistent and internally reliable (Asher, et. al, 1984; Parker & Asher, 1993). Renshaw and Brown's (1993) longitudinal study of loneliness in middle childhood indicates that reported feelings of loneliness were stable over time.

Sibling Relationship Questionnaire -Revised, brief version (Buhrmester & Furman, 1990). The Sibling Relationship Questionnaire (SRQ) consists of 15 scales each containing 2-3 items, for a total of 39 items that assess children's perceptions of their siblings (see Appendix O). The scales assess the following aspects of sibling relationships: Pro-social Behavior, Maternal Partiality, Paternal Partiality, Nurturance of Sibling, Nurturance by Sibling, Dominance of Sibling, Dominance by Sibling, Affection, Companionship, Antagonism, Similarity, Intimacy, Competition, Admiration of Sibling, Admiration by Sibling and Quarreling. These scales are also grouped into four SRQ factors: (1) Closeness/Intimacy, (2) Power, (3) Conflict, and (4) Rivalry.

Each item of the SRQ asks the child to rate how well a particular characteristic describes their relationship with their sibling. Each SRQ item uses a 5 point Likert scale which ranges from "Hardly Ever True" to "Extremely Much". Scores on each item range from 1-5, while overall scores for each scale range from 2-10 for scales involving two items, and from 3-15 for scales involving three items. Higher scores on each scale and factor indicate greater levels of the specified quality in the sibling relationship. For example, higher scores on the affection scale indicate greater perceived affection between siblings. Buhrmester and Furman (1990) report internal consistency coefficients for the SRQ that range from .71-.81 for children in the 3rd, 6th, 9th and 12th grades. Fifty-five of the 60 alpha coefficients calculated for the 15 scales in each age group of children were greater than .60 (Buhrmester and Furman, 1990).

Achenbach Child Behavior Checklist (Achenbach, 1991). The parent form of the Child Behavior Checklist (CBCL) utilized for children aged 4-18 was used in this study. The CBCL requires parents to rate how characteristic a list of 113 behaviors is of their child. A three point Likert scale is used to rate each item, that ranges from 0 (not true) to 2 (very true or often true). The CBCL also includes items that ask about the child's

participation in recreational activities, social competence and about the child's history of problems in school.

Separate norms for boys and girls are provided for children of three age groups (4-5, 6-11 and 12-16 years). Separate scales have been developed for each age group by factor analysis that identify particular patterns of problematic behavior including: Withdrawn Behavior, Somatic Complaints, Anxiety/Depression, Social Problems, Thought Problems, Attention Problems, Delinquency and Aggression. The scores on the separate scales are also grouped into two broad band factors namely Externalizing and Internalizing scores. The CBCL has been well standardized and has adequate validity and reliability (Achenbach, 1991).

Gilliam Autism Rating Scale (GARS). The GARS is a behavioral checklist that helps to identify the presence and severity of autism in individuals between the ages of 3 and 22 years. The GARS was normed on a sample of 1,092 children and young adults who had been diagnosed with autism. The checklist includes three subtests that include 42 items each. The subtests measure (a) Stereotyped Behaviors, (b), Communication, and (c) Social Interaction. A fourth subtest, Developmental Disturbances is optional for parents to complete. The total of the subtest scores yields an Autism Quotient. Items in the first three subtests are presented on a four point Likert scale (0-3). The fourth subtest, Developmental Disturbance uses Yes/No questions. The GARS was included in this study as a measure of severity of autism.

Alpha coefficients for the GARS subtests are: Stereotyped Behaviors .90, Communication .89, Social Interaction .93, Developmental Disturbances .88, and Autism Quotient .96. Test-retest reliability for a two week interval for each subtest ranges from .81 to .88. Inter-rater reliabilities have been calculated between teachers, parents and between a teacher and a parent. Reliabilities ranged from .55 for parent-to-parent ratings

of Social Interaction to .99 for teacher-to-parent ratings of Stereotyped Behaviors and the Autism Quotient.

<u>Demographics Questionnaire</u>. Parents were asked a series of 13 questions about family members (see Appendix P). This questionnaire asks questions pertaining to family size, socio-economic status and presence of children with disabilities in the home.

Adaptive Behaviors Questionnaire. Parents of children who have Down syndrome and parents of children with autism were asked a series of 15 items partially adapted form the Vineland Adaptive Behavior Scales (see Appendix Q). These items were administered to parents in order to gain information about the adaptive level of functioning of the child.

Sibling Perceptions Questionnaire. Siblings of children who have autism or Down syndrome were asked several questions about their understanding and perceptions of what it is like to have a sibling with a disability (see Appendix R). They were also asked to whom they spoke to about issues surrounding their siblings disability. These questions were taken from items utilized in Bagenholm & Gillberg's (1991) study of siblings of children with autism.

### **Procedures**

After parental and child consent was obtained, participants completed questionnaires administered by the experimenter. Siblings were administered the Social Support Scale for Children (Harter, 1985) the Loneliness and Social Dissatisfaction Questionnaire (Asher & Wheeler, 1985) and the Sibling Relationships Questionnaire (Buhrmester & Furman, 1990). The order that the questionnaires were presented to the child was randomized. Each questionnaire was carefully explained to the participant by the researcher. The first two questions of each questionnaire were completed with the researcher's assistance. Children below the age of 12 years were asked to read the first

few questions aloud, in order to evaluate the child's reading skills. Children who required additional help with reading items on the questionnaires were provided with assistance.

All participants were encouraged to ask the experimenter any questions that arose.

Siblings of children with autism or Down Syndrome were also asked several questions about their perceptions and understanding of their sibling's disability. These questions were asked by the experimenter, following the completion of the self-report questionnaires.

Parents were asked to complete a family demographics questionnaire and report on the behavior of participating siblings using the Achenbach's Child Behavior Checklist-parent form (CBCL). Parents of children with autism were also administered the Gilliam Autism Rating Scale (GARS). In addition, parents of children with autism or Down syndrome were administered a series of 15 items partially adapted from the Vineland Adaptive Behavior Scales. These questionnaires were not administered to parents in any fixed order. Each questionnaire was explained to parents.

The majority of participants (92%) participated in the study in their homes. Three participants in the group of siblings with Down syndrome and one in the normally developing group completed the questionnaires and interview with the researcher at an office at the University of Calgary. In addition, for two families who resided outside of Calgary the parental questionnaires were completed and mailed to the researcher, and the sibling was interviewed by telephone. The two siblings interviewed by telephone were 11 and 14 years of age and appeared to have no difficulty answering the questions over the telephone.

### RESULTS

## Family Characteristics

In order to assess whether groups differed on a variety of family demographic variables, a series of analyses of variance (ANOVA) and chi-square tests were performed. Analyses of variance (ANOVA) indicated no group differences on the following demographic variables: participating siblings' age,  $\underline{F}$  (2, 87)=.14,  $\underline{p}$ >05; disabled and normally developing childrens' age,  $\underline{F}$ (2, 87)=.07,  $\underline{p}$ >.05; and number of children per household,  $\underline{F}$ (2, 87)=1.33,  $\underline{p}$ >.05. Group means of participating siblings' and disabled and normally developing childrens' age, and the number of children in each household are presented in Table 1.

Chi-square analyses indicated that the gender of siblings was not significantly different between groups,  $X^2$  (2, N=90), p>.05. However, a significant difference between groups in the gender of children with disabilities and the normally developing control children, ( $X^2$  (2, N=90)=8.90, p<.05), was identified. To control for experiment wise error rate, a Bonferonni adjustment of .05/3=.017 was utilized. The Mann-Whitney test was used for follow-up testing. A significant difference was found between the gender of children with autism and the designated child in the normally developing group, U=285, p<.01. There was a substantially larger portion of male children with autism, with a 6:1 ratio of males to females. This finding was anticipated, given that the ratio of males to females with autism in the population is reported to be 4:1.

No significant group differences were identified on a variety of family constellation variables including: the birth order of siblings in relation to disabled or control children,  $X^2$  (4, N=90)=2.12, p>.05; type of family (two parent, single, or blended two parent),  $X^2$  (4, N=90)=7.09, p>.05; and the presence of an adopted child in the

Table 1
Family Characteristics

	Group							
	Autism		Down syndrome			Normally Developing		
Variables	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>		
Sibling's Age	11.67	2.95	11.88	2.14	11.54	2.33		
Child's Age	9.79	3.86	9.44	3.62	9.43	4.13		
Number of Children	2.47	0.68	2.80	0.85	2.60	0.86		
Father's SES Value	3.77	1.57	4.00	1.41	4.00	1.39		
Mother's SES Value	2.80	1.56	2.97	1.76	2.77	1.77		

family,  $X^2$  (2, N=88)=2.03, p>05. A trend towards differences among groups was found in the type of dyad (male-male, female-female, older male-younger female or older female-younger male) in relation to birth order and gender,  $X^2$  (6, N=90)=11.99, p=.06. This was due to the larger proportion of male siblings in the autism group.

No significant difference was found in the proportion of children with autism and Down syndrome and normally developing control children who had additional illnesses or disabilities,  $X^2$  (2, N=90)=4.28, p>.05. Six (20%) of the of children with autism had additional difficulties including: anxiety disorders, movement disorder, epilepsy, Landau-Kleffler syndrome and Tuberous sclerosis. Three normally developing children had asthma (10%) and one child with Down syndrome (3%) had juvenile diabetes.

Similarly, no significant group differences were identified in the presence of disability or illness in other children in the family, excluding the children with autism, Down syndrome, and normally developing controls,  $X^2(2, \underline{N}=90)=4.32$ ,  $\underline{p}>.05$ .

Socioeconomic status was assessed using a number of variables. No significant differences were found between groups for fathers' years of education,  $X^2$  (10, N=90)=11.50, p>.05 or annual family income,  $X^2$  (16, N=89)=13.34, p>.05. Years of mothers' education significantly differed by group,  $X^2$  (10, N=90)=22.50, N=900.5. Follow-up testing using the Mann-Whitney U test, and a Bonferroni correction of .05/3=.017, failed to reach significance. Correlational analyses indicated that mothers' years of education correlated with four variables of interest in the study: siblings' loneliness scores irrespective of group (N=90), CBCL Activeness (N=90) and Total Competency scales (N=90), and social support from parents in siblings of children with autism (N=90). Mothers' years of education was included as a covariate in analyses involving the aforementioned variables.

Socio-economic status of the groups was also compared by rating mothers and fathers occupations on the Blishen Index of Canadian Occupations (Blishen, Carroll & Moore, 1986). This index provides a numerical rating of occupations based on generated income, prestige and education requirements for specific occupations. Occupations can be divided into one of six class values based on the numerical ratings, with higher class values being associated with greater socio-economic status. No significant group differences were found on either mothers' class values,  $X^2$  (10, N=89)=8.22, p>.05 or fathers' class value  $X^2$  (10, N=89)=8.00, p>.05. Table 1 presents group means of mothers and fathers SES class values.

Correlations of Demographic Characteristics with Variables of Interest
Correlation analyses were performed with selected demographic variables and
siblings' CBCL T-scores, and scores on the social support scales, loneliness scale, and
SRQ factors. These analyses were conducted to evaluate how selected demographic
variables influenced psychosocial adjustment and sibling relationships. Analyses were
performed for all participants, for siblings in each group and also separately for younger
and older siblings in each of the three sibling groups (See Tables 2-5 for significance
levels). Due to the small number of younger children in each group (6), these correlations
are not specifically discussed, but are included in Appendix S. Further, because of the
greater proportion of older children in the sample, the correlations for older children were
similar to those for younger and older children combined. As a result they will not be
specifically discussed. Correlations for older children are presented in Appendix T.

Correlations between Demographic Variables and Dependent Variables for the Entire

Sample

Correlations between demographic variables and dependent variables for the entire sample are presented in Table 2. A Bonferroni adjustment of .05/4=.013 was used to control for experiment wise error rate for correlations with each demographic variable and the four CBCL competency scales. When all participants were included, regardless of group, significant correlations were found between family income, and CBCL Activeness (<u>r</u>=.29), Social Competence (<u>r</u>=.27) and Total Competence scores (<u>r</u>=.34). Mothers' years of education significantly correlated with CBCL Activeness (<u>r</u>=.36) and Total Competence scores (<u>r</u>=.31). Mothers' education also correlated with sibling loneliness (<u>r</u>=-.29), with higher education being associated with lower levels of loneliness. Fathers' education (<u>r</u>=.27) was positively correlated with CBCL Total Competence scores.

Demographic variables also correlated significantly with SRQ factor scores. A Bonferroni adjustment of .05/4=.13, was used. Sibling age correlated with the SRQ Rivalry factor ( $\underline{r}$ =-.31), while the number of children per household correlated significantly with the SRQ Conflict factor ( $\underline{r}$ =-.26).

# Correlations between Demographic Variables and Dependent Variables for Each Group

Correlations between demographic variables and dependent variables for each group are present in Tables 3, 4, and 5. The pattern of correlations for siblings of children with autism differed from those of the control groups. Bonferroni adjustments of .05/3=.017, .05/4=.013, and .05/6=.008, respectively were used to control for error rate in correlations for the three CBCL adjustment factors, four CBCL competency scales and six CBCL individual scales. Significant correlations were found between demographic

Table 2

<u>Correlations Between Demographic and Dependent Variables for the Entire Sample</u>

	Number of	Sibling's	Disabled	Family	Fathers'	Mothers'
	Children	Age	Child's A	ge Income	Education	Education
Total						
Competency	.07	20	05	.34**	.27*	.31*
Activeness	.08	20	06	.29*	.22	.36**
Social						
Competence	09	15	14	.27*	.21	.16
Academic	.08	.12	.15	.05	.03	.03
Total						
Adjustment	15	.04	.04	01	09	.02
Externalizing	15	.14	.16	.01	08	.03
Internalizing	13	02	.03	04	04	.01
Withdrawn	10	06	12	.01	09	04
Somatic	04	03	02	02	06	05
Anxious/						
Depressed	14	.02	.01	.00	.00	.07
Social Problem	ns12	01	19	.00	01	.04

Table 2 (continued)

	Number of	Sibling's	Disabled	Family	Fathers'	Mothers'
	Children	Age	Child's Ag	ge Income	Education	Education
Thought	02	13	11	.14	.02	02
Attention	05	06	07	.11	.06	02
Delinquency	10	04	.02	02	.03	.08
Aggression	12	.10	.13	.07	.04	.15
Social Support						
from Parents	02	10	06	.03	.02	.23
Social Support						
from Teachers	10	19	.02	.05	05	.32
Social Support						
from Friends	08	.09	01	04	.05	.01
Social Support						
from Class	05	01	.11	.07	05	.05
Loneliness	02	02	.05	08	21	29*
Closeness Facto	or .10	17	05	.03	.18	.17
Power Factor	.10	.21	25	.06	05	17
Conflict Factor	26*	.01	.03	.09	05	02
Rivalry Factor	02	31*	.07	.05	01	.04

<sup>\*</sup>p<.01. \*\*p<.001.

Table 3

Correlations Between Demographic and Dependent Variables for the Autism Group

	Number of	Sibling's	Disabled	Family	Fathers'	Mothers'
	Children	Age	Child's Age	Income	Education	Education
Total				<del>-</del>		
Competency	.35	21	22	.35	.50*	.38
Activeness	.05	32	39	.27	.28	.38
Social						
Competence	.17	20	18	.24	.42	.07
Academic	.35	.33	.28	02	.16	.10
Total						
Adjustment	53*	03	15	10	30	38
Externalizing	50*	.13	.06	21	39	24
Internalizing	44*	05	18	.05	20	05
Withdrawn	23	.06	13	.11	12	.00
Somatic	18	07	10	02	15	03
Anxious/ Depressed	37	.01	14	.08	15	.06
Social Problem	m46+	27	33	.10	21	08

Table 3 (continued)

	Number of	Sibling's	Disabled	Family	Fathers'	Mothers'
	Children	Age	Child's Ag	e Income	Education	Education
Thought	35	05	20	.11	02	.00
Attention	52+	15	37	.10	11	02
Delinquency	44	17	21	23	16	06
Aggression	28	.20	04	.07	27	.00
Social Support						
from Parents	.07	42	53*	.16	.19	.49*
Social Support						
from Teachers	.01	33	49*	.23	.19	.22
Social Support						
from Friends	02	.15	03	05	.01	19
Social Support						
from Classmate	es .14	.09	.05	.12	.12	.22
Loneliness	07	02	.05	30	20	35
Closeness Facto	or .07	10	25	07	.32	.27
Power Factor	.23	.42	.07	.04	.02	05
Conflict Factor	32	11	.03	21	26	13
Rivalry Factor	48*	13	17	.41	04	02

<sup>\*</sup>p<.01. \*\*p<.001. + p<.01, but does not reach significance after Bonferroni correction.

Table 4

<u>Correlations Between Demographic and Dependent Variables for the Down Syndrome Group</u>

	Number of	Sibling's	Disabled	Family	Fathers'	Mothers'
	Children	Age	Child's Age	Income	Education	Education
Total				<u> </u>		
Competency	.04	16	01	.49*	.23	.33
Activeness	.01	.06	.18	.56**	.31	.43*
Social						
Competence	.06	21	16	.40	.11	.25
Academic	18	17	14	.09	.11	.11
Total						
Adjustment	.11	.13	.33	.04	02	.12
Externalizing	02	.22	.34	.05	07	.12
Internalizing	17	02	.29	03	.09	.10
Withdrawn	.17	.00	06	06	.00	08
Somatic	.08	17	.26	11	18	08
Anxious/						
Depressed	.05	03	.26	.03	.18	.13
Social Problem	s .22	.27	04	11	.01	.06

Table 4 (continued)

	Number of	Sibling's	Disabled	Family	Fathers'	Mothers'
	Children	Age	Child's Age	Income	Education	Education
Thought	.18	19	.08	.28	.12	.12
Attention	.29	.13	.26	.18	.14	.16
Delinquency	03	.11	.17	.05	.07	.09
Aggression	03	.19	.30	.04	.08	.18
Social Support						
from Parents	.10	.27	.17	13	14	.10
Social Support						
from Teachers	.00	.27	03	.11	09	05
Social Support						
from Friends	23	.13	.25	.00	.07	.19
Social Support						
from Class	15	.12	.04	12	14	16
Loneliness	.12	27	16	.00	15	21
Closeness						
Factor	03	18	.00	.00	.02	02
Power Factor	04	.21	15	.06	03	07
Conflict Factor	25	.22	.22	.07	.07	03
Rivalry Factor	.09	38	.15	05	.04	.00

<sup>\*&</sup>lt;u>p</u><.01. \*\*<u>p</u><.001.

