SIBLINGS OF CHILDREN WITH AUTISM: PSYCHOSOCIAL ADJUSTMENT AND THE EVALUATION OF GROUP INTERVENTION

by

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A thesis submitted in conformity with the requirements for the degree of Master of Arts
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Siblings of Children with Autism:  
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of Group Intervention  

Degree of Master of Arts, 2000  
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Abstract  
The present study\(^1\) examined whether siblings of children with autism were at risk for  
experiencing psychosocial adjustment difficulties, and whether severity of the child’s disability  
and siblings’ knowledge of autism were related to siblings’ adjustment. This study also  
systematically evaluated the effectiveness of a sibling support group. Participants included 31  
siblings of children with autism, between ages 6 to 16, that received group intervention. Results  
indicated that these siblings exhibited significantly more internalizing problems than average, but  
did not show more externalizing behaviours, total problem behaviours, or poor self-concepts. In  
this group, there were no significant relationships between severity of the child’s disability and  
siblings’ knowledge of autism with siblings’ psychosocial adjustment. However, siblings did  
significantly improve their self-concepts and knowledge of autism from the beginning to the end  
of the sibling support group. Clinical implications are discussed and directions for future  
research are presented.  

\(^1\) These data were collected as part of the ongoing study, “Sibling Groups for Siblings of Autistic Children” of the  
Treatment, Research and Education for Autism and Developmental Disorders (TRE-ADD) Program at Thistletown  
Regional Centre, investigated by Dr. Adrienne Perry and her collaborators.
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CHAPTER 1: INTRODUCTION

Everyone in a family is affected when one of the children has a disability. Therefore, the impact on siblings of children with disabilities becomes an important area for clinical and research focus. Interest in examining the siblings of children with disabilities began for many researchers and clinicians with the assumption that these siblings experience greater stress than most siblings, thereby being at greater risk for having psychosocial adjustment problems (Lobato, 1983; see also McHale, Simeonsson, & Sloan, 1984; McKeever, 1983). Past research and clinical observations have identified a variety of circumstances that are believed to contribute to siblings' psychosocial adjustment difficulties (Hannah & Midlarsky, 1985; Seligman, 1983).

In the following introduction, I first discuss the factors that have been noted in the literature to be associated with risk of psychosocial adjustment problems for siblings of children with disabilities (e.g., emotional and behavioural problems, self-concept). I then go on to review the few studies that have examined siblings of children with autism in particular. In addition to summarizing the literature on psychosocial adjustment, I consider the influence of two factors I believe to be important based on clinical work with this population: severity of the child's disability and siblings' knowledge of autism. Finally, since the present study is derived from an evaluation of a clinical service, I present the empirical literature describing sibling support groups and their evaluation.

Siblings of children with disabilities often experience a decrease in parental attention because parents become preoccupied with meeting the needs of the child with a disability (Hannah & Midlarsky, 1985). Given that parents often need to devote a lot of their time and energy to the child with the disability, siblings may be burdened with excessive child-care and household responsibilities (see reviews by Hannah & Midlarsky, 1985; Lobato, 1983;
As a result of the siblings' responsibilities in the home, they may miss out on important relationships and experiences outside of the home (Seligman, 1983), for example, spending time with peers after school. A study by McHale and Gamble (1989) found that siblings of children with mental retardation reported spending more time in care-giving activities and chores than siblings of children with no disabilities. The sisters of children with mental retardation reported spending the most time in such activities. Most important however, McHale and Gamble (1989) found that the amount of time siblings spent in care-giving activities was significantly related to anxiety, with siblings that spent more time in care-giving activities reporting more symptoms.

Not only may siblings feel burdened by their responsibility for child-care and household activities, but they may also feel ignored and unappreciated for their accomplishments (Seligman, 1983). Some clinicians and researchers have suggested that parents have higher expectations for typically developing siblings to succeed in order to compensate for the limitations of the child with the disability (Hannah & Midlarsky, 1985; Seligman, 1983). Such expectations may produce resentment and anxiety for the sibling (Meyer & Vadasy, 1994). Furthermore, siblings may place very high expectations on themselves for excelling in areas such as academics and athletics (McHale et al., 1984) which, for some siblings, may be motivated by the quest for parental attention (Meyer & Vadasy, 1994). It has also been suggested that siblings may experience "role tension", independent of birth order, as the child with the disability essentially becomes the "youngest" family member as a result of his/her degree of dependency (McHale et al., 1984; see review by Simeonsson & McHale, 1981).