Table 5

<u>Correlations Between Demographic and Dependent Variables for the Normally Developing Group</u>

	Number of	Sibling's	Disabled	Family	Fathers'	Mothers'
	Children	Age	Child's Age	Income	Education	Education
Total		···		<del></del>		
Competency	08	04	.08	.15	.19	.15
Activeness	.19	20	.12	07	17	.12
Social						
Competence	45	.02	09	.19	16	.14
Academic	.29	.19	.37	.13	25	09
Total						
Adjustment	11	03	08	.01	.14	.14
Externalizing	03	.10	.10	.11	.25	.16
Internalizing	13	.01	07	06	.09	.06
Withdrawn	21	38	24	.09	05	.13
Somatic	.03	.16	14	.06	.18	.08
Anxious/						
Depressed	08	01	08	07	.06	.06
Social Problem	ns21	.01	.23	.02	.13	.09

Table 5 (continued)

	Number of	Sibling's	Disabled	Family	Fathers'	Mothers'
	Children	Age	Child's Age	Income	Education	Education
Thought	13	17	28	07	16	28
Attention	23	22	21	.04	.17	.23
Delinquency	.12	06	.03	23	.28	.35
Aggression	19	07	.08	.04	.25	.20
Social Support						
from Parents	19	.06	.39	03	30	.08
Social Support						
from Teachers	22	21	.17	.13	21	.05
Social Support						
from Friends	14	11	04	15	.12	.06
Social Support						
from Class	21	15	.18	.13	21	.00
Loneliness	01	.10	09	.15	30	24
Closeness						
Factor	.08	29	.13	.16	.33	.26
Power Factor	.18	.05	57**	.16	.04	24
Conflict Factor	29	.02	11	.26	28	11
Rivalry Factor	01	11	.21	13	18	.09

<sup>\*</sup>p<.01. \*\*p<.001.

variables and CBCL factors and scales for the autism group. The number of children per household was significantly correlated with CBCL Total Adjustment scale (<u>r</u>=-.53), CBCL Internalizing factor (<u>r</u>=-.44) and CBCL Externalizing factor (<u>r</u>=-.50), indicating that siblings of children with autism with greater numbers of siblings displayed better adjustment. Fathers' education was also correlated with CBCL Total Competency scale (.50), with higher education being associated with greater sibling competency.

A Bonferroni adjustment of .05/4=.013 was used to control for error rate in the correlations of demographic variables with the four social support scales. The number of children in the household and the age of the child with autism appeared to have important implications for the perceived social support of siblings of children with autism.

Significant correlations were found between the age of the child with autism and siblings' perceived social support from parents (r=-.53) and teachers (r=-.49). Specifically, the older the child with autism was, the greater amount of social support their sibling reported. Mothers' education was also correlated with social support from parents (r=.49).

A Bonferroni correction of .05/4=.013 was used to control for experiment wise error rate in correlations with the four SRQ factors. Sibling age was negatively correlated with scores on the SRQ Rivalry scale in the group of siblings of children with autism. The older the sibling of the child with autism the less rivalry they reported with their sibling.

Significant correlations for the Down syndrome group were found between socio-economic variables and CBCL Competency scales. Family income ( $\underline{r}$ =.56) and mothers' level of education ( $\underline{r}$ =.43), were positively correlated with the CBCL Activeness scale. In addition, annual family income correlated with total CBCL Competency score ( $\underline{r}$ =.49).

Only two correlations reached significance for the normally developing group.

Specifically number of children in the household was found to correlate negatively with

the CBCL Social Competence scale ( $\underline{r}$ =-.45), and the control child's age was found to correlate negatively with the SRQ Power factor ( $\underline{r}$ =-.57).

# **Psychosocial Functioning**

## Sibling Adjustment

In order to explore whether siblings of children with autism were more likely to have adjustment difficulties than controls, a series of 3 (group) x 2 (gender) ANOVAs were performed. Results of analyses of the CBCL Total Adjustment scale indicated no significant Group x Gender interaction ( $\underline{F}(2, 87)=.43$ ,  $\underline{p}>.05$ ) or main effect of group ( $\underline{F}(2, 87)=.04$ ,  $\underline{p}>.05$ ) or gender ( $\underline{F}(1, 88)=.48$ ,  $\underline{p}>.05$ ). Similar results were found for CBCL Internalizing and Externalizing factors. For the Externalizing factor, no significant Group x Gender interaction ( $\underline{F}(2, 87)=.32$ ,  $\underline{p}>.05$ ) or effects of group ( $\underline{F}(2, 87)=.91$ ,  $\underline{p}>.05$ ) or gender ( $\underline{F}(1, 88)=.08$ ,  $\underline{p}>.05$ ) were identified. Further, no Group x Gender interactions ( $\underline{F}(2, 87)=.23$ ,  $\underline{p}>.05$ ), or main effects of group ( $\underline{F}(2, 87)=1.51$ ,  $\underline{p}>.05$ ), or gender ( $\underline{F}(1, 88)=.11$ ,  $\underline{p}>.05$ ), were identified for the Internalizing factor.

A multivariate analysis of variance (MANOVA) was used to evaluate the influence of siblings' group and gender on the CBCL individual adjustment scales. All assumptions of MANOVA were upheld. The following scales were included in the analysis: Withdrawn, Somatic, Anxiety/Depression, Social Problems, Thought Problems, Attention Problems, Delinquency and Aggression. Results indicated no significant Group x Gender interaction (Wilks-Lambda  $\underline{F}(14, 158)=1.40$ ,  $\underline{p}>.05$ ), or main effect of group (Wilks Lambda  $\underline{F}(14, 154)=1.30$ ,  $\underline{p}>.05$ ) or gender (Wilks Lambda  $\underline{F}(7, 78)=1.50$ ,  $\underline{p}>.05$ ).

CBCL measures of involvement and competency in recreational and social domains and in academic functioning were also examined to determine whether siblings of children with autism were more likely to have adjustment difficulties than controls. Multivariate analysis of covariance (MANCOVA) was used to assess group and sibling gender differences on CBCL Social Competence score, Activeness score, and Academic Performance score, with mothers' years of education included as a covariate. Results of evaluation of the assumptions of normality, linearity, homogeneity of variance and homogeneity of regression were satisfactory. A significant interaction of Group x Gender was identified, (Wilks  $\underline{F}(6, 85)=2.20$ ,  $\underline{p}<.05$ ). Univariate F's indicated significant Group x Gender interactions for the Social Competence scale,  $\underline{F}(2, 87)=3.80$ ,  $\underline{p}<.05$ ; and Activeness scale,  $\underline{F}(2, 87)=3.31$ ,  $\underline{p}<.05$ . No significant Group x Gender interaction ( $\underline{F}(2, 87)=3.4$ ,  $\underline{p}>.05$ ), or main effect of gender ( $\underline{F}(1, 88)=.02$ ,  $\underline{p}>.05$ ) or group ( $\underline{F}(2, 87)=1.02$ ,  $\underline{p}>.05$ ) was identified for the Academic Performance scale.

Follow-up univariate testing of simple effects, using mothers' years of education as a covariate were conducted on the CBCL Social Competence and Activeness scores. A Bonferroni adjustment of .05/5=.01 was used to control for experiment wise error rate. In terms of Activeness scores, a trend of effect of gender across groups was found  $\underline{F}(1, 88)=6.71$ ,  $\underline{p}=.011$ , with males tending to report higher levels of activeness ( $\underline{M}=50.46$ ), particularly in the Down syndrome and normally developing groups than females ( $\underline{M}=47.90$ ). No significant influence of female gender was found  $\underline{F}(1, 88)=.81$ ,  $\underline{p}>.01$ . Examination of differences in activeness for boys and girls by group indicated a significant relationship for gender in siblings of normally developing children only,  $\underline{F}(1, 88)=9.32$ ,  $\underline{p}<.01$ , with males in this group reporting greater activeness ( $\underline{M}=53.73$ ) than females ( $\underline{M}=48.40$ ). No differences in activeness were found for gender in siblings of

children with autism,  $\underline{F}(1, 88)=.46$ ,  $\underline{p}>.01$ , or siblings of children with Down syndrome,  $\underline{F}(1, 88)=3.31$ ,  $\underline{p}>.01$ .

Univariate tests of the influence of gender on social competence indicated a trend for male gender across groups,  $\underline{F}(1, 88)=6.33$ ,  $\underline{p}=.014$ , with males ( $\underline{M}=47.22$ ) tending to have lower Social Competence scores than females ( $\underline{M}=50.02$ ) across groups. No significant influence of female gender was found,  $\underline{F}(1, 88)=.32$ ,  $\underline{p}>.01$ . A significant influence of gender was found for siblings of children with autism,  $\underline{F}(1, 88)=10.50$ ,  $\underline{p}<.01$ , with females ( $\underline{M}=51.50$ ) having significantly higher scores than males ( $\underline{M}=44.80$ ). Female siblings of children with autism had higher CBCL Social Competence scores than both male and female siblings in the Down syndrome and normally developing groups, while brothers of siblings with autism, had the lowest average Social Competence scores overall. No gender differences in relation to group were found for either siblings of children with Down syndrome,  $\underline{F}(1, 88)=.10$ ,  $\underline{p}>.01$ , or siblings of normally developing children,  $\underline{F}(1, 88)=.15$ ,  $\underline{p}>.01$ .

Analysis of covariance (ANCOVA), with mothers' years of education as a covariate, was used to evaluate group and gender differences for the CBCL Total Competence score. The assumptions of ANCOVA were upheld. A significant Gender x Group interaction (F(2, 87)=30.42, p<.05) was found on the Total Competence score.

Follow-up univariate testing on the Total Competence scale used a Bonferroni correction of .05/5=.01. Results indicated a trend towards significance for male gender across groups (F (2, 87)=2.70, p=.08), with males tending to have higher Total Competence scores (M=51.35) than females (M=50.80), irrespective of group. No significant influence of female gender was found, (F(2, 87)=1.04, p>.01. Univariate F's indicated a trend towards a significant effect of gender in the group of siblings of normally developing children, (F(1, 88)=3.92, p=.05), with males having higher

Competency scores (M=55.33) than females (M=51.10). No significant gender differences were found in siblings of children with autism ( $\underline{F}(1, 88)=1.90, \underline{p}>.01$ ), or Down syndrome ( $\underline{F}(1, 88)=.32, \underline{p}>.01$ ).

Overall, all groups of siblings had adjustment and competency scores that were in the average range. See Table 6 group means on the CBCL.

### Loneliness in Siblings

An ANCOVA, with mothers' years of education as a covariate, investigated the hypothesis that siblings of children with autism would report greater loneliness relative to controls. This analysis evaluated the effect of group and sibling gender on loneliness scores. No violations of the assumptions of ANCOVA were identified. The hypothesis of equal slope was accepted, F(5, 78)=.217, p>.05, which indicates that ANCOVA is an appropriate model for the data. The estimate of the common slope is -1.34 (t(83)=1.61, p=.11. Results indicated no significant Group x Gender interaction, F(2, 89)=1.33, p>.05, and no significant effects of group (F(2, 87)=1.62, p>.05) or gender (F(1, 88)=.21, p>.05). Siblings in all groups reported low mean levels of loneliness. The mean loneliness score of the entire sample was 30.48, lower than Asher et. al's (1984) sample of third through sixth grade children (M=32.51). Table 7 presents mean loneliness scores by group.

## Social Support Resources of Siblings

Social support from parents, teachers, classmates and close friends in relation to group and sibling gender was evaluated using multivariate analysis of covariance (MANCOVA). Mothers' years of education was entered as a covariate. The assumptions of MANCOVA were upheld. The hypothesis of equal slope was accepted with the following values for each scale: social support from parents,  $\underline{F}(5, 78)=.9155$ , p>.05;

Table 6

Group Means on CBCL Factors and Scales

			Gro	oup		
	Autistic		Down s	yndrome	Normally Developing	
Variables	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>
Total				·	<del></del>	
Adjustment	49.6	10.4	49.7	10.7	49.7	8.1
Externalizing	47.4	9.0	48.6	10.2	50.6	8.0
Internalizing	54.3	9.9	50.1	10.3	51.5	8.0
Withdrawn	55.4	6.3	53.0	5.2	52.8	4.1
Somatic	53.9	6.5	53.6	4.2	54.6	5.1
Anxiety/						
Depression	56.9	8.2	54.7	6.8	55.0	6.2
Social Problems	53.2	4.6	52.6	5.2	53.6	5.8
Thought						
Problems	52.9	4.8	53.9	7.8	52.9	5.4
Attention Problems	53.8	4.6	54.8	7.2	53.8	5.5
Delinquency	53.8	4.5	52.6	5.9	52.8	5.5
Aggression	52.3	3.9	53.6	7.3	53.8	5.3

Table 6 (continued)

		Group						
	Autistic		Down sync		Normal	ally Developing		
Variables	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>		
Total								
Competency	50.2	9.5	49.8	9.7	53.2	7.5		
Activeness	47.6	7.9	48.9	6.7	51.1	5.5		
Social								
Competence	48.1	7.2	47.0	6.7	50.6	5.5		
Academic	50.6	5.9	48.5	7.4	48.6	5.2		

Table 7

Group Means on the Loneliness and Social Dissatisfaction Scale

		Group									
(1984)	Autis	tic	Down s	Down syndrome		Normal Develop		et.al			
Variables	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>			
Loneliness	32.7	10.2	28.4	10.2	30.3	8.2	32.5	11.8			

social support from friends  $\underline{F}(5, 78)=1.49$ ,  $\underline{p}>.05$ ; social support from classmates,  $\underline{F}(5, 78)=1.03$ ,  $\underline{p}>.05$ ; and social support from teachers,  $\underline{F}(5, 78)=.48$ ,  $\underline{p}>.05$ ; therefore, indicating that MANCOVA was an appropriate model for the data. The following estimates of common slopes for each of the measures of social support are as follows: social support from parents (.08 (t(.04)=1.96,  $\underline{p}=.06$ ), friends (-.04 (t(.05)=-.87,  $\underline{p}=.38$ ), classmates (.01(t(.05)=.15,  $\underline{p}=.88$ ), and teachers (.03(t(.05)=.65,  $\underline{p}=.52$ ).

Results indicated a significant effect for group on social support, (Wilks-Lambda  $\underline{F}(8,83)=162.00$ , p<.05). A Bonferroni adjustment of .05/4 =.013 was utilized to control for experiment wise error rate in subsequent analyses. Univariate F's indicated a trend for group differences in relation to social support from close friends,  $\underline{F}(2,87)=4.52$ , p=.014. Post-hoc comparisons using the Scheffe method indicated that siblings of children with Down syndrome tended to report higher levels of social support from friends in comparison to siblings of normally developing children. No group differences were found for social support from parents ( $\underline{F}(2,87)=.048$ , p>.05), classmates ( $\underline{F}(2,87)=2.0$ , p>.05) or teachers ( $\underline{F}(2,87)=2.19$ , p>.05). Further, no significant Group x Gender interaction, (Wilks-Lambda  $\underline{F}(8,83)=.44$ , p>.05) or effect of gender (Wilks-Lambda  $\underline{F}(4,87)=1.79$ , p>.05) was identified for the social support scales.

Siblings in all groups reported that they felt somewhat to very supported by parents, teachers, classmates and close friends. Mean scores indicated that none of the sibling groups reported a lack of social support from individuals in their lives. As shown in Table 8, siblings in every group consistently reported receiving higher average levels of

Table 8

Group Means on the Social Support Scale

	Group							
	Autistic		Down	Down syndrome		Normal Develop		er (1985)
Variables	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>
Social Suppor	t	<del></del>		···				
from Parents	3.6	.4	3.6	.4	3.6	.4	3.4	.6
Social Suppor	τ							
from Teacher	3.6	.4	3.4	.5	3.3	.5	3.2	.6
Social Suppor	t.							
from Friends	3.3	.6	3.7	.4	3.5	.5	3.1	.7
Social Suppor	rt							
from Class	3.2	.5	3.4	.5	3.3	.5	3.1	.7

social support than the Harter's (1985) normative sample of children in the 3rd through 8th grade.

# Correlations Among Psychosocial Variables

A series of correlational analyses were performed with CBCL factors and scales, social support scales and the loneliness scale. Analyses were conducted for the three sibling groups combined and for each group separately (see Tables 9-12). Correlations of psychosocial variables for younger and older siblings in each group are not specifically discussed due to the small proportion of younger children in each group, but are included in Appendix U. Correlations of older children, which tend to be similar to those of younger and older children combined in each group, are presented in Appendix V.

When participants in all three groups were included in the analyses, loneliness was negatively correlated with social support from parents ( $\underline{r}$ =-.62), classmates ( $\underline{r}$ =-.62), and close friends ( $\underline{r}$ =-.42), indicating that high social support was associated with low levels of loneliness. Social support from parents was significantly correlated with CBCL Activeness scores ( $\underline{r}$ =.34), with increased levels of social support being associated with greater sibling activeness. In addition, social support from teachers correlated with CBCL Total Competency scores ( $\underline{r}$ =.28), indicating that high social support from teachers was associated with higher parental ratings of child competency. A Bonferroni correction of .05/4=.013, was used to control for experiment wise error rate in the analyses.