All of the factors described above, such as loss of parental attention, increased responsibilities, and pressure to achieve, may lead siblings to develop feelings of anger and resentment that could, in turn, lead to psychosocial maladjustment (McHale & Gamble, 1989;
Meyer & Vadasy, 1994; Seligman, 1983). Siblings may then feel guilty for having these feelings about a brother or sister that has special needs (McHale & Gamble, 1989).

As a result, researchers and clinicians have examined whether there is any truth to the commonly held belief that siblings of children with various disabilities are at higher risk for having psychosocial adjustment difficulties. Research studies have yielded inconsistent findings. Some studies have found that siblings with a brother or sister with a disability do not exhibit more adjustment difficulties than siblings of children with no disability (Ferrari, 1984; Hannah & Midlarsky, 1999). Other studies have found that siblings of children with a disability do have poorer psychological adjustment, such as externalizing (e.g., hyperactivity, conduct problems) and/or internalizing problems (e.g., anxiety, depression), than siblings of children without a disability (Breslau & Prabucki, 1987; Lobato, Barbour, Hall, & Miller, 1987; McHale & Gamble, 1989; Tew & Laurence, 1973; Tritt & Esses, 1988).

The discrepancy in findings across studies may be accounted for by several methodological differences. Such differences include studying varying populations (e.g., Mental Retardation, Down Syndrome, and Spina Bifida), use of different methodologies (e.g., standardized tests, and interviews), and use of different outcome measures (adjustment measures such as emotional problems, behavioural problems, and self-concept, and personality measures) (Fisman et al., 1996; McHale et al., 1984; McHale, Sloan, & Simeonsson, 1986; McKeever, 1983). These discrepancies make it difficult to make comparisons across studies, generalize findings, and determine whether siblings of children with disabilities are at increased risk for having adjustment problems.

In addition to methodological differences, the studies cited above relied on the reports of the parents, usually the mother, which is a limitation prevalent in the research literature (Fisman et al., 1996; McKeever, 1984; McHale et al., 1986). There are several problems associated with relying on parental reports, since they may be influenced by parents' tolerance of child aberrant
behaviour, the depth of knowledge they have about the typicality of behaviours displayed by the siblings, and their willingness to admit the siblings’ difficulties to non-family members (Tew & Laurence, 1973). Therefore, when examining siblings’ psychosocial adjustment, it is extremely important to obtain self-report information from the siblings themselves in addition to information from others, such as teachers.

In addition to examining internalizing and externalizing difficulties, some researchers have examined siblings’ self-concepts as indicative of their adjustment. Self-concept can be described as a relatively stable set of self-attitudes reflected by an individual’s perceptions of being capable, significant, successful, and worthy with respect to his/her behaviours and attributes (Auletta & DeRosa, 1991; Piers & Harris, 1984). The clinical assumption underlying research on self-concept in siblings has been based on anecdotal reports that siblings over-identify with their handicapped brother or sister (Ferrari, 1984; Meyer & Vadasy, 1994; Simeonsson & McHale, 1981; Wilson, Blacher, & Baker, 1989). Siblings know that they are in some ways similar to their brother or sister, such as sharing similar physical characteristics (e.g., hair and/or eye colour), as well as sharing the same parents and last name, and therefore may become concerned with how many characteristics they actually have in common (McHale et al., 1984; Simeonsson & McHale, 1981). As a result of these concerns, over-identification may follow, whereby siblings wonder whether they also share the child’s problems (Meyer & Vadasy, 1994), internalize the features of the child’s disability, and develop self-concept problems.

McHale and Gamble (1989) examined the self-esteem of 62 children using the Harter Perceived Competence Scale. Half of the children had a younger sibling with mental retardation, while the other half had a younger sibling with no identified disability. The results indicated that the groups differed significantly on the subscales of perceived social acceptance and perceived conduct. Siblings of children with mental retardation scored significantly lower than siblings of children with no disability on their perceptions of their social acceptance and behavioural
conducted. Also, sisters of children with disabilities reported lower global self-worth than sisters of children without a disability and the brothers of children from either group. In contrast to these findings, other studies have consistently found that siblings’ self-concepts are similar to those of siblings of children with no disability (Auletta & DeRosa, 1991; Hannah & Midlarsky, 1999; Lobato et al., 1987; Tritt & Esses, 1988).