Significant correlations were also found when the group of siblings of children with autism were analyzed separately. Social support from classmates was significantly correlated with measures of loneliness ( $\underline{r}$ =-.65) and academic problems ( $\underline{r}$ =.60),

Table 9

Correlations Between Psychosocial Variables for the Entire Sample

	Loneliness	Social Support Parents	Social Support Teachers	Social Support Friends	Social Support Classmates
Loneliness	-	45**	14	42**	62**
Total					
Competency	17	.23	.28*	04	.13
Activeness	16	.34**	.22	.01	.06
Social					
Competence	.06	.03	.19	12	01
Academic	14	.08	.05	.03	.20
Total					
Adjustment	.16	16	05	.01	.00
Externalizing	.02	20	12	.08	.14
Internalizing	.21	11	01	03	10
Withdrawn	.23	14	.08	16	07
Somatic	.10	13	01	.04	17
Anxious/					
Depressed	.10	11	03	01	.05
Social Problem	ms .25	13	22	.00	25

Table 9 (continued)

	Loneliness	Social Support Parents	Social Support Teachers	Social Support Friends	Social Support Classmates
Thought					
Problems	.06	.04	01	.10	.05
Attention					
Problems	.09	03	08	01	08
Delinquency	11	.02	04	.11	.25
Aggression	10	07	10	.09	.16

<sup>\* &</sup>lt;u>p<.01</u>. \*\*<u>p</u><.001

Table 10

Correlations Between Psychosocial Variables for Siblings of Children with Autism

	Loneliness	Social	Social	Social	Social	
		Support Parents	Support Teachers	Support Friends	Support Classmates	
Loneliness	<del>-</del>	43	06	41	65**	
Total						
Competency	.28	.34	.28	.05	.34	
Activeness	26	.42	.31	.10	.15	
Social						
Competency	.01	02	.26	.00	.14	
Academic	33	10	06	02	.60**	
Total						
Adjustment	.16	23	.09	21	02	
Externalizing	.11	35	08	15	.11	
Internalizing	.17	30	.03	32	07	
Withdrawn	.11	29	.06	32	03	
Somatic	04	.04	.08	.08	.01	
Anxious/						
Depressed	.14	30	03	39	.02	
Social Proble	m .33	01	.00	05	48+	

Table 10 (continued)

	Loneliness	Social Support Parents	Social Support Teachers	Social Support Friends	Social Support Classmates
Thought					
Problems	11	.19	.08	05	10
Attention					
Problems	.15	.12	.16	01	34
Delinquency	.03	13	.02	19	.28
Aggression	09	18	04	05	.32

<sup>+</sup> p<.01, not significant after Bonferroni correction of .05/6=.08. \*\* p<.001.

Table 11

<u>Correlations Between Psychosocial Variables for Siblings of Children with Down Syndrome</u>

	Loneliness	Social Support Parents	Social Support Teachers	Social Support Friends	Social Support Classmates
Loneliness	-	42	13	33	74**
Total Competency	.00	07	.25	13	21
Activeness	.06	.21	.26	07	20
Social					
Competence	.10	18	.16	17	22
Academic	09	13	04	.09	13
Total					
Adjustment	.07	.09	07	.15	.14
Externalizing	16	.03	.01	.27	.29
Internalizing	.20	.18	13	.14	01
Withdrawn	.39	02	25	12	29
Somatic	.07	.19	.11	.34	.11
Anxious/					
Depressed	04	.15	07	.26	.17
Social Problem	m .05	.22	28	01	.00

Table 11 (continued)

	Loneliness	Social Support Parents	Social Support Teachers	Social Support Friends	Social Support Classmates
Thought					
Problems	.05	.15	.14	.15	.11
Attention					
Problems	.05	.08	24	08	.08
Delinquency	25	.16	07	.20	.28
Aggression	23	.10	13	.23	.24

<sup>\*</sup> p<.01. \*\* p<.001.

Table 12

<u>Correlations Between Psychosocial Variables for Siblings of Normally Developing Children</u>

	Loneliness	Social Support Parents	Social Support Teachers	Social Support Friends	Social Support Classmates
Loneliness	-	53*	33	40	45*
Total					
Competency	23	.56**	.42	.02	.32
Activeness	26	.43+	.23	04	.23
Social					
Competence	.03	.30	.27	13	.11
Academic	08	.52	.15	.12	.31
Total					
Adjustment	.29	38	18	.18	11
Externalizing	.17	31	22	.16	.01
Internalizing	.19	25	02	.27	13
Withdrawn	.14	10	.34	.12	.19
Somatic	.33	56**	20	17	56**
Anxious/					
Depressed	.13	13	06	.34	.00
Social Problem	n .39	47+	29	.07	31

Table 12 (continued)

	Loneliness	Social Support Parents	Social Support Teachers	Social Support Friends	Social Support Classmates
Thought					
Problems	.36	22	25	.11	.03
Attention					
Problems	.15	28	04	.01	08
Delinquency	13	05	11	.46+	.29
Aggression	.10	29	06	.06	.01

<sup>+</sup> p<.01, but not significant after Bonferroni correction of .05/6=.08. \* p<.01. \*\* p<.001.

with greater levels of social support being associated lower levels loneliness and higher academic functioning.

The only significant correlation identified for siblings of children with Down syndrome, was a relationship between social support from classmates and loneliness (r=-.74), with greater social support being associated with lower loneliness.

Among siblings of normally developing children, loneliness was negatively correlated with social support from parents (r=-.53) and classmates (r=-.45), indicating that greater support from parents and classmates was associated with lower loneliness scores in siblings of normally developing children. Significant correlations were also found between social support from parents and CBCL Activeness (r=.43), Academic Problems (r=.51) and Total Competence scores (r=.56). A Bonferroni correction of .05/4=.013 was used to calculate significant correlations between the social support scales and CBCL competency scales. Furthermore, a significant relationship was found between social support from parents (r=-.56) and classmates (r=-.56) and the CBCL Somatic Problems scale, with greater support being associated with fewer somatic problems. A Bonferroni correction of .05/6=.008 was applied to correlations with the CBCL adjustment scales.

#### Factors that Influence Sibling Adjustment

The influence of several psychosocial and demographic variables on CBCL Total Adjustment score and the Externalizing and Internalizing factors was also explored for each of the three groups using stepwise regression. These analyses were included in order to investigate which psychosocial and demographic factors were the most important predictors of adjustment in siblings of children with autism. Social support from parents, social support from friends, social support from classmates, disabled or normally

developing control child's age, family income and the number of children in the family were used to predict adjustment in all three groups. The aforementioned factors were selected for the analyses based their correlations with CBCL scores in the present study.

Results indicated that the number of children in the household and social support from parents predicted the adjustment of siblings of children with autism. The number of children in the home was the most significant predictor of CBCL Total Adjustment score (F(1, 28)=11.67, p<.05); and CBCL Externalizing factor score (F(1, 28)=10.01, p<.05), and CBCL Internalizing factor score (F(1, 28)=7.50, p<.05) in siblings of children with autism. The number of children in the family accounted for 29% of the variance in siblings' Total adjustment scores, 25% of the variance in scores on the Externalizing factor and 20% of the variance in scores on the Internalizing factor. Siblings of families with greater numbers of children tended to exhibit fewer symptoms of adjustment difficulties.

In addition, social support from parents added significantly to the prediction of externalizing problems in siblings of children with autism,  $\underline{F}(2, 27)=7.98$ ,  $\underline{p}=.05$ . Siblings of children with autism who reported greater support from parents had fewer symptoms of externalizing disorders. A trend for child with autism's age to predict sibling's Externalizing scores was also identified,  $\underline{F}(3, 26)=3.08$ ,  $\underline{p}=.07$ . The older the child with autism was the more likely their sibling was to exhibit externalizing symptoms. A trend for the influence of social support from friends to predict siblings' scores on the Internalizing factor was also found,  $\underline{F}(2, 27)=3.18$ ,  $\underline{p}=.09$ , with higher support from friends being associated with less symptoms of internalizing problems.

In contrast, none of the variables yielded regression coefficients that differed significantly from zero in the group of siblings of children with Down syndrome. Only one significant predictor was identified for adjustment measures on the CBCL for siblings

of normally developing children. Social support from parents was a significant predictor of siblings' CBCL Total Adjustment scores,  $\underline{F}(1, 28)$ =4.63,  $\underline{p}$ <.05, accounting for 14% of the variance in adjustment of siblings of normally developing children. Siblings who reported greater support from parents tended to have fewer symptoms of maladjustment. No significant predictors of Externalizing or Internalizing factors were identified for normally developing children.

### Factors Relating to Sibling Loneliness

The influence of group status and psychosocial variables in the prediction of loneliness was also assessed. Stepwise regression was performed to explore which variables were the most important predictors of loneliness in the entire sample of siblings. The influence of group status (autism, Down syndrome or normally developing), social support from parents, social support from friends, social support from classmates, CBCL Total Adjustment score and CBCL Internalizing factor were included as variables in the analysis. These variables were selected either because they had a significant correlation with loneliness in this study, or a relationship with loneliness was reported in previous studies. The assumptions of regression were upheld.

Results indicated that social support from classmates was the most important predictor of loneliness in the sample of siblings,  $\underline{F}(1, 86)=54.32$ ,  $\underline{p}<.05$ . Social support from friends ( $\underline{F}(2, 85)=34.61$ ,  $\underline{p}<.05$ ) and parents ( $\underline{F}(3, 84)=25.41$ ,  $\underline{p}<.05$ ) were also significant predictors of loneliness in siblings. Membership in the autism, Down syndrome or normally developing groups did not significantly predict loneliness, nor did scores on CBCL measures of Total Adjustment or Internalizing problems.

# Sibling Relationships

### Sibling Relationship Factor Scores

In order to explore how autism influences aspects of sibling relationships, the following analyses with the Sibling Relationship Questionnaire (SRQ) were conducted. SRQ factor scores were assessed in relation to sibling group and gender using multivariate analysis of variance (MANOVA). Four SRQ factor scores were included in the analysis: Closeness/Intimacy, Power, Conflict and Rivalry. All assumptions of MANOVA were upheld. A Group x Gender interaction was not identified, Wilks' Lambda  $\underline{F}(8, 83)$ =.86,  $\underline{p}$ >.05. Results indicated a significant overall effect for group, Wilks' Lambda  $\underline{F}(8, 83)$ =4.62,  $\underline{p}$ <.05 and a significant overall effect for sibling gender, Wilks' Lambda,  $\underline{F}(4, 87)$ =3.49,  $\underline{p}$ <.05. A Bonferroni adjustment of .05/4=.013, was utilized to control for experiment wise error rate in subsequent analyses. All post-hoc comparisons were performed using Scheffe's method.

Univariate F's indicated a significant group difference in the Closeness/Intimacy factor,  $\underline{F}(2, 87)=5.31$ , p<.01. Post-hoc comparisons showed that siblings of children with Down syndrome report significantly higher levels of closeness and intimacy. A significant effect for group was also found on the Conflict factor,  $\underline{F}(2, 87)=8.72$ , p<.01. Siblings of children with autism and Down syndrome reported significantly less conflict with their sibling compared to siblings of normally developing children. No significant group differences were found for the SRQ Power ( $\underline{F}(2, 87)=3.04$ ,  $\underline{p}>.02$ ) and Rivalry factors ( $\underline{F}(2, 87)=1.95$ ,  $\underline{p}>.02$ ).

Univariate F's indicated no significant effects of sibling gender on the following SRQ factors: Closeness/Intimacy,  $\underline{F}(1, 88)=.26$ ,  $\underline{p}>.02$ ; Power,  $\underline{F}(1, 88)=2.04$ ,  $\underline{p}>.02$ ; and Rivalry,  $\underline{F}(1, 88)=6.12$ ,  $\underline{p}>.02$ . A trend towards a significant effect for sibling gender was

found on the Conflict factor, ( $\underline{F}(1, 88)=6.12$ ,  $\underline{p}=.015$ ), with males ( $\underline{M}=2.78$ ) reporting more conflict with their siblings than females ( $\underline{M}=2.40$ ), irrespective of group.

# Sibling Relationship Individual Scales

Each of the 15 individual scales of the SRQ were also evaluated for sibling group and gender differences. See Table 13 for all F values for Group x Gender interactions and overall effects of gender and group. A series of 3 (group) x 2 (gender) ANOVA's indicated no significant Group x Gender interactions. Significant effects for gender were found on the scales measuring Pro-social behavior (F(1, 88)=7.50, p<.05), Nurturance by sibling (F(1, 88)=7.78, p<.05), Affection (F(1, 88)=6.23, p<.05) and Competition (F(1, 88)=10.16, p<.05).

A review of means for each gender indicated that males, irrespective of group, reported less pro-social behavior ( $\underline{M}$ =2.90) and affection ( $\underline{M}$ =4.03) in their sibling relationships, less nurturance by their siblings ( $\underline{M}$ =1.70) and greater competition ( $\underline{M}$ =2.5) with their siblings as compared to females. Females had the following scores on the Prosocial behavior ( $\underline{M}$ =3.33), Affection ( $\underline{M}$ =4.43), Nurturance by Sibling ( $\underline{M}$ =2.20), and Competition scales ( $\underline{M}$ =1.82). A trend towards a gender effect was found for the Maternal Partiality scale, with males regardless of group indicating greater maternal partiality ( $\underline{F}$ (1, 88)=2.86,  $\underline{p}$ =.09). No significant differences due to gender were found on the remaining scales.

Significant effects of group were found on the following scales: Pro-social behavior,  $\underline{F}(2, 87)=3.96$ ,  $\underline{p}<.05$ ; Nurturance of sibling,  $\underline{F}(2, 87)=6.28$ ,  $\underline{p}<.05$ ; Nurturance by sibling,  $\underline{F}(2, 87)=5.37$ ,  $\underline{p}<.05$ ; Affection,  $\underline{F}(2, 87)=5.67$ ,  $\underline{p}<.05$ ; Intimacy,  $\underline{F}(2, 87)=7.79$ ,  $\underline{p}<.05$ ; Competition,  $\underline{F}(2, 87)=9.20$ ,  $\underline{p}<.05$ ; Admiration of sibling,  $\underline{F}(2, 87)=7.56$ ,  $\underline{p}<.05$ ; Admiration by sibling,  $\underline{F}(2, 87)=4.80$ ,  $\underline{p}<.05$ ; and Quarreling,  $\underline{F}(2, 87)=8.82$ ,  $\underline{p}<.05$ .

Table 13

ANOVAs for Sibling Relationship Questionnaire (SRQ) Scales

Source	Dependent Variable	Univariate <u>F</u>	
Group X Gender <sup>a</sup>	Pro-Social Behavior	.18	
	Maternal Partiality	.17	
	Paternal Partiality	.39	
	Nurturance of Sibling	.30	
	Nurturance by Sibling	1.92	
	Dominance of Sibling	.28	
	Dominance by Sibling	2.05	
	Affection	.79	
	Companionship	.07	
	Antagonism	.39	
	Sibling Similarity	.67	
	Intimacy	.46	
	Competition	.48	
	Admiration of Sibling	.69	
	Admiration by Sibling	.26	
	Quarreling	.42	

Table 13 (continued)

Source	Dependent Variable	Univariate <u>F</u>	
Groupb	Pro-Social Behavior	3.96*	
	Maternal Partiality	.99	
	Paternal Partiality	1.16	
	Nurturance of Sibling	3.70**	
	Nurturance by Sibling	5.37**	
	Dominance of Sibling	.29	
	Dominance by Sibling	2.05	
	Affection	5.67**	
	Companionship	2.16+	
	Antagonism	1.91	
	Sibling Similarity	2.67+	
	Intimacy	7.80**	
	Competition	9.20***	
	Admiration of Sibling	7.60**	
	Admiration by Sibling	4.80*	
	Quarreling	8.82***	
Gender <sup>C</sup>	Pro-Social Behavior	7.50**	

Table 13 (continued)

Source	Dependent Variable	Univariate <u>F</u>	
Gender <sup>C</sup>	Maternal Partiality	2.90+	······································
	Paternal Partiality	.01	
	Nurturance of Sibling	6.30**	
	Nurturance by Sibling	7.80**	
	Dominance of Sibling	.78	
	Dominance by Sibling	.07	
	Affection	6.23*	
	Companionship	.00	
	Antagonism	1.73	
	Sibling Similarity	1.11	
	Intimacy	.01	
	Competition	10.16**	
	Admiration of Sibling	.39	
	Admiration by Sibling	.04	
	Quarreling	2.30	

a For group x gender interaction, df= 2, 87. b For group effects df= 2, 87.

<sup>&</sup>lt;sup>c</sup> For gender effects  $\underline{df}$ = 1, 88. +  $\underline{p}$ <.10 (trend towards significance). \*  $\underline{p}$ <.05.

<sup>\*\* &</sup>lt;u>p</u><.001.

A trend for a group effect was found for the scale measuring companionship, <u>F</u>(2, 87)=2.45, p=.09. No significant group effects were identified for the Maternal Partiality, Dominance of Sibling, Dominance by Sibling, Paternal Partiality and Antagonism scales.

Post-hoc analyses using Scheffe's method indicated a variety of differences between groups on the SRQ scales. The Pro-social, Intimacy and Nurturance by Sibling scales differentiated siblings of children with autism from other groups of siblings. Siblings of children with autism report less pro-social behavior as compared to siblings of children with Down syndrome only. Siblings of children with autism also report less intimacy with their sibling and less nurturance by their sibling than both siblings of children with Down syndrome and siblings of normally developing children.

Three scales of the SRQ, the Nurturance of Sibling, Admiration of Sibling and Affection scales, identified differences in the relationships of siblings of children with Down syndrome. Siblings of children with Down syndrome reported that they were more nurturing of their sibling than the other groups of siblings. They also reported that their sibling admired them more than did siblings of children with autism or normally developing children. Siblings of children with Down syndrome also reported more affection in their sibling relationships than siblings of normally developing children, but not siblings of children with autism.

The Competition, Admiration by Sibling and Quarrel subscales identified differences between siblings of children with disabilities and siblings of normally developing children. Siblings of children with autism and siblings of children with Down

syndrome reported greater admiration of their sibling than siblings of normally developing children. Siblings of children with disabilities also reported that they were less competitive with their sibling and quarreled less than normally developing siblings.

In general, siblings in all three groups reported quite positive relationships with their siblings. Table 14 presents the means and standard deviations of SRQ factor and scale scores for each group, as well as average scale scores for Buhrmester & Furman's (1984) sample.