**Psychosocial Adjustment of Siblings of Children with Autism**

Interest in examining the psychosocial adjustment of siblings of children with autism in particular has been increasing in the last several years. Examining literature on parents that have children with autism may help explain why the very nature of autism may place siblings at even greater risk for poor psychosocial adjustment than siblings of children with other disabilities. The child with autism often appears normal physically; therefore it may be unclear to family members and the community whether or not the child has a disability (Bristol, 1984). When a child with autism then exhibits disruptive, rigid and stereotyped behaviours, parents may feel inadequate as caregivers, rather than attributing the behaviours to the characteristics that define autism. Furthermore, the community may view the child’s behaviours as a consequence of poor child rearing by the parents, subsequently contributing to parents’ feelings of inadequacy and resulting in greater family stress (Bristol, 1984). In addition, children with autism show marked impairment in their social interactions and communication with others, thereby making it difficult to relate to members in the family (Bristol, 1984).

Fisman et al. (1996) found parents of children with Pervasive Developmental Disorders (PDD) reported significantly higher levels of distress and depression in comparison to parents of children with Down Syndrome or no disability. The higher levels of distress reported by both mothers and fathers of PDD children were described as related to the inability of the children to adapt to environmental change as well as being extremely demanding, due to the frequency and severity of the child’s behaviour problems. Therefore, it may be assumed that siblings are
exposed to high levels of stress in the family (Fisman et al., 1996), as well as having a “qualitatively” different relationship than other siblings would have with one another (e.g., more impoverished interactions as a result of social and communication difficulties). Moreover, they face the same issues that other siblings of children with disabilities face, perhaps to a greater extent (e.g., increased responsibilities, decreased parental attention, and changes in family roles), potentially resulting in increased risk for psychosocial adjustment problems.

Studies have started to explore the unique difficulties siblings of children with autism may face. Bagenholm and Gillberg (1991) reported that siblings of children with autism experienced more problems with their brother/sister bothering them and breaking their things than siblings of children with either mental retardation or no disability. In addition, Roeyers and Mycke (1995), using the Sibling Inventory of Behaviour, found that siblings of children with autism reported feeling more embarrassment than siblings of children with mental retardation or a control group.

Some researchers found that siblings of children with autism exhibited a greater number of either emotional or behavioural problems than siblings of children from a control group. Bagenholm and Gillberg (1991) found that siblings of children with autism (n = 20) and mental retardation (n = 20) were reported by their mothers to exhibit significantly more problems in the areas of inattention/hyperactivity and conduct problems on the Rutter parent questionnaire than siblings of children with no disability (n = 20). Gold (1993) examined whether 22 siblings of boys with autism were exhibiting more psychosocial difficulties, including depression, compared to a control group of 34 siblings of boys with no disability. In contrast to the results found by Bagenholm and Gillberg (1991), Gold (1993) found no significant differences for behaviour problems for siblings of children with autism compared to the control group using parents’ reports on the Child Behavior Checklist (CBCL). However, siblings of boys with autism scored significantly higher on the Childhood Depression Inventory (CDI) than the comparison group.
Based on the most conservative cutoff score of 13, 50% of siblings of boys with autism were in the depressed range compared to only 26% in the comparison group. Gold (1993) also found that adolescent siblings over 12 years of age scored significantly higher on the CDI than siblings under age 12. One must interpret these results carefully since there were proportionately more adolescents in the autistic group, although there was not a significant age difference between the two groups.

Studies comparing the psychological functioning of siblings of children with autism/PDD, Down Syndrome, or no handicap found that siblings of children with autism were reported by parents, using the Child Behavior Checklist or the Survey Diagnostic Instrument, to exhibit a greater number of both externalizing and internalizing behaviour problems than siblings of children with no disability (Fisman et al., 1996; Rodrigue et al., 1993). However, there were no significant differences for internalizing or externalizing behaviours between the siblings of children with autism or Down Syndrome. Fisman et al. (1996) also found that teachers reported significantly more internalizing problems for siblings of children with autism than for siblings of children with either Down syndrome or no disability. Although Rodrigue et al. (1993) found siblings of children with autism exhibiting more internalizing and externalizing problems, their scores as a group were not in the clinical range.

Therefore, based on the studies investigating the psychological functioning of siblings of children with autism, it appears that they are at greater risk for exhibiting adjustment problems. However, it is not certain whether they exhibit more externalizing difficulties, more internalizing difficulties, or both. Although these more recent studies have stronger methodologies (e.g., use of a comparison and/or control group), the inconsistencies are likely the result of some of the same methodological limitations that have prevailed in the research literature. For example, apart from Fisman et al. (1996), the studies are comprised of relatively small clinical samples. Furthermore, all the studies include participants of varying ages, and use different measures to
examine siblings' psychosocial adjustment. However, the findings from Fisman et al. (1996) and Rodrigue et al. (1993) may be viewed as making a stronger case for their results. These researchers examined the adjustment of siblings of similar ages, used psychometrically sound measures, included both a comparison and control group and Fisman et al. included multiple respondents.

Researchers have also investigated the self-concepts of siblings of children with autism as indicative of their psychosocial adjustment. Two studies examining the self-concepts of children who had siblings with autism, siblings of children with mental retardation/Down Syndrome, and siblings of children with no disability (Bagenholm & Gillberg, 1991; Rodrigue et al., 1993) have found no significant differences between the groups on self-concept. Moreover, Bagenholm and Gillberg (1991) found that all groups attained mean scores close to the standardization sample reported in the Piers-Harris manual.

Mates (1990) wanted to assess whether gender of the sibling or family size played a role in the self-concepts of siblings of children with autism. The Piers-Harris Self-Concept Scale was administered to 33 siblings of children with autism. There were no significant differences in self-concept between males and females or between siblings from two-child and multi-child families. Also, none of the groups had scores that were significantly different from those of the normative sample reported in the Piers-Harris manual.

While findings to date suggest that siblings of children with autism as a group have average self-concepts similar to siblings of children with other disabilities or no handicap, there remain relatively few studies that have examined this issue. This is surprising given that clinicians suggest, based on anecdotal reports, that siblings have difficulty establishing their own identity, and may internalize the features of the disability (Meyer & Vadasy, 1994). As a result, clinicians have felt that improving self-concept is an important and necessary goal for sibling support groups (Meyer & Vadasy, 1994). Therefore, more research is needed in order to confirm
or disconfirm these assumptions, and studies should incorporate self-concept as an important indicator of siblings' overall psychosocial adjustment.

**Severity of Disability**

Researchers have discussed the possibility that severity of a child's disability may be a characteristic that is related to siblings' psychosocial adjustment (Breslau, et al., 1981; Gold, 1993), with past findings suggesting that siblings are more adversely affected when the child's disability is more severe (see reviews by McHale et al., 1984; Powell & Ogle, 1985; Simeonsson & McHale, 1981). The expectation has been that parents will need to devote even more time and attention to care for the child's needs when the disability is severe, resulting in less attention and resources for the siblings (Breslau et al., 1981; Tew & Laurence, 1973), and greater child-care and household responsibilities (Hannah & Midlarsky, 1999). However, support for this finding has been drawn from studies of siblings of children with mental retardation (Vadasy, Fewell, Meyer, & Schell, 1984).

Breslau et al. (1981) examined the linear relationship between mothers' ratings of siblings' psychological functioning, using the Psychiatric Screening Inventory, and severity of the children's disability. Severity of disability was measured using a 6-item Level of Disability Scale based on the extent to which the disabled child needed help in eating, dressing, washing, toileting, going up/down stairs, and going outside. The sample included 239 siblings, ages 6 to 18 years, of children with various disabilities (cystic fibrosis, cerebral palsy, myelodysplasia, and multiple handicaps). In contrast to past research, Breslau et al. (1981) found no linear relationship between the total score on the Psychiatric Screening Inventory and severity of disability.

Tew and Laurence (1973) investigated the psychosocial maladjustment of 44 siblings of children with spina bifida. Maladjustment was measured using the total score from the Bristol Social Adjustment Guide, using teacher reports of school behaviour. Severity of disability was
divided into three groups based on an indicator of physical symptoms: slight handicap (e.g., slight limp or squint); moderate handicap (e.g., needing splinting or bracing); severe handicap (e.g., chair-bound or bed-ridden). Although children’s cognitive functioning had been measured, it was not used as a determinant of severity of disability. Tew and Laurence (1973) did not find a significant linear relationship between siblings’ psychosocial maladjustment and severity of disability. However, they did find a nonlinear relationship with siblings of children with slight handicaps and severe handicaps showing higher maladjustment scores than the siblings of children with moderate handicaps.