#### Correlations of Sibling Relationship Factors and Psychosocial Variables

Correlational analyses between the four sibling relationship factors (Closeness/Intimacy, Power, Conflict, Rivalry) and scores on the CBCL, social support scale and loneliness questionnaire were performed. Analyses were completed on all siblings regardless of group (Table 15), and on siblings in each group separately (Tables 16-18) and on younger and older siblings in each group. Correlations for younger and older siblings are presented in Appendices W-X. A Bonferroni correction of .05/4=.13 was used to account for experiment wise error rate.

When siblings in all groups were included in the analysis, significant correlations were found between the SRQ Closeness/Intimacy factor and level of loneliness ( $\underline{r}$ =-.34) and social support from friends ( $\underline{r}$ =.36). Higher levels of closeness with siblings were associated with lower loneliness and greater social support from friends. The SRQ Conflict factor was significantly negatively correlated with social support from friends ( $\underline{r}$ =-.28), with greater sibling conflict being associated with less support from friends. A significant correlation was also found between social support from parents and the Sibling Rivalry factor ( $\underline{r}$ =.28).

Table 14

Group Means on Sibling Relationship Questionnaire (SRQ) Factors and Scales

	Group								
	Autis	tic	Dow	n syndrome	Norn	nal Dev	elop		ester & n (1990)
Variables	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>		<u>M</u>	<u>SD</u>
SRQ Factors					·				
Closeness	3.0	.6	3.5	.7	3.1	.6	-		
Power	2.6	1.5	1.9	1.7	1.4	2.2	-		
Conflict	2.3	.8	2.4	.9	3.1	.9	-		
Rivalry	2.9	.3	2.8	.4	3.0	.3	-		
SRQ Scales									
Pro-social	2.8	.9	3.4	.8	3.1	.7	3.3	.9	
Maternal									
Partiality	2.8	.3	2.7	.5	2.9	.5	2.8	.9	
Paternal									
Partiality	2.8	.5	2.8	.5	2.9	.3	2.8	.9	
Nurturance									
of Sibling	3.3	.8	3.7	.8	3.1	.7	2.6	.8	
Nurturance									
by Sibling	1.5	.7	2.1	1.0	2.1	1.0	2.3	.7 conti	nued

Table 14 (continued)

				Group				
	Autis	stic	Down	syndrome	Norn	nal Develop		nester & n (1990)
Variables	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>
SRQ Scales								<del></del>
Dominance								
of Sibling	2.5	1.0	2.6	.9	2.7	.9	2.4	.9
Dominance								
by Sibling	1.9	.9	2.4	1.1	2.2	.9	2.4	1.0
Affection	4.4	.8	4.5	.8	3.9	.8	3.9	.9
Companion	3.2	1.1	3.7	.9	3.4	.8	3.1	1.0
Antagonism	2.4	.9	2.7	1.1	2.9	.7	2.6	1.1
Similarity	2.6	.9	3.1	.8	2.8	1.2	3.0	1.0
Intimacy	1.4	.6	2.1	.9	2.1	.9	2.7	1.2
Competition	1.8	1.0	1.9	1.0	2.8	1.3	2.7	.8
Admiration o	f							
Sibling	3.7	.9	3.9	1.0	3.1	.8	3.6	.9
Admiration								
by Sibling	3.3	1.1	3.9	1.0	3.2	.7	3.5	1.0
Quarreling	2.6	.9	2.6	1.2	3.5	.9	2.9	1.1

Table 15

Correlations Between SRQ Factors and Psychosocial Variables for Entire Sample

	SRQ Closeness/ Intimacy Factor		SRQ Conflict Factor	SRQ Rivalry Factor
Total				
Competency	.13	02	10	.07
Activeness	.11	04	01	.11
Social				
Competence	.00	05	02	.08
Academic	.09	.09	12	08
Total				
Adjustment	15	03	.11	.06
Externalizing	08	05	.11	02
Internalizing	20	04	.01	.13
Withdrawn	18	.04	07	.07
Somatic	10	10	.03	.09
Anxious/				
Depressed	07	.04	01	.00
Social Problems	14	13	.22	.05
Thought				
Problems	.01	.12	.00	.04

Table 15 (continued)

	SRQ Closeness/ Intimacy Factor		SRQ Conflict Factor	SRQ Rivalry Factor
Attention				
Problems	07	10	.09	.00
Delinquency	01	.04	07	03
Aggression	.03	04	.03	08
Loneliness	34**	.04	.16	10
Social Support				
Parents	.31*	15	12	.28*
Social Support				
Teachers	.18	04	22	.15
Social Support				
Friends	.36**	.10	28*	02
Social Support				
Classmates	.30*	04	07	.09

<sup>\* &</sup>lt;u>p<.01</u>. \*\* <u>p</u><.001.

Table 16

<u>Correlations Between SRQ Factors and Psychosocial Variables for Siblings of Children with Autism</u>

	SRQ Closeness/ Intimacy Factor		SRQ Conflict Factor	SRQ Rivalry Factor
Total				
Competency	31	.11	26	02
Activeness	.34	09	23	.03
Social				
Competence	.14	05	25	.14
Academic	.06	.29	02	30
Total				
Adjustment	13	11	.14	.19
Externalizing	21	07	.16	.10
Internalizing	10	22	.02	.22
Withdrawn	03	13	07	.29
Somatic	13	38	.03	.19
Anxious/				
Depressed	05	09	01	.01
Social Problems	43	40	.26	.36

Table 16 (continued)

	SRQ Closeness/ Intimacy Factor		SRQ Conflict Factor	SRQ Rivalry Factor
Thought				
Problems	30	.05	.05	.24
Attention				
Problems	24	14	.14	.15
Delinquency	17	17	.23	.14
Aggression	.06	.11	.04	17
Loneliness	32	06	.02	12
Social Support				
Parents	.37	.08	24	.02
Social Support				
Teachers	.31	.02	22	.16
Social Support				
Friends	.23	.05	27	09
Social Support				
Classmates	.24	.22	02	03

<sup>\*</sup> p<.01. \*\*p<.001.

Table 17

<u>Correlations Between SRQ Factors and Psychosocial Variables for Siblings of Children with Down Syndrome</u>

	SRQ Closenes Intimacy Factor	ss/ SRQ Power or Factor	SRQ Conflict Factor	SRQ Rivalry Factor
Total				
Competency	.19	.01	28	10
Activeness	.10	.16	11	06
Social				
Competence	.03	.10	28	09
Academic	.19	.08	12	13
Total				
Adjustment	05	10	.07	.01
Externalizing	.06	07	07	08
Internalizing	13	13	.11	.09
Withdrawn	35	.14	.05	18
Somatic	.25	18	13	.21
Anxious/				
Depressed	.07	04	.09	05
Social Problems	.17	30	.12	.04

Table 17 (continued)

	SRQ Closeness/ Intimacy Factor	-	SRQ Conflict Factor	SRQ Rivalry Factor
Thought				
Problems	.06	.18	19	02
Attention				
Problems	.00	14	01	.05
Delinquency	.08	.02	24	13
Aggression	.12	06	13	11
Loneliness	27	.18	.16	.04
Social Support				
Parents	.44*	20	25	.27
Social Support				
Teachers	.26	.00	15	.03
Social Support				
Friends	.39	.12	21	.07
Social Support				
Classmates	.27	27	08	01

<sup>\*</sup> p<.01. \*\* p<.001.

Table 18

<u>Correlations Between SRQ Factors and Psychosocial Variables for Siblings of Normally Developing Children</u>

	SRQ Closeness/ Intimacy Factor	-	SRQ Conflict Factor	SRQ Rivalry Factor
Total				
Competency	.02	07	.10	.38
Activeness	11	05	.10	.43*
Social				
Competence	.04	09	.30	.11
Academic	.16	15	17	.24
Total				
Adjustment	31	.12	.12	07
Externalizing	17	.10	.10	17
Internalizing	27	.09	08	.06
Withdrawn	04	03	06	.25
Somatic	32	.17	.11	23
Anxious/				
Depressed	21	.15	07	.08
Social Problems	25	.13	.25	20

Table 18 (continued)

	SRQ Closeness/ Intimacy Factor	-	SRQ Conflict Factor	SRQ Rivalry Factor
Thought				
Problems	.04	.13	.27	.06
Attention				
Problems	13	07	.27	18
Delinquency	.10	.18	11	05
Aggression	19	02	.12	01
Loneliness	35	06	.40	37
Social Support				
Parents	.20	27	.09	.58**
Social Support				
Teachers	.17	23	.18	.36
Social Support				
Friends	.30	.19	40	.06
Social Support				
Classmates	.25	02	08	.41

<sup>\*</sup> p<.01. \*\* p<.001

When only siblings of children with autism were included in the analysis, no significant correlations between SRQ factors and psychosocial adjustment measures were identified. The only significant correlation identified for siblings of children with Down syndrome was a relationship between the SRQ Closeness/Intimacy factor and social support from parents (<u>r</u>=.44), indicating that for siblings of children with Down syndrome, greater parental social support was associated with greater reported closeness among siblings. For siblings of normally developing children, significant correlations were identified with the SRQ Rivalry factor and social support from parents (<u>r</u>=.58). The rivalry factor was also correlated with the CBCL Activeness scale (<u>r</u>=.43) in siblings of normally developing children.

# Severity of Disability

An ANOVA was used to examine whether there were differences in overall severity of disability in the autism and Down syndrome groups, as measured by total scores on the adaptation questionnaire. No effect for group on overall level of disability was found,  $\underline{F}(1, 58)=2.60$ ,  $\underline{p}>.05$ . Group differences in ability on nine basic adaptation skills were also assessed. Only the ability to communicate through language (either spoken or sign) was found to be significantly different,  $X^2(1, \underline{N}=60)=6.67$ ,  $\underline{p}<.05$ , (see Table 19). Group means indicated that children with autism were less likely to communicate through language as compared to children with Down syndrome. Interestingly, however the child with autism's ability to communicate was not significantly correlated with any psychosocial adjustment measures in siblings nor with any of the four SRQ factor scores (Table 20).

Parents were also asked about their child's severity of disability, mental age and Intelligence Quotient. Less than 50% of parents knew the degree of their child's disability

Table 19

<u>Chi-Square for Skills of Children with Autism or Down Syndrome</u>

Source	Dependent Variable	X <sup>2</sup> Value <sup>a</sup>
Group	Use of Four Word Sentences	.74
	Communicates Through Language	6.67*
	Communicates Needs to Others	1.07
	Follows Parent's Instruction	2.07
	Reads	1.15
	Prints Own Name	.00
	Dresses Self Completely	.34
	Ties Own Shoes	1.50
	Feeds Self with Utensil	.35

a  $\chi^2$  with  $\underline{df}$  (1,  $\underline{N}$ =60). \*  $\underline{p}$ <.01.

Table 20

<u>Correlations Between Communication Skills of Child with Autism and Sibling's scores on SRQ Factors and Psycho-Social Variables</u>

	Communication Score
SRQ Closeness/ Intimacy Factor	35
SRQ Power Factor	22
SRQ Conflict Factor	.06
SRQ Rivalry Factor	.24
CBCL Total Competency	.05
CBCL Activeness	13
CBCL Social Competence	.22
CBCL School Performance	04
CBCL Total Adjustment	.05
CBCL Externalizing	.06
CBCL Internalizing	.14
Loneliness	02
Social Support from Parents	25
Social Support from Teachers	26
Social Support from Friends	.03
Social Support from Classmates	22

<sup>\* &</sup>lt;u>p</u><.01. \*\*<u>p</u><.001.

as based on these measures of functioning. Thus severity of disability, mental age and Intelligence Quotient were not included in analyses comparing the level of disability in children with autism and Down syndrome.

Regression analysis was used to evaluate the hypothesis that siblings of children with more severe autism would experience greater loneliness. Overall severity scores on the GARS were used as the measure of autism severity. No violations of regression assumptions were identified. Results indicated that there was a trend for autism severity to predict loneliness,  $\underline{F}(1, 28)=3.84$ ,  $\underline{p}=.06$ . A stepwise regression was performed on the four GARS subscales (Stereotyped Behaviors, Communication, Social Interaction and Developmental Disturbances) to ascertain whether there were particular symptoms of autism that have a greater influence on sibling loneliness. Results indicated that only the Social Interaction subscale contributed significantly to the prediction of loneliness in siblings,  $\underline{F}(1, 25)=5.44$ ,  $\underline{p}<.05$ . Eighteen percent of the variability in loneliness in siblings could be accounted for by the social interaction abilities of the child with autism. The scales measuring Stereotyped Behaviors ( $\underline{F}(1, 25)=.54$ ,  $\underline{p}>.05$ ); Communication Abilities, ( $\underline{F}(1, 25)=.06$ ,  $\underline{p}>.05$ ); and Developmental Disturbances ( $\underline{F}(1, 25)=.02$ ,  $\underline{p}>.05$  did not differ significantly from zero.

Regression analyses were also used to identify whether severity of autism influenced siblings' overall CBCL Adjustment score and CBCL Externalizing and Internalizing factor scores. Results did not indicate significant relationships between overall scores on the GARS and siblings' overall CBCL Adjustment score (<u>F(1, 28)=1.25, p>.05)</u>, and CBCL Externalizing (<u>F(1, 28)=2.05, p>.05)</u> and Internalizing factors (<u>F(1, 28)=2.17, p>.05)</u>. A series of stepwise regressions was also performed to assess whether the severity of particular symptoms of autism had an influence on sibling adjustment. The influence of scores on the four GARS subscales (Stereotyped Behaviors,

Communication, Social Interaction, and Developmental Disturbances) on sibling's scores on CBCL measures of overall adjustment and externalizing and internalizing problems was assessed. Results indicated that the regressions of the GARS scales and measures of sibling adjustment did not differ significantly from zero.

#### Services for Families with Disabilities

Chi squares were utilized to assess any differences in service availability for families of children with autism as compared to families of children with Down syndrome. Table 21 presents the percentage of families with autism and Down syndrome who receive each service. No differences were found in the proportion of children with each disability who had a teacher assistant ( $X^2$  (1 N=60)=2.22, p>.05) or occupational therapy ( $X^2$  (1,N=60)=1.18, p>.05). The portion of siblings of children with disabilities who reported attending a sibling support group did not differ by group,  $X^2$  (1 N=60)=2.05, p<.05.

A significant group difference was found in how likely it was that children received special education services,  $X^2$  (1, N=60)=7.18, p<.05. Children with autism were more likely than children with Down syndrome to be in a special school, a special class, or a modified academic program. Groups also differed significantly the proportion of children receiving speech,  $X^2$  (1, N=60)=5.55, p<.05 and behavioral therapies,  $X^2$ (1, N=60)=4.04, p<.05. Children with autism were more likely to receive behavioral interventions, while a greater portion of children with Down syndrome received speech therapy.

Results also indicated that families with children with disabilities differed in how likely they were to receive respite services,  $X^2$  (1, N=60)=5.45, p<.05. Families of

Table 21

Proportion of Services Used by Families of Children with Autism or Down syndrome

	Group	
	Autistic	Down syndrome
Variables		
Behavioral Interventions	6 (20%)	1 (3.3%)
Occupational Therapy	6 (20%)	3 (10%)
Speech Therapy	8 (27%)	17 (57%)
Special Education	24 (80%)	14 (47%)
Teacher Assistant	20 (67%)	25 (83%)
Respite Services	26 (87%)	18 (60%)
Sibling Support Group	6 (20%)	11 (37%)

children with autism were more likely to report that they received respite services than families of children with Down syndrome.

# Perceptions of Siblings of Children with Disabilities

The responses of siblings of children with autism and Down syndrome regarding their perceptions and understanding of their brother or sister's disability were assessed. Results indicated that the majority of siblings of children with disabilities (52%) indicated that other people do not know what it was like to have a sibling with a disability, while 37% of siblings indicated that some, but not all people understand. The remaining siblings (12%) stated that people understood what it was like to have their brother or sister as a sibling. No group differences were found in the responses of siblings of children with autism as compared to siblings of children with Down syndrome,  $X^2$  (2, N=60)=.18, p>.05.

siblings of children with autism and Down syndrome provided varied explanations about how their sibling with a disability was different than other children. A review of responses indicated that a high proportion of siblings (92%) had some way of explaining what was different about their sibling. Approximately one-third of siblings of children with autism stated that their sibling had a disability (40%), while others referred to autism (27%) or made reference to their siblings lack of speech (27%). Approximately half (47%) of siblings of children with Down syndrome stated that their sibling learns slower than others, while others indicated that their sibling had Down syndrome (40%), had a disability (10%) or that their sibling has an extra chromosone (10%). Some siblings of children with disabilties used multiple explanations in their responses such as "He has Down syndrome, so he learns slower than others". A significant group difference was found in how likely siblings were to think that others would understand their explanation

of how their brother or sister with a disability was different  $X^2$  (1, N=60)=10.70, p<.05. Siblings of children with autism were less likely to indicate that others fully understood their explanation as compared to siblings of children with Down syndrome.

A high percentage (87%) of siblings of children with disabilities stated that they had someone whom they could talk to regarding their sibling with a disability. Siblings mentioned talking to their friends (38%), parents (26.7%), both friends and family (17%), extended family (3.3%) and teacher (1.7%). No group differences were found in the portion of siblings who had someone to talk to about their sibling with a disability,  $X^2$  (1, N=60=.58, p>.05. Siblings of children with autism and siblings of children with Down syndrome also did not differ in whom they spoke to about their sibling  $X^2$  (5, N=60=1.94, p>.05.

Forty percent of siblings of children with disabilities stated that they had a friend who had a sibling with the same disability as their brother or sister. There was no significant difference between siblings of children with autism and siblings of children with Down syndrome on this variable,  $X^2(1, \underline{N}=60)=1.11$ ,  $\underline{p}>.05$ .

#### **DISCUSSION**

#### Group Differences on Psychosocial Variables

# Sibling Loneliness

Recent research has suggested that siblings of children with autism are more likely to experience loneliness and difficulties with peers than siblings of children with intellectual disabilities or siblings of normally developing children (Bagenholm and Gillberg, 1991). Hence, the first hypothesis of this study was that siblings of children with autism would report higher levels of loneliness than siblings of children with Down syndrome and siblings of normally developing children. The results did not support this hypothesis. Siblings of children with autism were found to have similar levels of loneliness as the other two groups of siblings. Siblings of children with autism reported levels of loneliness that were very similar to those found Asher et. al.'s, (1984) normative sample, while siblings of children with Down syndrome and siblings of normally developing children reported slightly lower levels of loneliness.

Loneliness and social isolation in childhood have been associated with higher rates of adjustment difficulties in children and adolescents in the normal population (Kupersmidt & Patterson, 1991; Parkhurst & Asher, 1992; Rubin, Hymel & Mills, 1989). Thus, it was also hypothesized that siblings in this sample as a whole, who reported high levels of loneliness would be more likely to have adjustment difficulties. This hypothesis was not supported in the present study. Scores on the CBCL adjustment scales did not significantly correlate with scores on the loneliness measure. Further the CBCL scales did not predict levels of loneliness in siblings. This finding may be due to the fact that children in this sample reported low average levels of loneliness. Even siblings who expressed feeling the most lonely had levels of loneliness that were only in the moderate range. If siblings had reported higher levels of loneliness, an association with sibling adjustment may have been found.

# Social Support

There has been a paucity of research on the social support resources of siblings of children with autism. The third hypothesis of this study was that the persons whom provide social support to siblings of children with autism would differ compared to siblings of children with Down syndrome and siblings of normally developing children. The results of this study did not support this hypothesis. Siblings of children with autism reported similar levels of social support from parents, teachers, classmates, and close friends as siblings of children with Down syndrome and siblings of normally developing children. Siblings in all groups reported high levels of support from individuals in their lives.

The fourth hypothesis of this study was that siblings who reported high levels of social support would be less likely to have adjustment difficulties, than siblings that reported low levels of social support from individuals in their lives. This hypothesis was partially confirmed in the present study. Although scores on social support scales did not significantly correlate with scores on the majority of the CBCL factors and scales, social support did appear to have important implications for particular aspects of adjustment. Social support was more strongly related to adjustment in siblings of children with autism and siblings of normally developing children, than in siblings of children with Down syndrome. Interestingly, no relationships were found between social support and levels of adjustment in siblings of children with Down syndrome.

Greater support from classmates was correlated with better academic performance and a trend towards reduced levels of social problems in siblings of children with autism. In siblings of normally developing children, social support from parents was related to better academic performance, greater sibling activeness, overall competence and a trend towards lower levels of social problems. High social support from parents and classmates

was also associated with fewer somatic problems in siblings of normally developing children.

Social support from parents significantly predicted levels of externalizing difficulties in siblings of children with autism and CBCL Total Adjustment scores in siblings of normally developing children. In both cases, greater support from parents was associated with fewer adjustment difficulties. A trend towards significance was found for the influence of social support from friends and levels of internalizing symptoms in siblings of children with autism. High social support from friends was related to lower levels of internalizing problems in siblings of children with autism.

The importance of social support in the adjustment of siblings of children with autism is consistent with the research on social support of parents of children with autism. Research has indicated that social support is important in reducing stress and facilitating healthy adjustment in parents of children with autism (Gray & Holden, 1992; Wolf et. al, 1989). Parents who experience high levels of social support tend to have lower levels of depression, anxiety and anger, and report greater life satisfaction (Failla & Jones, 1991; Gray & Holden, 1992).

The fifth hypothesis of this study was that there would be a relationship between levels of social support and feelings of loneliness. Siblings who reported high levels of loneliness were expected to report low levels of social support, particularly from friends and classmates. This hypothesis was supported in the present study. Social support from classmates was the most important predictor of loneliness in siblings in the entire sample, followed by social support from friends and parents. High support was associated with low levels of loneliness in siblings. Social support from teachers did not have a significant influence on sibling loneliness.

When examining the three groups of siblings individually, significant correlations between social support and loneliness were found for the autism and normally developing groups only. Levels of social support in siblings of children with Down syndrome did not appear to be related to feelings of loneliness. High social support from classmates was associated with low levels of loneliness in siblings of children with autism and siblings of normally developing children. Greater social support from parents was associated with lower loneliness in siblings of normally developing children only.

Due to the lack of studies on social support in siblings of children with disabilities, few explanations could be offered as to why levels of social support were not related to levels of adjustment or loneliness in siblings of children with Down syndrome. Possibly other factors, which were not investigated in the present study, are more salient in the prediction of loneliness and adjustment in siblings of children with Down syndrome than social support. Further, a lack of association between social support and loneliness and adjustment scores may have been related to the high average social support scores and relatively low levels of loneliness and adjustment difficulties in siblings of children with Down syndrome.

#### Sibling Adjustment

Past research has reported mixed results as to whether siblings of children with autism are more likely to have adjustment difficulties than siblings of children with intellectual disabilities or siblings of normally developing children (Ferrari, 1984; Mates, 1990; Bagenholm & Gillberg, 1991). Previous studies are limited by methodological weaknesses such as small sample sizes and a lack of adequate comparison groups. Given the lack of rigorous research in this area, and the contradictory findings in available research, exploratory analyses were conducted on the adjustment of siblings with autism

in comparison to controls. The results of this study support the findings of Ferrari (1984), Mates (1990), and Gillberg, et. al, (1992), which indicate that siblings of children with autism tend to be well adjusted. Siblings of children with autism did not have significantly greater levels of adjustment problems, as measured by CBCL factors and scales, than siblings of children with Down syndrome and siblings of normally developing children. Overall, siblings in all groups tended to be well-adjusted.

This finding contradicts Bagenholm & Gillberg's (1991) study which indicated that both siblings of children with autism and siblings of children with developmental delays had higher levels of attention and conduct problems relative to siblings of normally developing children. Furthermore, this study contradicts a number of studies which have indicated that siblings of children with Down syndrome, particularly girls are more likely to have conduct disorder than siblings of normally developing children (Cuskelly & Dadds, 1992; Cuskelly & Dunn, 1993; Gath, 1973). Results of the present study indicate that siblings of children with autism and Down syndrome are well adjusted and do not differ from normal controls on scales measuring conduct and attention difficulties, as well as on all other measures of adjustment.

Particular gender and group interactions were identified on the CBCL measures of activeness and social competence. Males in the normally developing group tended to be more active than females. However, no gender differences were identified in the activeness of siblings in the autism and Down syndrome groups. This results indicates that male and female siblings of children with disabilities are equally involved in sports and other recreational activities. This finding is interesting, given that past research and anecdotal reports suggest that siblings of children with autism in general, and sisters in particular tend to feel overburdened with child care and household responsibilities (Simeonsson & McHale, 1981; Stoneman et. al, 1991). Although this study did not

explicitly investigate sibling's responsibilities in their homes, it is evident that neither brothers nor sisters of children with autism or Down syndrome were so overburdened with household chores that it limited them from recreational and physical activities.

Gender was found to have an impact on the social competence of siblings of children with autism exclusively. Sisters of children with autism had the highest average Social Competence scores on the CBCL, while brothers of children with autism had the lowest Social Competence scores in this sample. This result partially supports the findings of Ferrari's (1984) study of siblings of boys with autism. The results of Ferrari's study indicated that siblings of children with autism and siblings of chronically ill children tended to have greater social competence than siblings of normally developing children. Girls in the entire sample were found to have higher social competence scores than boys. However, interactions between sibling gender and group were not tested in Ferrari's (1984) study. Thus, both the present study and Ferrari's (1984) study seem to suggest that sisters of children with autism may be more socially competent than brothers.

Males and females did not differ in their levels of adjustment on any of the other scales on the CBCL. This indicates that sibling's gender did not increase the risk for maladjustment in siblings of children with disabilities. This contradicts previous research which has suggests that sisters of children with disabilities tend to be at increased risk for maladjustment (Cuskelly & Dadds, 1992; Gath, 1974).

The present study also found that particular demographic variables have an important impact on the adjustment of siblings of children with autism. Results indicated that the number of children in the family had the greatest influence on the CBCL Total Adjustment scores and Externalizing and Internalizing scores of siblings with children with autism. Family size explained 29% of the variance in sibling's total adjustment scores, 25% of the variance in scores on the Externalizing factor and 20% of the variance

in sibling's Internalizing scores. Siblings of children with autism who had greater numbers of siblings had fewer adjustment difficulties. This result is consistent with previous research which has indicated that siblings of children with intellectual disabilities from families with two children are more at risk for maladjustment than multichild families (Gath, 1973; McKeever, 1983). The present study, is the first controlled study to indicate that greater numbers of siblings are associated with better adjustment in siblings of children with autism in particular. Previous studies of siblings of children with autism have not found a significant influence of the number of children in the family on adjustment (Mates, 1990; Ferrari, 1984).

There are a variety of possible explanations for the impact of family size on adjustment in siblings of children with autism. McHale et. al, (1986) indicated that siblings of children with autism whom came from larger families felt less embarrassed about their sibling's disability and felt fewer feelings of burden regarding their sibling. Having additional siblings in the family may therefore help siblings to feel less pressure in terms of their present and future responsibilities towards their sibling with a disability. Furthermore, having additional non-disabled siblings in the family may provide a particularly important source of social support to siblings of children with autism. Positive sibling relationships in normally developing families have been found to be important in buffering stressful experiences in families in general (Jenkin & Smith, 1990). Thus, having another normally developing child in the family to relate to about the stressful aspects of having a sibling with autism may be very helpful.

A trend towards significance was found for the influence of the age of the child with autism in relation to sibling's externalizing scores. The older the child with autism was, the greater the levels of externalizing symptoms in their sibling. One possible explanation of this result is that as children with autism grow older, parents may need to

spend greater amounts of time with the child with autism in order to manage their behavior, and encourage their academic functioning. The extra time spent with the child with autism may result in increases in attention seeking and "acting out" behaviors in the non-disabled sibling. Few studies however, have investigated how the age of the child with autism influences sibling adjustment.

# Severity of Autism and Psychosocial Functioning in Siblings

Little research has focused on how severity of the child's autism influences the adjustment of siblings. Given that more severe autism may cause increased stress and disruption in family life, the sixth hypothesis of this study was that siblings of children with more severe autism would experience greater loneliness and more adjustment difficulties than siblings of children with less severe autism. This hypothesis was partially supported. The severity of autism appeared to have a more important influence on sibling loneliness than it did on the adjustment of siblings. The severity of autism did not significantly predict CBCL Total Adjustment or Externalizing and Internalizing scores in siblings. However, a trend towards significance was found for the relationship between the severity of autism and loneliness in siblings. Interestingly, particular symptoms of autism appeared to have an important impact on sibling loneliness. Children with autism with greater deficits in social interaction skills tended to have siblings with higher levels of loneliness. This finding makes intuitive sense, given that children with autism who had limited social skills, may be unable to form warm, supportive and fully interactive relationships with their siblings.

# Sibling Relationships in Families of Children with Autism

Very few studies have investigated siblings' perceptions of their relationship with their sibling with autism. This study investigated aspects of sibling relationships which have not been previously investigated in siblings of children with disabilities. Thus, no specific hypotheses were made about how sibling relationships would differ amoung the three groups of siblings. However, it was anticipated that some group differences in sibling relationships would be found. This expectation was confirmed in the present study.

Results indicated that siblings of children with autism reported less intimacy with their sibling and less nurturance by their sibling than siblings of children with Down syndrome and siblings of normally developing children. Siblings of children with autism also reported less pro-social behavior in their sibling relationship than siblings of children with Down syndrome. Although no previous literature has addressed how autism influences these aspects of sibling relationships, discussion of particular features of autism provides some insight into these findings.

Siblings of children with autism may be less likely to report high levels of prosocial behavior, intimacy and nurturance by their sibling, because of the variety of social deficits related to autism. Children with autism may be rated as less nurturant by their siblings, because they often have deficits in understanding others perspectives, and tend to be unresponsive to other's emotions (Rutter & Schopler, 1987). Limitations in cognitive functioning may further impede children with autism from assisting and attending to their normally developing siblings.

Similarly, intimacy and pro-social behavior in sibling relationships with children with autism may be inhibited by social and communicative deficits, which are characteristic of autism. Children with autism have deficits such as a lack of reciprocity in

conversation, or an overall lack of speech, which likely inhibit intimate interchanges with siblings such as sharing thoughts and feelings (Rutter & Schopler, 1987). Twenty percent of children with autism in the present study could not communicate through either spoken or sign language.

Furthermore, many children with autism rarely seek out others for comfort, affection or to initiate play. Sibling relationships with children with autism may be characterized by less pro-social behavior because children with autism are less likely to initiate interactions with their siblings. This result also corresponds with Knott et. al.'s, (1995) observational study of children with autism and their siblings, which found that children with autism tend to initiate both less pro-social and antagonistic initiations with their siblings. In addition, both children with autism and their siblings were less likely to respond to each others initiations in this study (Knott et. al, 1995).

Siblings of children with both autism and Down syndrome reported differences in their relationships compared to siblings of normally developing children in the present study. Siblings of children with disabilities reported greater admiration of their sibling than siblings of normally developing children. They also reported that they were less competitive and quarreled less with their sibling than normally developing siblings. These results confirm previous studies which have indicated that siblings of children with disabilities tend to feel quite positive about their sibling (Bagenholm & Gillberg, 1991; McHale et. al, 1986).

Previous research has not addressed how having a sibling with a disability influences antagonistic interaction such as quarreling and competitiveness. However, it can be speculated that the cognitive limitation of the child with a disability may result in siblings feeling less inclined to compete with them. Furthermore, a portion of children with disabilities, particularly in the autism group had considerable deficits in

communication abilities that would likely result in a reduction in the level of negative verbal interactions among siblings.

Particular aspects of sibling relationships also differentiated siblings of children with Down syndrome from siblings of children with autism and siblings of normally developing children. Siblings of children with Down syndrome reported that they were more nurturant of their sibling and had higher levels of overall closeness and intimacy than the other groups of siblings. They also indicated that their sibling admired them more than did siblings of children with autism or siblings of normally developing children. Interestingly, siblings of children with Down syndrome reported greater affection in their sibling relationships than siblings of normally developing children, but not more than siblings of children with autism.

These results correspond with previous observational studies which indicate that siblings of children with Down syndrome tend to be more pro-social towards their sibling than siblings of normally developing children (Abramovitch, et. al, 1987). The present results also correspond with research on pre-school siblings of children with disabilities, which has reported that siblings of children with disabilities tend to be more nurturing of their sibling than normally developing controls (Lobato, 1981). Furthermore, the finding that children with Down syndrome tended to have greater admiration of their sibling corresponds with the stereotypes that children with Down syndrome are more affectionate and appreciative of others.

An additional, interesting result was that siblings of children with autism and Down syndrome did not report greater parental partiality towards their sibling than normally developing children. This finding contradicts anecdotal reports which have stated that siblings of children with intellectual disabilities tend to resent the attention and time that the child with a disability requires from parents (Howlen, 1988; Lobato, 1983).

Several differences were found between male and female siblings in the entire sample. Males tended to report less pro-social behavior and affection in their sibling relationships, less nurturance by their siblings, and greater competition with their siblings compared to females. A trend towards significance was also found for maternal partiality, with males regardless of group reporting greater maternal favoritism than females.

#### Services for Families with Disabilities

Results indicated that families of children with autism received a variety of support services. Families with children with autism were particularly likely to receive special education services, behavioral interventions and respite care compared to families of children with Down syndrome. A large proportion of families of children with autism, particularly those from the city of Calgary, utilized a variety of helpful support services. Respite care was used by a particularly large percentage of families with autism (87%). Access to respite services may have helped to facilitate healthy adjustment in the parents and siblings of children with autism.

#### Perceptions of Siblings with Autism

Few studies have assessed sibling's perceptions and understanding of their brother's or sister's disability. No specific hypothesis was made regarding sibling perceptions. This study produced interesting results which contrasted with Bagenholm & Gillberg's (1991) study. The results of the present study indicated that approximately 50% of siblings of children with autism and siblings of children with Down syndrome suggest that other people do not know what it is like to have a sibling with a disability, while 40% indicate that some, but not all people understand. The vast majority of siblings of children with disabilities (92%) in this study had some way of explaining how their sibling was

different than other children. In contrast, in Bagenholm & Gillberg's (1991) sample, only 45% of siblings of children with autism and 35% of siblings of children with intellectual disabilities were able to explain how their sibling was different.

In the present research, siblings of children with autism were less likely than siblings of children with Down syndrome to indicate that others would understand their explanation of their siblings disability. This finding is not surprising given that autism is a less common disorder in the general population, it's symptoms are more complex and varied, and it's etiology is less established.

Furthermore, in the present study a high percentage of siblings of children with disabilities (87%) indicated that they had someone whom they could talk to about their sibling with a disability. Most siblings indicated that they talked to either immediate family or friends about their sibling. Siblings of children with autism and siblings of children with Down syndrome did not differ in whom they talked to. In contrast, in Bagenholm and Gillberg's (1991) research, siblings of children with autism were more likely than siblings of children with developmental delays to indicate that they could only talk to people outside the home about their brother or sister with a disability.

The fact that many more siblings in this sample were able to explain what was different about their sibling and were able to speak to a variety of people about their sibling, may relate to sampling differences between the present study and Bagenholm & Gillberg's (1991) research. Bagenholm & Gillberg's (1991) study was conducted in Sweden with a sample of families of children with autism which were identified from the general population. In contrast, the present study was largely composed of families who attended parent support groups. Siblings of children with autism whose parents are active in support groups may have more information about autism and may be more likely to interact with other families of children with autism. Parents who are active in support

groups may also be generally better adjusted compared to parents who do not attend support groups. Furthermore, cultural differences or an increase in the publics' awareness of autism over the last few years may also have contributed to the differences in the findings of these studies.

#### Observations of Siblings of Children with Disabilities

One noteworthy observation was made during meetings with families whom participated in this study. It was noticed that siblings of children with autism or Down syndrome appeared to be very mature during their interactions with the researcher. Siblings of children with disabilities tended to be very compliant and diligent while filling out questionnaires. In contrast, a greater portion of siblings of normally developing children tended to be less focused and interested during their participation in the research. This observation corresponds with anecdotal reports that siblings of children with disabilities tend to be more mature and responsible than siblings of normally developing children (Howlin, 1988).