The study by Tew and Laurence (1973) is a classic study often quoted in the literature when discussing the relationship between disability severity and psychosocial adjustment. Their findings suggest that there may not be a simple linear relationship between the severity of a child’s disability and the adjustment of siblings (Lobato, 1983). Some researchers have proposed that siblings are more poorly adjusted when the child’s disability is ambiguous or undefined (Gold, 1993; McHale et al., 1984). Based on the parent literature, Bristol (1984) suggested that parents of children with less severe forms of autism may experience greater stress because there is more uncertainty as to the nature and cause of the child’s behaviours, greater difficulty setting realistic expectations for the child, and they may encounter less community acceptance and support. For similar reasons, siblings of children with mild autism may experience more psychosocial adjustment difficulties. Given that siblings may not be able to recognize what is wrong with their brother or sister, they may feel that the differential treatment afforded to the child with a disability is a result of parental favouritism rather than the child’s special needs (Hannah & Midlarsky, 1985).

Studies investigating the relationship between severity of disability and siblings’ psychosocial adjustment are sparse, have mixed findings depending on the population studied, have different definitions of what constitutes severity, and are not based on standardized
measures of severity. In fact, the measures of severity often involve use of a nominal scale with a limited range, and confound physical disability with the degree of developmental delay. In addition, there are currently no studies that have examined this relationship when the child has autism. Therefore, research is needed in order to examine the relationship between the severity of children's disabilities and siblings' psychosocial adjustment using standardized measures.

Knowledge of Disability

The inability to understand or explain to others the nature of their brother or sister's disability may be an obstacle for siblings' acceptance of the disability (Howlin & Yates, 1990). One of the implications when siblings do not have knowledge of their brother or sister's disability is that they may create their own stories for explaining the behaviours exhibited by the child with the disability (Meyer & Vadasy, 1994). These explanations may be erroneous, resulting in unnecessary worries (e.g., I could catch autism), thereby creating anxiety and stress. i.e., psychosocial adjustment difficulties.

Chinitz (1981) found that siblings of children with disabilities (cerebral palsy, mental retardation, or multiple handicaps) had very little information about disabilities. In the beginning of a sibling support group, only one child demonstrated any knowledge of his sibling's disability. Howlin and Yates (1990) held a one-day sibling group for siblings of children with autism. At the beginning of the sibling group, 10 children aged 10 to 16 were asked about their general knowledge of autism. Consistent with the findings by Chinitz (1981), half of the children answered "I don't know" to the question "What is autism?" Only two children described autism as being caused by brain damage or abnormal brain processes. When asked the same question at the end of the day, over half of the children responded that autism was an abnormality of the brain or brain processes.

Lobato et al. (1987) conducted a more systematic evaluation of 46 preschool-aged children's understanding of developmental disabilities. The control group included 22 siblings
of children with no disability, while the experimental group included 24 siblings of children with a disability (spina bifida, cerebral palsy, Down syndrome, profound hearing loss, blindness, William syndrome, congenital hydrocephalus, mental retardation). The children's definitions of disability terms using the Family Role Play Assessment were coded as accurate, inaccurate, or partially accurate. There were no significant differences found between the groups in understanding of developmental disabilities. Therefore, having a sibling with a disability did not result in any more knowledge about disabilities than siblings of a child without a disability. In fact, Lobato et al. (1987) found that most siblings of children with disabilities could not accurately describe their own sibling's disability.

Roeyers and Mycke (1995) examined understanding of autism in 20 siblings of children with autism. The 30-item true or false “Knowledge of the Autistic Syndrome” questionnaire was mainly based on the DSM-III-R information. In contrast to other studies, the authors found that the siblings had a fair understanding of the autistic syndrome, with a mean total score of 81% correct, and only one subject scoring lower than 50%. However, two components created difficulty for the children: many overestimated the prevalence of autism as well as the cognitive abilities of the child with a disability. The siblings in the study may have had a greater knowledge of autism due to the fact that they were from families who were members of a parents' association. Roeyers and Mycke (1995) presumed that parents' communication within the family about the disability would influence siblings' knowledge. Interestingly, knowledge of autism was independent of the sibling's age. One might have expected that as siblings got older they would have gained more knowledge of autism.

Roeyers and Mycke (1995) also investigated whether knowledge of autism was related to quality of the sibling relationship assessed with the Sibling Inventory of Behaviour. The siblings completed this 24-item questionnaire by rating the frequency (1 = never to 5 = always) with which they engage in certain positive and negative behaviours towards their brother/sister with
the disability. This questionnaire has a total score representing the quality of the sibling relationship, and is comprised of four subscales: acceptance-rejection; warmth-hostility; contact-leadership; and embarrassment. Roeyers and Mycke (1995) found that children with a greater understanding of autism, in particular, knowledge about the etiology of autism, had more positive sibling relationships.

Besides the study by Roeyers and Mycke (1995), the literature is lacking any systematic research on what information siblings have about autism and their understanding of this information. The majority of the studies that exist have asked one or two very general questions to tap siblings’ knowledge of disabilities. In addition, there are no studies that have examined the degree to which knowledge of autism may be related to psychosocial adjustment. Those children with a greater knowledge of autism may be protected from having adjustment difficulties. Since they will better understand autism, they won’t need to create their own erroneous explanations for the behaviours exhibited by the child with the disability. Also, their understanding of their brother or sister’s behaviours may lead to a more positive sibling relationship.

Evaluation of Sibling Groups

While there is some literature describing sibling support groups in clinical settings, there is little research that has examined the potential benefits of sibling support groups in a more systematic empirical fashion, apart from Lobato (1985). Many clinicians and service providers working with children with autism and their families tend to offer, at most, group interventions, assuming that sibling groups may be an effective means to providing support and information to siblings of children with disabilities (Ferrari, 1984; Howlin & Yates, 1990; Lobato, 1985; McKeever, 1983; Roeyers & Mycke, 1995; Summers, Bridge, & Summers, 1991).

The sibling support groups reported in the clinical literature share several similarities. Many of the goals include providing information on disabilities to improve siblings’
understanding, discussing problems encountered and adaptive ways of coping, and encouraging siblings to express their feelings about having a brother/sister with a disability. In meeting the goals of the groups, the leader(s) guide the discussion, activities are structured, a selection of movie clips and books are used to illustrate specific points, and role-play is used as a way to assist in problem solving (Chinitz, 1981; Howlin & Yates, 1990; Lobato, 1985; Summers et al., 1991).

However, there are many differences among the sibling support groups as well. One primary difference is in group membership, with some studies reporting on a sibling group for siblings of children with a wide range of disabilities (Chinitz, 1981; Lobato, 1985), and others focusing on siblings of children with one particular disability, such as autism (Howlin & Yates, 1990). The age of the participants in the sibling support groups is another main difference found in the literature. For example, Lobato (1985) held a group for preschoolers, Chinitz (1981) included a wide range of siblings between the ages of 7 to 14, and Howlin and Yates (1990) had siblings between 10 to 14 years in the group. Another difference in the sibling groups reported in the literature includes the number of sessions. For example, Chinitz (1981) reported on a sibling group with eight sessions, Lobato (1985) held a group over six sessions, and Howlin and Yates (1990) held only a one-day session in order to examine whether a more long-lasting sibling group may be beneficial.

Of those studies with published descriptions and evaluations, different methods were used in order to evaluate the benefits of sibling support groups. Chinitz (1981) evaluated a sibling support group qualitatively, by giving anecdotes elicited by the siblings during the groups. Howlin and Yates (1990) examined the potential benefits of a sibling group by having the siblings complete a questionnaire at the beginning and end of the day. The questionnaire included general questions covering various topics, such as knowledge of autism (e.g., “What do you think autism is?”) and future concerns (e.g., “Do you worry about the future?”). Lobato
(1985) used a role-play assessment in order to measure siblings' knowledge of developmental disabilities, as well as the affective quality (e.g. positive, negative, or neutral) of statements they made about themselves, parents, or brother/sister with the disability.

In conclusion, a support group may be an effective forum for siblings to gain age-appropriate information about developmental disabilities, thereby providing the siblings with explanations of their brother or sister's behaviour to peers. Participating in a sibling support group may also help siblings develop their own sense of identity by understanding the differences and similarities between themselves and the child with the disability (McKeever, 1983). Also, a sibling group may offer siblings a place to share experiences with peers in similar situations as well as improve problem solving and coping abilities (Lobato, 1983). However, in order to evaluate the benefits of sibling support groups consistently across studies, more formal and systematic methods for measuring the various goals becomes a necessity.

**Aims of the Current Study**

A primary purpose of the following study is to examine whether siblings of children with autism are at greater risk for experiencing psychosocial adjustment difficulties (e.g., emotional and behavioural problems, and poor self-concepts). Another main purpose of the study is to provide a program evaluation of whether the sibling support groups are an effective means for increasing the siblings' self-concepts, improving their adjustment, and increasing their knowledge of autism.