# Limitations of the Study and Suggestions for Future Research

One limitation of the present study is the moderate sample size in relation to the number of variables included in this study. Since autism is a relatively rare disorder in the population, the number of possible participants was restricted. Furthermore, this study was limited to families of children with autism who had siblings who were within a specified age range. In order to obtain the sample size utilized in this study families had to be recruited from several organizations and in three urban centers. Although it would have been optimal to have included a larger sample size, given the numerous variables investigated, this was not possible within a limited time frame. Despite this limitation,

however, the sample size in this study exceeds the sample sizes of many published studies involving siblings of children with disabilities.

A second limitation of this study is that the majority of siblings in this sample (80%) were older rather than younger than the child with autism, Down syndrome, or the normally developing control child. This limits the applicability of the results of this study to siblings who are younger than the child with autism. Furthermore, the small number of younger siblings limited the practicality of analyses comparing younger and older children in the sample. Additional research is needed on the sibling relationships and psychosocial functioning of younger siblings of children with autism.

An additional limitation of this research relates to the gender distribution of children with autism in this study. As was expected, given the higher rate of autism in boys in the general population, the sample of children with autism had significantly larger numbers of males than children with Down syndrome or normally developing controls. This resulted in many more siblings in the autism group reporting about their relationship with a brother rather than a sister. Because of the lack of girls with autism, many analyses of interest could not be conducted, such as investigations of how same-sexed versus opposite sexed sibling dyads differ in terms of adjustment and sibling relationships. Additional research is needed in this area.

A fourth limitation relates to the applicability of this study's findings to families of children with autism in the general population. A large portion of families of children with autism and Down syndrome in this sample were recruited from parental support groups. Several parents whose families participated in the research were very active in support groups and two families had assisted in opening a school for children with autism. Families who tend to be active in such groups may have been more likely to volunteer for the study. The few families interviewed whom were not support group

members, and whom indicted that they largely "kept to themselves" appeared to have non-disabled siblings whom seemed less well adjusted. The small number of such families in this study, however, impeded formal analysis of this observation. Thus, the results of this study may not be representative of siblings of children with autism in the general population. Additional research is needed on siblings in families whom are less active in support groups. Research which compares siblings from families whom do or don't attend support groups would also be of interest.

A fifth possible limitation of this study relates to the Gilliam Autism Rating Scale (GARS), which was utilized as a measure of the severity of autism in this study. The GARS is a rating scale which was published recently in 1995. Very few studies are currently available on it's usefulness as a measure of autism severity. A few concerns regarding it's validity as a measure of severity were raised throughout this study. One concern about the GARS was that it does not consider the child's age in the rating of autism severity. Thus, although the scale may have provided a valid picture of the severity of autism the child currently displayed, it did not account for the fact that many older children with autism have received extensive interventions which have likely lowered their scores on GARS.

Furthermore, informal observations of the level of severity of the child with autism while meeting with the family, often did not seem to be consistent with the GARS ratings of severity. For instance, marked differences in the severity of symptoms of autism were observed in several children in the study whom received "average" ratings of autism severity on the GARS. However, part of this discrepancy was likely due to the fact that different parents may have tended to be more lenient than others when rating the frequency of the occurrence of symptoms of autism in their child.

Given the paucity of research on siblings of children with autism in general, there is a need for a considerable amount of research in this area. Replication of the present study is needed in order to confirm the study's results, particularly in areas which have not been investigated in controlled studies. This study investigated a variety of aspects which have not been previously investigated in studies of siblings of children with autism including: social support resources, the influence of severity of autism, as well as certain aspects of sibling relationships.

Further research is needed on demographic aspects and family characteristics which related to the prediction of adjustment and loneliness in siblings of children with autism. Future studies should formally investigate why siblings of children from larger families tend to be better adjusted than siblings from two-child families.

Longitudinal research that addresses how sibling relationships of children with autism and their siblings change throughout development is also lacking in the literature. Research that investigates whether siblings of children are particularly vulnerable to adjustment difficulties at particular stages of development would also be of interest.

Furthermore, additional research is needed on how the severity of symptoms of autism influences sibling adjustment. Research that further investigates how the severity of symptoms of autism influences loneliness, as well as other aspects of psychosocial adjustment may provide additional information on how siblings are influenced by having a brother or sister with autism.

# Concluding Remarks

In conclusion, this study supports previous research that has indicated that siblings of children with autism tend to be well adjusted (Ferrari, 1984; Mates, 1990; Gillberg, et. al, 1992). Siblings of children with autism in the present study were well adjusted and

reported low levels of loneliness. Female siblings of children with autism were found to have particularly high levels of social competence as compared to males. Siblings of children with autism also reported that they received high levels of social support in their lives. Factors such as large family size, and high levels of social support tended to facilitate healthy adjustment in siblings of children with autism. In contrast, deficits in social interaction skills in the child with autism appeared to place siblings at increased risk for loneliness.

The results of this research also provides new information as to how autism influences relationships between siblings. Siblings of children with autism reported lower levels of intimacy, pro-social behavior and nurturance by siblings than controls. However, this study also highlights some of the positive influences of having a sibling with a disability on sibling relationships. Both siblings of children with autism and Down syndrome reported greater admiration by their siblings and less competitiveness and quarreling in their relationship with their sibling than normally developing sibling pairs.

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# APPENDIX A: Parent Consent Form for Siblings of Children and Adolescents with Autism

# Consent Form for Siblings of Children and Adolescents with Autism

#### **CONSENT FORM**

**RESEARCH PROJECT:** Social support and loneliness in siblings of children

and adolescents with autism.

**INVESTIGATORS:** Laura Kaminsky B.A. (Hons) and Deborah Dewey, Ph.D

University of Calgary and Alberta Children's Hospital

This consent form is part of the process of informed consent. A copy of this form has been provided for you to keep. This form will give you a general idea of what the research project is about and what your participation will involve. If you would like additional information about the project please feel free to ask. Please take the time to read this carefully and understand any accompanying information.

The main purpose of this study is to examine social support resources and feelings of loneliness in siblings of children and adolescents with autism. As well, this study will look at the sibling relationships and adaptation of these children.

Your child will be interviewed by telephone or in person about the social support they receive from parents, teachers and peers. Children will also be asked about feelings of loneliness and about their relationship with their sibling. Parents will be interviewed about general information about the family (such as the number of children in the family). Parents will also be asked about the behavior of the sibling participating in the study. Completion of the interviews will take about 1 hour of your time in total.

The investigator will as appropriate, explain to your child the research and his or her involvement, and will seek his or her ongoing co-operation throughout the project.

Your child and family may not personally benefit from participating in this study, but by serving as participants, you and your child may provide new information about the siblings of children and adolescents with autism and Down's syndrome.

All information collected during this study will be completely confidential. Data will be used for research purposes only by the principal investigators. The results of the research will be reported as group data so that individual identities will not be revealed. Neither your name or identity will be used for publication or publicity purposes. Information will be kept in a locked filing cabinet and will be destroyed after five years of completion of the research project. A summary of the study's results will be mailed to you upon completion of the study.

Your signature on this form indicates that you have understood to your satisfaction the information regarding taking part in this study, and agree to your child's participation. In no way does this waive your legal rights nor release the investigators, sponsors, or

involved institutions from their legal and professional responsibilities. You are free to withdraw your child from the study at any time without jeopardizing your child's services and care. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout the study. If you have further questions concerning matters related to this research, please contact Dr. Deborah Dewey or Laura Kaminsky at (403) 229-7365.

If you have any questions about your child's rights or your rights as a possible participant in this research, please contact the Office of Medical Bioethics, Faculty of Medicine, The University of Calgary, at 220-7990.

(Name of Investigator)	(Signature of Investigator)
(Name of Child)	(Date)
(Name of Parent or Legal Guardian)	(Signature of Parent or Legal Guardian)
(Name of Witness)	(Signature of Witness)

A copy of this consent form is provided for you. Please keep it for your records and future reference.

# **APPENDIX B: Child Consent Form**

### Child Consent Form

I have been asked to take part in a study. I agree to answer some questions about myself and my feelings about people in my life. This will take me about 1 hour. I will try to answer each question as it best describes me. I understand no one else will know how I answered the questions. I know that I do not have to take part in this study. This study may not help me but it will help the researchers. I will not receive any reward for answering these questions.

(Name)	(Signature)
(Investigator's Name)	(Investigator's Signature)
(Name of Witness)	(Signature of Witness)
(Date)	

A copy of this consent form is provided for you

## **APPENDIX C: Letter to Parents Affiliated with Autism Manitoba**

November, 1997

Dear Parent,

I am sending letters to members of the Autism Manitoba parent group. I am currently looking for families who are willing to participate in research on the siblings of children and adolescents who have autism.

Researchers at the Alberta Children's Hospital and at the University of Calgary are conducting a study examining the social support resources, adaptation, sibling relationships and loneliness of siblings of children and adolescents, with autism in comparison to siblings of children and adolescents with Down's syndrome and siblings of normally developing children. Very little research has addressed the feelings and perceptions of siblings of children with autism in the family. One of the few studies that has been completed, found that children who have siblings with autism report less satisfaction with social relationships than other children. Siblings of children with autism have also been found to be more supportive of their sibling than other children and also more empathetic than other children. Research has not investigated the social support resources of siblings of children with autism.

The researchers are looking for families who are willing to participate in this study. Siblings in this study will be interviewed about their social support resources, possible feelings of loneliness and sibling relationships. Parents will be asked to answer questions regarding family demographics and behaviors of the sibling. In addition parents of children with autism will be asked to answer questions about the severity of their child's autism. The interviews will take approximately 60-90 minutes to complete. Siblings of children with autism must be between 8-18 years of age and be living in the same household as their brother or sister with autism, to be included in this study.

I am a Master's Clinical Psychology student at the University of Calgary. I was raised in Winnipeg, and I will be in Winnipeg from December 15-29th and also possibly later in the winter. If your family may be interested in receiving more information about participating in this study, please leave a message including your name and telephone number for Ms. Laura Kaminsky at my Winnipeg number, 475-0624. I will return your call as soon as possible. Once I have heard from you I will contact you by telephone to arrange for a time for an interview to take place. Remember, participation in this study is entirely voluntary.

Thank-you for your time and cooperation

Laura Kaminsky, B. A. (Hons) Clinical Psychology Graduate Student University of Calgary

## **APPENDIX D:** Letter to Parents Affiliated with the Edmonton Autism Society

January 27, 1998

Dear Parent/Guardian,

The Edmonton Autism Society is forwarding information to families who may be willing to participate in research on siblings of children with autism on our behalf. Researchers at the Alberta Children's Hospital and at the University of Calgary are conducting a study examining the social support resources, adaptation, sibling relationships and loneliness of siblings of children and adolescents, with autism in comparison to siblings of children and adolescents with Downs syndrome and siblings of normally developing children. Little research has addressed the feelings and perceptions of siblings of children with disabilities in the family. One of the few studies that has been completed, found that children who have siblings with autism report less satisfaction with social relationships than other children. Siblings of children with autism have also been found to be more supportive of their sibling than other children and also more empathetic than other children. Research has not investigated the social support resources of siblings of children with autism.

The researchers are looking for families who have children with autism that are willing to participate in this study. Siblings in this study will complete questionnaires about their social support resources, possible feelings of loneliness and relationship with their sibling with autism. Siblings will also be briefly interviewed about their understanding of and feelings about their brother or sister's autism. Parents will be asked to answer questionnaires regarding family demographics, behaviors of the sibling and the severity of their child's autism.

Siblings of children with autism must be between 8-18 years of age and be living in the same household as their brother or sister with autism, to be included in this study. Participation in this study would take approximately 40-60 minutes of your families time in total. I am planning to be in the Edmonton area during the first week of March. I am willing to travel to your home to meet with you.

If your family is willing to take part in this study, please complete one copy of the consent form and return it in the self-addressed stamped envelope provided. Please put the consent form in the mail by **February 16, 1998**, so that I receive it in time to contact you before arriving in Edmonton. The additional copy of the consent form is provided for your records. Once the consent form has been received you will be contacted by telephone to arrange a time when I can meet with you. I can also be reached at (403) 220-4965. Your should be aware that even if you give your permission, you and your child are free to withdraw from this study at any time.

Thank-you for your time and cooperation.

Laura Kaminsky, B. A. (Hons) Clinical Psychology Graduate Student Deborah Dewey, Ph.D Alberta Children's Hospital/

### APPENDIX E: Letter to Parents at the Society for the Treatment of Autism

January, 1998

#### Dear Parent/Guardian,

The Society for the Treatment of Autism is forwarding information to families who may be willing to participate in research on siblings of children with autism on our behalf. Researchers at the Alberta Children's Hospital and at the University of Calgary are conducting a study examining the social support resources, adaptation, sibling relationships and loneliness of siblings of children and adolescents, with autism in comparison to siblings of children and adolescents with Down's syndrome and siblings of normally developing children. Very little research has addressed the feelings and perceptions of siblings of children with autism in the family. One of the few studies that has been completed, found that children who have siblings with autism report less satisfaction with social relationships than other children. Siblings of children with autism have also been found to be more supportive of their sibling than other children and also more empathetic than other children. Research has not investigated the social support resources of siblings of children with autism.

The researchers are looking for families who are willing to participate in this study. Siblings in this study will be interviewed about their social support resources, possible feelings of loneliness and sibling relationships. Parents will be asked to answer questions regarding family demographics, behaviors of the sibling. In addition parents of children with autism will be asked to answer questions about the severity of their child's autism. The interviews will take approximately 40-60 minutes to complete. Siblings of children with autism must be between 8-18 years of age and be living in the same household as their brother or sister with autism, to be included in this study.

If your family is willing to take part in this study, please complete one copy of the consent form and return it in the self-addressed stamped envelope provided. The additional copy of the consent form is provided for your records. Once the consent form has been received you will be contacted by telephone to arrange a time when the interview can take place. I can also be reached at 220-4965. Your should be aware that even if you give your permission, you and your child are free to withdraw from this study at any time.

Thank-you for your time and cooperation.

Laura Kaminsky, B. A. (Hons) Clinical Psychology Graduate Student University of Calgary

Deborah Dewey, Ph.D Alberta Children's Hospital/ University of Calgary

### APPENDIX F: Advertisement for Families of Children with Autism

# Can you spare one hour? Are you interested in contributing to science research? Do you have a child or adolescent who has autism? Does your child with autism have a brother or sister who is 8-18 years old?

Researchers at the Alberta Children's Hospital and at the University of Calgary are conducting a study examining the social support resources, sibling relationships, and possible feelings of loneliness in brothers and sisters of children and adolescents with autism in comparison to siblings of children and adolescents with Down's syndrome and siblings of normally developing children. Very little research has addressed the feelings and perceptions of siblings of children with autism. One of the few studies that has been completed, found that children who have siblings with autism report less satisfaction with social relationships than other children. Siblings of children with autism have also been found to be more supportive of their sibling than other children and also more empathetic than other children. Research has not investigated the social support resources of siblings of children with autism.

The researchers are looking for families who are willing to participate in this study. Siblings in this study will be interviewed about their social support resources, sibling relationships, understanding of autism, and feelings of loneliness. Parents will be asked to answer questions regarding family demographics, behaviors of the sibling and the severity of their child's autism. The interviews will take approximately 60-90 minutes to complete. Siblings of children with autism must be between 8-18 years of age and be living in the same household as their brother or sister with autism, to be included in this study.

If your family may be interested in receiving more information about participating in this study, please contact Ms. Laura Kaminsky at 220-4965. Remember, participation in this study is entirely voluntary. Thank-you for your time and cooperation.

# APPENDIX G: Parental Consent Form for Siblings of Children and Adolescents with Down Syndrome

Consent Form for Siblings of Children and Adolescents with Down's Syndrome

### **CONSENT FORM**

**RESEARCH PROJECT:** Social support and loneliness in siblings of children

and adolescents with autism.

**INVESTIGATORS:** Laura Kaminsky B.A. (Hons) and Deborah Dewey, Ph.D

University of Calgary and Alberta Children's Hospital

This consent form is part of the process of informed consent. A copy of this form has been provided for you to keep. This form will give you a general idea of what the research project is about and what your participation will involve. If you would like additional information about the project please feel free to ask. Please take the time to read this carefully and understand any accompanying information.

The main purpose of this study is to examine social support resources and feelings of loneliness in siblings of children and adolescents with autism. As well, this study will look at the sibling relationships and adaptation of these children. Your child will be part of the *comparison group* of brothers and sisters of children with Down's syndrome.

Your child will be interviewed by telephone or in person about the social support they receive from parents, teachers and peers. Children will also be asked about feelings of loneliness and about their relationship with their sibling. Parents will be interviewed about general information about the family (such as the number of children in the family). Parents will also be asked about the behavior of the sibling participating in the study. Completion of the interviews will take about 1 hour of your time in total.

The investigator will as appropriate, explain to your child the research and his or her involvement, and will seek his or her ongoing co-operation throughout the project.

Your child and family may not personally benefit from participating in this study, but by serving as participants, you and your child may provide new information about the siblings of children and adolescents with autism and Down's syndrome.

All information collected during this study will be completely confidential. Data will be used for research purposes only by the principal investigators. The results of the research will be reported as group data so that individual identities will not be revealed. Neither your name or identity will be used for publication or publicity purposes. Information will be kept in a locked filing cabinet and will be destroyed after five years of completion of the research project. A summary of the study's results will be mailed to you upon completion of the study.

Your signature on this form indicates that you have understood to your satisfaction the information regarding taking part in this study, and agree to your child's participation. In

no way does this waive your legal rights nor release the investigators, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw your child from the study at any time without jeopardizing your child's services and care. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout the study. If you have further questions concerning matters related to this research, please contact Dr. Deborah Dewey or Laura Kaminsky at (403) 229-7365.

If you have any questions about your child's rights or your rights as a possible participant in this research, please contact the Office of Medical Bioethics, Faculty of Medicine, The University of Calgary, at 220-7990.