**Hypotheses of the Current study**

1. The parent(s) of the siblings in this study will report significantly more psychosocial adjustment difficulties than the average score as measured by the Child Behavior Checklist (internalizing behaviours, externalizing behaviours, and total score) and the Piers-Harris Children's Self-Concept Scale (total score).

Support for this hypothesis comes from the studies by Fisman et al. (1996) and Rodrigue
et al. (1993), which found that siblings were reported by their parents to exhibit more internalizing and externalizing behaviours. In addition, the clinical literature has suggested that siblings may be at risk for having poor self-concepts, as they often over-identify with the child with a disability (Meyer & Vadasy, 1994).

2. Severity of the child’s disability (indicators are the Childhood Autism Rating Scale (CARS) and IQ) will be significantly related to siblings’ psychosocial adjustment, as measured by the CBCL (internalizing behaviours, externalizing behaviour, and total score), the Piers-Harris Children’s Self-Concept Scale (total score), and “What It’s Like to Have a Brother or Sister with a Developmental Disorder” (total score). Therefore, siblings of children with a milder disorder (mild severity of autism and less cognitive impairment) will exhibit more externalizing and internalizing behaviour problems, lower self-concepts, and have higher maladjustment scores.

This hypothesis is supported by Tew and Laurence (1973) who found that siblings of children with slight handicaps experienced the greatest amount of psychosocial adjustment difficulties, followed closely by the siblings of children with severe handicaps. Furthermore, siblings, similar to parents, may experience greater stress as a result of the uncertainty of the nature and cause of the child’s behaviours when the autism is mild.

Consequently siblings may exhibit more psychosocial adjustment problems.

3. Siblings’ knowledge of autism will be significantly related to siblings’ age and psychosocial adjustment, measured by the CBCL (internalizing behaviours, externalizing behaviour, and total score), the Piers-Harris Children’s Self-Concept Scale (total score), and “What It’s Like to Have a Brother or Sister with a Developmental Disorder” (total score). The older the siblings’ chronological age, the more knowledge they will have about autism. Furthermore, siblings with more knowledge of autism will exhibit fewer internalizing and externalizing
problems, have higher self-concept scores, and have lower maladjustment scores (e.g. better adjustment).

This hypothesis is based on clinical literature that has found siblings have limited knowledge about disabilities (Chinitz, 1981; Howlin & Yates, 1990; Lobato et al., 1987). As a result, siblings may form inaccurate explanations to explain their brother or sister’s behaviours, develop false beliefs, such as “I could catch autism”, and become worried and anxious, leading to psychosocial adjustment difficulties.

4. Consistent with the goals of the sibling support group, the siblings will significantly enhance their self-concept on the Piers-Harris Children’s Self-Concept Scale from the beginning to end of the group.

5. Given that a particular focus of the sibling support group involves providing siblings with correct, age-appropriate information on autism, they will have significantly more knowledge of autism at post-test on the Autism Knowledge Measure for Young Children.

6. By having siblings share their experiences and the ways they have coped with certain situations unique to having a sibling with autism, it is predicted that they will have lower scores on “What It’s Like to Have a Brother or Sister with a Developmental Disorder” at post-test, thereby exhibiting better adjustment.
CHAPTER 2: METHOD

Participants

The participants for the following study were recruited from families in the TRE-ADD program at Thistletown Regional Centre, who have a child with autism (n = 23) or related disorder (e.g., Pervasive Developmental Disorder, Rett Disorder, or Developmental Delay) (n = 8) and a sibling that received group intervention. Several sibling groups have been run over the past few years for which ethical approval was obtained at Thistletown Regional Centre. In addition, parental consent was obtained for siblings to participate in the research component as well as the sibling support group. The participants in the present study include all the siblings from the sibling groups run at different times in the last several years. Seven of the siblings were in the group more than once, however, only the data from the first time they participated in the group was used in the current study. To ensure that siblings that repeated the group did not differ from siblings that attended the group only once on demographic variables or dependent measures (pre-test), independent t tests were computed for quantitative data and two-way contingency table analyses (using crosstabs) were computed for qualitative data. Using a more conservative alpha level of .01, the two groups did not significantly differ on any of the variables. As a result, 31 siblings of children with autism or related disorders (17 sisters and 14 brothers) between the ages of 6 years, 7 months and 16 years, 3 months ($M = 10.39$, $SD = 2.14$) participated in this study. Eighty-four percent of the siblings in this study completed the group intervention. Results from the independent t tests and two-way contingency table analyses (using crosstabs) indicated that there were no significant differences, at the .01 alpha level, between the siblings that finished the group and those that did not on any of the demographic variables or dependent measures (pre-test). Therefore, siblings that did not complete the group
were used for all analyses in which data were available, which excluded analyses related to the sibling group evaluation.