(Name of Investigator)	(Signature of Investigator)
(Name of Child)	(Date)
(Name of Parent or Legal Guardian)	(Signature of Parent or Legal Guardian)
(Name of Witness)	(Signature of Witness)

A copy of this consent form is provided for you. Please keep it for your records and future reference.

## APPENDIX H: Advertisement for Families of Children with Down Syndrome

# Can you spare one hour? Are you interested in contributing to science research? Do you have a child or adolescent who has Down syndrome? Does your child with Down syndrome have a brother or sister who is 8-18 years old?

Researchers at the Alberta Children's Hospital and at the University of Calgary are conducting a study examining the social support resources, sibling relationships, and possible feelings of loneliness in brothers and sisters of children and adolescents with autism in comparison to siblings of children and adolescents with Down syndrome and siblings of normally developing children. A limited amount of research has addressed the feelings and perceptions of siblings of children with disabilities in the family. One of the few studies that has been completed, found that children who have siblings with autism report less satisfaction with social relationships than siblings of children with developmental delays and siblings of normally developing children. Siblings of children with disabilities have been found to be more empathetic than other children. Research has not investigated the social support resources of siblings of children with autism or of siblings of children with Down syndrome.

The researchers are looking for families who are willing to participate in this study. Siblings in this study will be interviewed about their social support resources, sibling relationships, understanding of Down syndrome, and feelings of loneliness. Parents will be asked to answer questions regarding family demographics, behaviors of the sibling and the severity of their child's Down syndrome. The interviews will take approximately 40-60 minutes to complete. Siblings of children with Down syndrome must be between 8-18 years of age and be living in the same household as their brother or sister with Down syndrome, to be included in this study.

If your family may be interested in receiving more information about participating in this study, please contact Ms. Laura Kaminsky at 220-4965. I am willing to come to your home to meet with you. Remember, participation in this study is entirely voluntary. Thank-you for your time and cooperation.

### **APPENDIX I: Letter to Parents at the PREP Program**

January 18, 1998

Dear Parent/Guardian,

The PREP program has agreed to forward information to families regarding a proposal to parents to participate in a research project involving siblings of children with Down syndrome. Researchers at the Alberta Children's Hospital and at the University of Calgary are conducting a study examining the social support resources, adaptation, sibling relationships and loneliness of siblings of children and adolescents, with Down syndrome in comparison to siblings of children and adolescents with autism and siblings of normally developing children. Little research has addressed the feelings and perceptions of siblings of children with disabilities in the family. One of the few studies that has been completed, found that children who have siblings with autism report less satisfaction with social relationships than other children. Siblings of children with Down syndrome have been found to be more supportive of their sibling than other children and also more empathetic than other children. Research has not investigated the social support resources of siblings of children with Down syndrome nor in siblings of children with autism.

The researchers are looking for families who have children with Down syndrome that are willing to participate in this study. Siblings in this study will complete questionnaires about their social support resources, possible feelings of loneliness and relationship with their sibling with Down syndrome. Siblings will also be briefly interviewed about their understanding of and feelings about their brother or sister's Down syndrome. Parents will be asked to answer questionnaires regarding family demographics, behaviors of the sibling and the severity of their child's Down syndrome.

Siblings of children with Down syndrome must be between 8-18 years of age and be living in the same household as their brother or sister with Down syndrome, to be included in this study. Participation in this study would take approximately 40-60 minutes of your families time in total. I am willing to travel to your home to meet with you.

If your family is willing to take part in this study, please complete one copy of the consent form and return it in the self-addressed stamped envelope provided. The additional copy of the consent form is provided for your records. Once the consent form has been received you will be contacted by telephone to arrange a time when I can meet with you. I can also be reached at 220-4965. Your should be aware that even if you give your permission, you and your child are free to withdraw from this study at any time.

Thank-you for your time and cooperation.

Laura Kaminsky, B. A. (Hons) Clinical Psychology Graduate Student University of Calgary Deborah Dewey, Ph.D Alberta Children's Hospital/ University of Calgary

# **APPENDIX J: Advertisement for Families with Normally Developing Children**

# Can you spare one hour? Are you interested in contributing to science research? Are you a parent with at least two children/adolescents living at home? Are one or more of your children 8-18 years old?

This is a joint psychology research project with the University of Calgary and Alberta Children's Hospital. We are currently looking for volunteer participants in an ongoing study about children's relationships with their siblings. If you answered "yes" to all four of the above questions, we need you!

To receive further information regarding this study, please phone Ms. L. Kaminsky at 220-4965.

### APPENDIX K: Letter to Parents of Siblings of Normally Developing Children Through the Calgary Catholic School Board

March 27, 1998

#### Dear Parent/Guardian.

My name is Laura Kaminsky and I am a graduate student in the Department of Clinical Psychology at the University of Calgary. I am conducting a research project under the supervision of Dr. D. Dewey, as part of the requirements for a Master of Science degree. I am writing to provide information regarding my research project, "Loneliness and Social Support in Siblings of Children and Adolescents with Autism", so that you can make an informed decision regarding your child's participation.

The purpose of this study is to examine the social support resources, adaptation, sibling relationships and loneliness of siblings of children and adolescents who are normally developing, in comparison to siblings of children with autism and siblings of children with Down syndrome. Very little research has addressed the feelings and perceptions of siblings of children with disabilities in the family.

I am currently looking for families with children who have siblings, whom are willing to participate in this study. Your child would be part of a comparison group of normally developing children. Children must be between 8-18 years of age and be living in the same household with a brother or sister, to be included in this study.

Children in this study will fill out questionnaires about their social support resources, possible feelings of loneliness and sibling relationships. Parents will be asked to complete questionnaires regarding family demographics and the adaptation of their child who is participating in the study. Participation in this study will take approximately 40-60 minutes of your time in total. Participation in this study will involve no greater risks than those involved in ordinary life.

Data will be collected in a manner that ensures anonymity. Once collected, responses will be kept in strictest confidence. Participants will be assigned a participant number. All information on participants will only contain this number, so that information cannot be linked to participants names. Information containing your responses will be kept in a locked filing cabinet at the Behavioral Research Unit in the Alberta Children's Hospital. Only the researchers (myself and my supervisor), will have access to the data within the filing cabinet and it will be destroyed five years following the completion of the study. Only group results will be used in any published or unpublished reports of the study.

If your family is willing to take part in this study, please sign one copy of the enclosed consent form and return it to your child's home room teacher by **April 6**, **1998**. The additional copy of the consent from is provided for your records. Once the consent form has been received you will be contacted by telephone to arrange a time when you are available to participate. I am willing to meet with you at St. John Fine Arts School, The University of Calgary, or at your hone, whichever is most convenient for you. You should

be aware that even if you give your permission, you and your child are free to withdraw from the study at any time, for any reason without penalty.

This study has received ethics approval from the Calgary Catholic School Board and Alberta Children's Hospital. I have also met with your principal, Mrs. Ashcroft who has given me authorization to forward this information to you. If you have any questions, please feel free to contact me at 220-4965, my supervisor, Dr. Dewey at 229-7365, the Office of the Chair, Faculty of Education Joint Ethics Review Committee at 220-5626, or the Office of the Vice-President (Research) at 220-3381.

Thank-you for your time and cooperation.

Laura Kaminsky, B. A. (Hons) Clinical Psychology Graduate Student University of Calgary

# APPENDIX L: Parental Consent Form for Siblings of Normally Developing Children

### Consent Form for Siblings of Normally Developing Children

### **CONSENT FORM**

**RESEARCH PROJECT:** Social support and loneliness in siblings of children

and adolescents with autism.

**INVESTIGATORS:** Laura Kaminsky B.A. (Hons) and Deborah Dewey, Ph.D

University of Calgary and Alberta Children's Hospital

This consent form is part of the process of informed consent. A copy of this form has been provided for you to keep. This form will give you a general idea of what the research project is about and what your participation will involve. If you would like additional information about the project please feel free to ask. Please take the time to read this carefully and understand any accompanying information.

The main purpose of this study is to examine social support resources and feelings of loneliness in siblings of children and adolescents with autism. As well, this study will look at the sibling relationships and adaptation of these children. Your child will be part of the *comparison group* of siblings of normally developing children.

Your child will be interviewed by telephone or in person about the social support they receive from parents, teachers and peers. Children will also be asked about feelings of loneliness and about their relationship with their sibling. Parents will be interviewed about general information about the family (such as the number of children in the family). Parents will also be asked about the behavior of the sibling participating in the study. Completion of the interviews will take about 1 hour of your time in total.

The investigator will as appropriate, explain to your child the research and his or her involvement, and will seek his or her ongoing co-operation throughout the project.

Your child and family may not personally benefit from participating in this study, but by serving as participants, you and your child may provide new information about the siblings of children and adolescents with autism.

All information collected during this study will be completely confidential. Data will be used for research purposes only by the principal investigators. The results of the research will be reported as group data so that individual identities will not be revealed. Neither your name or identity will be used for publication or publicity purposes. Information will be kept in a locked filing cabinet and will be destroyed after five years of completion of the research project. A summary of the study's results will be mailed to you upon completion of the study.

Your signature on this form indicates that you have understood to your satisfaction the information regarding taking part in this study, and agree to your child's participation. In

no way does this waive your legal rights nor release the investigators, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw your child from the study at any time without jeopardizing your child's services and care. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout the study. If you have further questions concerning matters related to this research, please contact Dr. Deborah Dewey or Laura Kaminsky at (403) 229-7365.

If you have any questions about your child's rights or your rights as a possible participant in this research, please contact the Office of Medical Bioethics, Faculty of Medicine, The University of Calgary, at 220-7990.

(Name of Investigator)	(Signature of Investigator)
(Name of Child)	(Date)
(Name of Parent or Legal Guardian)	(Signature of Parent or Legal Guardian)
(Name of Witness)	(Signature of Witness)

A copy of this consent form is provided for you. Please keep it for your records and future reference.

## **APPENDIX M: Social Support Scale for Children**

### PEOPLE IN MY LIFE

Really True for Me	Sort of True for Me		le Item	Sort of True for Me	Really True for Me
		Some kids like to do fun things with a lot of other people.	BUT	Other kids like to do fun things with just a few people.	
1.		Some kids have paren who don't really understand them.	ts BUT	Other kids have parents who really do understand them.	
2.		Some kids have classmates who like them the way they are.	BUT	Other kids have classmates who wish they were different.	
3.		Some kids have a teacher who helps them if they are upset and have a problem.	BUT	Other kids don't have a teacher who helps them if they are upset and have a problem.	
4.		Some kids have a close friend who they can tell problems to.	BUT	Other kids don't have a close friend who they can tell problems to.	
5.		Some kids have parents who don't seem to want to hear about their children's problems.	BUT	Other kids have parents who do want to listen to their children's problems.	
6.		Some kids have classmates that they can become friends with.	BUT	Other kids don't have classmates that they can become friends with.	

(over)

Really True for Me	Sort of True for Me			Sort of True for Me	Really True for Me
7.		Some kids don't have teacher that helps them do their very best.	BUT	Other kids do have a that helps them do their very best.	teacher
8.		Some kids have a close friend who really understands them.	BUT	Other kids don't have a close friend who really understands them.	
9.		Some kids have parents who care about their feelings.	BUT	Other kids have parents who don't seem to care very much about their feelings.	
10.		Some kids have classmates who who sometimes make fun of them.	BUT	Other kids don't have classmates who make fun of them.	
11.		Some kids have a teacher who cares about them.	BUT	Other kids don't have a teacher who cares about them.	
12.		Some kids have a close friend who they can talk to about things that bother them.	BUT	Other kids don't have a close friend who they can talk to about things that bother them.	
13.		Some kids have parents who treat their children like a person that really	BUT	Other kids have parents who don't treat their children like a	
		matters.	(over)	person who matters.	

Really True for Me	Sort of True for Me			Sort of True for Me	Really True for Me
14.		Some kids have classmates who who pay attention to what they say.	BUT	Other kids have classmates who usually don't pay attention to what they say.	
15.		Some kids don't a teacher who is fair to them.	BUT	Other kids do have a teacher who is fair to them.	
16.		Some kids don't a close friend who they like to spend time with	BUT	Other kids do have a close friend who they like to spend time with.	
17.		Some kids have parents who like them the way they are.	BUT	Other kids have parents who wish they were different.	
18.		Some kids don't get asked to play in games with their classmates very often.	BUT	Other kids often get asked to play in games by their classmates.	
19.		Some kids don't have a teacher who cares if they feel bad.	BUT	Other kids do have a teacher who cares if they feel bad	
20.		Some kids don't have a close friend who really listens to what they say.	BUT	Other kids do have a close friend who really listens to what they say.	

Really True for Me	Sort of True for Me			Sort of True for Me	Really True for Me
21.	p a c	Some kids have parents who don't act like what their children do is mportant.	BUT	Other kids have parents who do act like what their children do is important.	
22.	S	Some kids often spend recess being alone.	BUT	Other kids spend recess being with their classmates.	
23.	a tı	Some kids have a teacher who reats them like a person.	BUT	Other kids don't have a teacher who treats them like a person.	
24.	h w a	Some kids don't nave a close friend who cares about about their relings.	BUT	Other kids do have a close friend who cares about their feelings.	

Note. From Manual for the Social Support Scale for Children, by S. Harter, 1985, Denver: University of Denver.

### **APPENDIX N: Loneliness and Social Dissatisfaction Questionnaire**

### How I Feel

1. It's easy for me to make new friends at school.
() Always True () True Most of the Time () True Sometimes () Hardly Ever True () Not True at All
2. I like to read.
() Always True () True Most of the Time () True Sometimes () Hardly Ever True () Not True at All
3. I have nobody to talk to.
() Always True () True Most of the Time () True Sometimes () Hardly Ever True () Not True at All
4. I am good at working with other children.
() Always True () True Most of the Time () True Sometimes () Hardly Ever True () Not True at All
5. I watch TV a lot.
() Always True () True Most of the Time () True Sometimes () Hardly Ever True () Not True at All

6. It's hard for me to make friends.
() Always True () True Most of the Time () True Sometimes () Hardly Ever True () Not True at All
7. I like school.
() Always True () True Most of the Time () True Sometimes () Hardly Ever True () Not True at All
8. I have lots of friends.
<ul><li>() Always True</li><li>() True Most of the Time</li><li>() True Sometimes</li><li>() Hardly Ever True</li><li>() Not True at All</li></ul>
9. I feel alone.
() Always True () True Most of the Time () True Sometimes () Hardly Ever True () Not True at All
10. I can find a friend when I need one.
<ul><li>() Always True</li><li>() True Most of the Time</li><li>() True Sometimes</li><li>() Hardly Ever True</li><li>() Not True at All</li></ul>

11. I play sports a lot.
() Always True () True Most of the Time () True Sometimes () Hardly Ever True () Not True at All
12. It's hard to get other kids to like me.
() Always True () True Most of the Time () True Sometimes () Hardly Ever True () Not True at All
13. I like science.
() Always True () True Most of the Time () True Sometimes () Hardly Ever True () Not True at All
14. I don't have anyone to play with.
() Always True () True Most of the Time () True Sometimes () Hardly Ever True () Not True at All
15. I like music.
() Always True () True Most of the Time () True Sometimes () Hardly Ever True () Not True at All

16. I get along with other kids.
() Always True () True Most of the Time () True Sometimes () Hardly Ever True () Not True at All
17. I feel left out of things.
() Always True () True Most of the Time () True Sometimes () Hardly Ever True () Not True at All
18. There's nobody I can go to when I need help.
() Always True () True Most of the Time () True Sometimes () Hardly Ever True () Not True at All
19. I like to paint and draw.
() Always True () True Most of the Time () True Sometimes () Hardly Ever True () Not True at All
20. I don't get along with other children.
() Always True () True Most of the Time () True Sometimes () Hardly Ever True () Not True at All

21. I'm lonely
() Always True () True Most of the Time () True Sometimes () Hardly Ever True () Not True at All
22. I am well-liked by kids in my class.
() Always True () True Most of the Time () True Sometimes () Hardly Ever True () Not True at All
23. I like playing board games a lot.
() Always True () True Most of the Time () True Sometimes () Hardly Ever True () Not True at All
24. I don't have any friends.
() Always True () True Most of the Time () True Sometimes () Hardly Ever True () Not True at All

### **APPENDIX O: Sibling Relationship Questionnaire**

### SIBLING RELATIONSHIP QUESTIONNAIRE

1. Some siblings do nice things for each other a lot, while other siblings do nice things for each other a little. How much do both you and this sibling do nice things for each other?
() Hardly at all () Not too much () Somewhat () Very much () EXTREMELY much
2. Who usually gets treated better by your mother, you or this sibling?
<ul> <li>() My sibling almost always gets treated better</li> <li>() My sibling often gets treated better</li> <li>() We get treated about the same</li> <li>() I often get treated better</li> <li>() I almost always get treated better</li> </ul>
3. How much do you show this sibling how to do things he or she doesn't know how to do?
() Hardly at all () Not too much () Somewhat () Very much () EXTREMELY much
4. How much does this sibling show you how to do things you don't know how to do?
() Hardly at all () Not too much () Somewhat () Very much () EXTREMELY much
5. How much do you tell this sibling what to do?
() Hardly at all () Not too much () Somewhat () Very much () EXTREMELY much

6. How much does this sibling tell you what to do?
() Hardly at all () Not too much () Somewhat () Very much () EXTREMELY much
7. Who usually gets treated better by your father, you or this sibling?
<ul> <li>() My sibling almost always gets treated better</li> <li>() My sibling often gets treated better</li> <li>() We get treated about the same</li> <li>() I often get treated better</li> <li>() I almost always get treated better</li> </ul>
8. Some siblings care about each other a lot while other siblings don't care about each other that much. How much do you and this sibling care about each other?
() Hardly at all () Not too much () Somewhat () Very much () EXTREMELY much
9. How much do you and this sibling go places and do things together?
() Hardly at all () Not too much () Somewhat () Very much () EXTREMELY much
10. How much do you and this sibling insult and call each other names?
() Hardly at all () Not too much () Somewhat () Very much () EXTREMELY much

11. How much do you and this sibling like the same things?
() Hardly at all () Not too much () Somewhat () Very much () EXTREMELY much
12. How much do you and this sibling tell each other everything?
() Hardly at all () Not too much () Somewhat () Very much () EXTREMELY much
13. Some siblings try to out-do or beat each other at things a lot while other siblings try to out-do each other a little. How much do you and this sibling try to out-do each other at things?
() Hardly at all () Not too much () Somewhat () Very much () EXTREMELY much
14. How much do you admire and respect this sibling?
() Hardly at all () Not too much () Somewhat () Very much () EXTREMELY much
15. How much does this sibling admire and respect you?
( ) Hardly at all ( ) Not too much ( ) Somewhat ( ) Very much ( ) EXTREMELY much

16. How much do you and this sibling disagree and quarrel with each other?
( ) Hardly at all ( ) Not too much ( ) Somewhat ( ) Very much ( ) EXTREMELY much
17. Some siblings cooperate a lot, while other siblings cooperate a little. How much do you and this sibling cooperate with each other?
() Hardly at all () Not too much () Somewhat () Very much () EXTREMELY much
18. Who gets more attention from your mother, you or this sibling?
<ul> <li>() My sibling almost always gets more attention</li> <li>() My sibling often gets more attention</li> <li>() We get about the same amount of attention</li> <li>() I often get more attention</li> <li>() I almost always get more attention</li> </ul>
19. How much do you help this sibling with things he or she can't do by herself?
() Hardly at all () Not too much () Somewhat () Very much () EXTREMELY much
20. How much does this sibling help you with things you can't do by yourself?
() Hardly at all () Not too much () Somewhat () Very much () EXTREMELY much

21. How much do you make this sibling do things?
() Hardly at all () Not too much () Somewhat () Very much () EXTREMELY much
22. How much does this sibling make you do things?
( ) Hardly at all ( ) Not too much ( ) Somewhat ( ) Very much ( ) EXTREMELY much
23. Who gets more attention from your father, you or this sibling?
<ul> <li>() My sibling almost always gets more attention</li> <li>() My sibling often gets more attention</li> <li>() We get about the same amount of attention</li> <li>() I often get more attention</li> <li>() I almost always get more attention</li> </ul>
24. How much do you and this sibling love each other?
( ) Hardly at all ( ) Not too much ( ) Somewhat ( ) Very much ( ) EXTREMELY much
25. Some siblings play around and have fun with each other a lot, while other siblings play around and have fun with each other a little. How much do you and this sibling play around and have fun with each other?
( ) Hardly at all ( ) Not too much ( ) Somewhat ( ) Very much ( ) EXTREMELY much

26. How much are you and this sibling mean to one another?
() Hardly at all () Not too much () Somewhat () Very much () EXTREMELY much
27. How much do you and this sibling have in common?
( ) Hardly at all ( ) Not too much ( ) Somewhat ( ) Very much ( ) EXTREMELY much
28. How much do you and this sibling share secrets and private feelings?
() Hardly at all () Not too much () Somewhat () Very much () EXTREMELY much
29. How much do you and this sibling compete with each other?
( ) Hardly at all ( ) Not too much ( ) Somewhat ( ) Very much ( ) EXTREMELY much
30. How much do you look up to and feel proud of this sibling?
( ) Hardly at all ( ) Not too much ( ) Somewhat ( ) Very much ( ) EXTREMELY much

31. How much does this sibling look up to and feel proud of you?
( ) Hardly at all ( ) Not too much ( ) Somewhat ( ) Very much ( ) EXTREMELY much
32. How much do you and this sibling get mad and get in arguments with each other?
() Hardly at all () Not too much () Somewhat () Very much () EXTREMELY much
33. How much do both you and your sibling share with one another?
() Hardly at all () Not too much () Somewhat () Very much () EXTREMELY much
34. Who does your mother usually favor you or this sibling?
<ul> <li>() My sibling is almost always favored</li> <li>() My sibling is often favored</li> <li>() Neither of us is favored</li> <li>() I am often favored</li> <li>() I am almost always favored</li> </ul>
35. How much do you teach this sibling things that he or she doesn't know?
( ) Hardly at all ( ) Not too much ( ) Somewhat ( ) Very much ( ) EXTREMELY much

36. How much does this sibling teach you things that you don't know?
( ) Hardly at all
() Not too much
() Somewhat
() Very much
() EXTREMELY much
37. How much do you order this sibling around?
( ) Hardly at all
() Not too much
() Somewhat
() Very much
() EXTREMELY much
38. How much does this sibling order you around?
( ) Hardly at all
() Not too much
() Somewhat
() Very much
() EXTREMELY much
39. Who does your father usually favor, you or this sibling?
() My sibling is almost always favored () My sibling is often favored () Neither of us is favored () I am often favored
( ) I am almost always favored

## **APPENDIX P: Demographic Questionnaire**

#### GENERAL QUESTIONNAIRE FOR PARENTS

First we would like to ask you some questions about your family.

1.	Please compl	lete the following	information abou	at all members of your household
	Name	<b>:</b>	Sex	Date of Birth
Father	r			
Mothe	er			
Child				
Child_				
Child	<del> </del>		·····	
langua chron				th autism, Down's syndrome, a roblem, attentional problem or a
3. If Y		rific illness(es) or	type of problem(	s) and which child(ren) is/are
	Name	Type of	Problem	
	ou have a chile E (attached).	d with Down's sy	ndrome autism pl	ease complete questions 1-16 on

5. Are any of your children add	opted?
Yes No	<del></del>
6. If YES, specify which child	(ren) is/are adopted.
Name	
7. What is your annual family	income?
below 10,000	51,000-60,000
10,000-20,000	61,000-70,000
21, 000-30,000	71,000-80,000
31,000-40,000	81,000-90,000
41,000-50,000	91,000-100,000

FOR M	NOTHER:		
8. Wha	at is your present marital status? (pleas	se check all	that apply)
	Married		Separated
	Living with someone	I	Never married and not living with someone
	Divorced		Widowed
9. Fron	n the list below, please indicate the hi	ghest level o	of education that you completed.
a)	No high school		
b)	Some high school		
c)	High school diploma		
d)	Some post-secondary, but no diploma	_	
e)	Post-secondary diploma (e.g., technic	cal)	
f)	University degree		

10. What is your occupation?

	Married	Separated
	Living with someone	Never married and not living
	Divorced	with someone Widowed
a)	from the list below, please indicate t	he highest level of education that you complete
	rom the list below, please indicate t	The state of the s

## APPENDIX Q: Adaptive Behavior Questionnaire

# FORM FOR PARENTS OF CHILDREN WITH AUTISM OR DOWN SYNDROME

Please answer the following questions about your child's abilities and level of independence.

1. What is the name and age of your chi	ald with autism or Down's syndrome?
Name	Age
	<del>-</del>
	<del></del>
2. What is this child's I.Q., mental age, a specify.	and/or degree of disability (if known), please
3. What grade is your child in at school	?
4. At grade level or age level does your	child currently perform at in school?
5. Have you received any special service placement in special classes, teachers ai	es from the school system for this child such as id. Please specify.
6. Have you received any other types of services, assistance of a professional car Please specify.	f support services for this child such as respite regiver in the home etc.

7. Can your child comm	unicate with others through spoken language (or sign language)?
Yes	No
8. Does your child use so	entences of four or more words?
Yes	No
9. Can your child comm	unicate his/her wants or needs to others?
Yes	No
10. Can your child read?	
Yes	No
·	l, at what grade level are they currently reading at?
	write his or her first name?
Yes	No
13. Can your child follo	w simple instructions given to them by a parent?
Yes	No
14. Can your child dress	his/herself completely?
Yes	No
15. Can your child tie sh	oelaces into a bow without assistance?
Yes	No
16. Can your child feed	nis/herself with a fork or spoon?
Vec	No

## **APPENDIX R: Sibling Perceptions Questionnaire**

.

#### SIBLING PERCEPTIONS INTERVIEW QUESTIONS

- 1. Do you think others know how it is to have your brother/sister as a sibling?
- 2. How do you explain to others what is different about your brother/sister?
- 3. Do they understand?
- 4. Have you got anybody that you feel you can talk to about your brother/sister?
- 5. With whom do you talk?
- 6. Have you ever attended a group for children who have brothers or sisters with autism or Down's syndrome?
- 7. Do you have any friends that have brothers or sisters that have Autism or Down's syndrome.

APPENDIX S: Correlations Between Demographic and Dependent Variables for Younger Siblings in the Entire Sample

	Number	Sibling's	Disabled	Family	Fathers'	Mothers'
	Children	Age	Child's Age	Income	Education	Education
Total						
Competency	.03	23	20	.21	.05 .	17
Activeness	.05	42	30	.21	.32	53
Social						
Competence	.09	15	13	.31	070	3
Academic	16	.17	.15	29	182	25
Total						
Adjustment	24	09	04	.18	.30	29
Externalizing	18	.01	.06	.07	.23	21
Internalizing	06	09	12	.19	.36 .	32
Withdrawn	20	29	32	13	.03 .0	08
Somatic	.03	.14	.11	.54	.49	22
Anxious/						
Depressed	11	08	08	.22	.37 .	35
Social Problem	n15	.07	.00	.20	.25	23
Thought						
Problems	.10	21	13	.33	.18 .	16

	Number of	Sibling's	Disabled	Family	Fathers'	Mothers'
	Children	Age	Child's Age	Income	e Education	n Education
Attention						
Problems	03	10	05	.19	.33	.31
Delinquency	06	19	15	.00	.10	.14
Aggression	17	09	05	.28	.43	.36
Social Support						
from Parents	10	23	24	.26	.46	76**
Social Support						
from Teachers	.18	02	.01	11	.11	.15
Social Support						
from Friends	.34	.10	.07 -	.10	.40	.10
Social Support						
from Classmate	:09	26	35	.11	.24	.46
Loneliness	.21	.34	.46	10	23	49
Closeness Facto	or08	09	.05	.25	.41	.39
Power Factor	.09	19	36	.32	08	08
Conflict Factor	70**	.01	14	.24	09	.04
Rivalry Factor	38	11	24	.14	.08	.16

<sup>\*</sup>p<.01. \*\*p<.001.

# APPENDIX T: Correlations Between Demographic and Dependent Variables for Older Siblings in the Entire Sample

	Number	Sibling's	Disabled	Family	Fathers'	Mothers'
	Children	Age	Child's Ag	e Income	Education	on Education
Total					<del> · .</del>	<del></del>
Competency	.09	09	05	.38**	.30*	.35*
Activeness	.10	08	06	.32*	.19	.31**
Social						
Competence	13	12	14	.28*	.30*	.25
Academic	.11	.12	.15	.13	.07	.08
Total						
Adjustment	14	.09	.04	05	15	03
Externalizing	16	.19	.16	.00	16	02
Internalizing	12	01	.03	06	07	.01
Withdrawn	08	02	12	.05	08	08
Somatic	03	02	02	10	14	14
Anxious/						
Depressed	13	.04	.01	03	05	05
Social Problem	12	07	19	02	.01	.01
Thought						
Problems	05	10	11	.05	03	03

····	Number of	Sibling's	Disable	d Far	nily Fat	thers' Mothers'
	Children	Age	Child's	Age Inc	ome Edu	cation Education
Attention			- <del></del>	<del></del>		
Problems	06	03	07	.12	.01	.01
Delinquency	13	.01	.02	03	.01	.01
Aggression	14	.21	.13	01	07	.05
Social Support						
from Parents	01	10	06	05	05	.07
Social Support						
from Teachers	15	26	.02	.07	06	.00
Social Support						
from Friends	21	.09	01	07	01	09
Social Support						
from Classmate	s09	.02	.11	.03	10	08
Loneliness	02	06	.05	04	19	20
Closeness Facto	or .10	24	05	04	.16	.11
Power Factor	.12	41**	25	.06	.00	16
Conflict Factor	15	.03	.03	.09	.05	02
Rivalry Factor	.02	39**	.07	.05	.04	.01

<sup>\*</sup>p<.01. \*\*p<.001.

# APPENDIX U: Correlations Between Psychosocial Variables for Younger Siblings in the Entire Sample

	Loneliness	Social Support Parents	Social Support Teachers	Social Support Friends	Social Support Classmates
Loneliness	-	37	20	30	70**
Total					
Competency	.42	.24	.01	22	06
Activeness	.01	.33*	.50	.01	.34
Social					
Competence	.49	02	.04	28	21
Academic	.36	.15	55	.02	36
Total					
Adjustment	51	17	11	01	05
Externalizing	40	02	.36	.04	.30
Internalizing	51	07	.04	.52	.31
Withdrawn	22	24	10	04	.07
Somatic	.03	.06	02	.28	06
Anxious/					
Depressed	56*	01	.12	.43	.39
Social Proble	m29	.04	06	.08	.07
Thought					
Problems	26	.06	.21	.21	.17

	Loneliness	Social Support Parents	Social Support Teachers	Social Support Friends	Social Support Classmates
Attention					
Problems	39	.12	.21	.22	.34
Delinquency	42	06	.46	.20	.37
Aggression	37	.07	.31	.14	.32

<sup>\* &</sup>lt;u>p</u><.01. \*\*<u>p</u><.001

# APPENDIX V: Correlations Between Psychosocial Variables for Older Siblings in the Entire Sample

	Loneliness	Social Support Parents	Social Support Teachers	Social Support Friends	Social Support Classmates
Loneliness	-	40**	14	42**	57**
Total					
Competency	30*	.23	.28*	.01	.19
Activeness	21	.31*	.22	.03	.04
Social					
Competence	07	02	.19	05	.08
Academic	21	.13	.14	.06	.31*
Total					
Adjustment	.25	17	05	01	05
Externalizing	.12	27	21	.12	.10
Internalizing	.26	08	.02	10	10
Withdrawn	.21	14	.08	19	04
Somatic	.07	12	01	.04	17
Anxious/					
Depressed	.14	06	03	06	.04
Social Probler	ns .27	12	22	01	27
Thought					
Problems	.18	.03	01	.01	01

	Loneliness	Social Support Parents	Social Support Teachers	Social Support Friends	Social Support Classmates
Attention		······································			<del></del>
Problems	.20	07	15	06	17
Delinquency	03	.02	.03	.11	.23
Aggression	.01	19	26	.12	.13

<sup>\*</sup> p<.01. \*\*p<.001

APPENDIX W: Correlations Between SRQ Factors amd Psychosocial Variables for Younger Siblings in the Entire Sample

	SRQ Closeness/ Intimacy Factor		SRQ Conflict Factor	SRQ Rivalry Factor
Total				
Competency	.31	25	03	.37
Activeness	.21	26	35	.16
Social				
Competence	.00	27	.10	.49
Academic	08	22	.19	.10
Total				
Adjustment	.32	.03	.05	17
Externalizing	.20	06	.08	05
Internalizing	.24	.12	08	46
Withdrawn	.03	.01	.06	12
Somatic	.23	15	.18	10
Anxious/				
Depressed	.29	.19	10	33
Social Problems	.13	34	.46	.45
Thought				
Problems	.35	.32	37	58*

	SRQ Closeness/ Intimacy Factor	SRQ Power Factor	SRQ Conflict Factor	SRQ Rivalry Factor
Attention		-		
Problems	.40	.02	07	.00
Delinquency	.06	.18	07	24
Aggression	.22	02	.01	09
Loneliness	15	.04	.06	15
Social Support	t			
Parents	.24	17	14	.29
Social Support	t			
Teachers	.19	06	41	.05
Social Support	t			
Friends	.38**	.08	48	31
Social Support	t			
Classmates	.36*	09	29	.13

<sup>\*</sup> p<.01. \*\* p<.001.

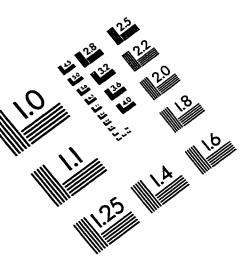
APPENDIX X: Correlations Between SRQ Factors amd Psychosocial Variables for Older Siblings in the Entire Sample

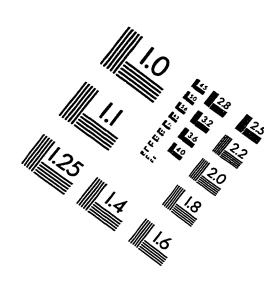
	SRQ Closeness/ Intimacy Factor	-	SRQ Conflict Factor	SRQ Rivalry Factor
Total				
Competency	.13	.01	10	.06
Activeness	.04	.04	.08	.10
Social				
Competence	.01	01	07	.06
Academic	.12	.12	21	10
Total				
Adjustment	25	01	.10	.06
Externalizing	14	.06	.04	08
Internalizing	25	06	01	.17
Withdrawn	20	04	09	.13
Somatic	16	07	02	.09
Anxious/				
Depressed	11	.00	02	.03
Social Problems	13	20	.19	.06
Thought				
Problems	16	.03	.18	.14

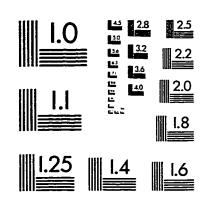
	SRQ Closeness/ Intimacy Factor	-	SRQ Conflict Factor	SRQ Rivalry Factor
Attention				
Problems	20	11	.13	.00
Delinquency	01	.06	04	03
Aggression	05	.09	04	17
Loneliness	36**	.04	.16	10
Social Support				
Parents	.24	17	04	.30*
Social Support				
Teachers	.19	06	14	.18
Social Support				
Friends	.38**	.08	19	01
Social Support				
Classmates	.36*	09	02	.05

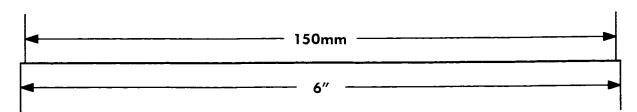
<sup>\* &</sup>lt;u>p<.01</u>. \*\* <u>p<.001</u>.

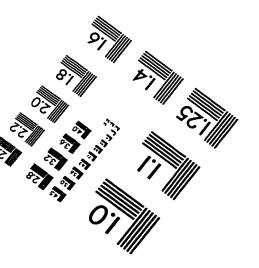
# IMAGE EVALUATION TEST TARGET (QA-3)













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