Seventeen of the siblings were older than the child with autism, 13 were younger, and one sibling was a twin to the child with autism. Twenty-six siblings were from two-parent families, four were from single-parent families, and one was from another family constellation. In terms of the family’s estimated socioeconomic status (SES), 12 families fell into the lower SES category (e.g., did not complete high school, have unskilled or manual labour job), 17 in the middle SES category (e.g., finished high school, maybe some college/university, have job in technical, clerical, sales area or skilled trade), and 2 in the upper SES category (e.g., university or professional degree(s), high level executive or professional occupations like lawyer, dentist). Twenty-nine mothers completed and returned the parent form of the Achenbach Child Behavior Checklist.

Measures

Demographic Information

TRE-ADD Sibling Group Study Summary Sheet. This form was constructed in order to obtain relevant background information. The Family Support and Research staff completed the form before the sibling support group began by obtaining the information from clinical files. Family Support staff provided information on the family (family size, family constellation, and socioeconomic status), as well as information on the sibling taking part in the group (gender, age, and birth order relative to the child with autism). The Research staff obtained information on the child with autism from clinical files as per the parent consent form (gender, age, diagnosis, intellectual functioning, and adaptive behaviour).

Dependent Variables

Childhood Autism Rating Scale (CARS) (Schopler, Reichler, & Renner, 1988)
This is a 15-item instrument developed to measure severity of autism and distinguish children with autism from children with other developmental disabilities or normal functioning. Each item is rated from 1 (normal for age) to 4 (highly abnormal for age and characteristic of severe autism). The scores are summed, yielding a Composite Score ranging from 15 to 60. Scores of 30 or greater are indicative of the presence of autism. The CARS is often administered as part of the psychological assessment, therefore many clinical files contain more than one. The CARS score used for each child was the one measured at the time closest to that of the sibling’s participation in the sibling group.

The CARS is a highly reliable and valid measure of the severity of autism (Schopler et al., 1988). The CARS has high internal consistency, with a coefficient of .94. The test-retest reliability of the CARS is .88, and is therefore a stable measure of the severity of autism over time (approximately one-year interval). The CARS has also been found to have good criterion-related validity, range of .80 to .84, when compared to criterion clinical ratings and the expert clinical judgements of a child psychologist and psychiatrist.

CARS scores were missing for 11 of the children with autism. The CARS was not given as part of the psychological assessment for some of the children with autism, and therefore was not available from the clinical file.

Cognitive Functioning

The IQ scores of the child with autism used in the current study were obtained from the clinical files. The measures that had been administered were most appropriate for clinical purposes, based on the children’s ages and cognitive levels. These included the Wechsler Intelligence Scale for Children – Third Edition, Stanford-Binet Intelligence Scale –Third Edition, Stanford-Binet Intelligence Scale – Fourth Edition, and the Bayley Scales of Infant Development – Revised. The IQ score available in the clinical file, at the time closest to the time the sibling
participated in the group, was used in the present study. Data were missing for 6 of the siblings in the sample because IQ scores were not available from the clinical files.

Achenbach Child Behavior Checklist (CBCL) (Achenbach, 1991). This is a 124-item standardized parent-report questionnaire examining both internalizing (e.g., depression, anxiety) and externalizing (e.g., hyperactivity, conduct problems) behaviour problems, and comparing the scores to norms that reflect both gender and age differences. The scores obtained on the Internalizing Scale, Externalizing Scale, and Total Scale (which includes items not included in either domain) were used in the present study. The parent(s) were asked to complete the CBCL on the siblings participating in the sibling group at pre-test (within two weeks before the first session of the sibling group).

The reliability and validity of the CBCL has been supported by several studies (Achenbach, 1991). The internal consistency for the Total problem score was .96 for boys and girls between the ages 4–18. For the Internalizing score, internal consistency ranged from .89 (boys aged 4–11) to .92 (girls aged 12–18), and the internal consistency score for the Externalizing score was .93 for all groups. The validity of the CBCL scales has been supported by its significant associations with other measures, such as the Revised Behavior Problem Checklist, and the ability of nearly all the items (excluding allergies and asthma) to discriminate referred and nonreferred children that were matched on demographic factors.

Data were missing for 2 of the siblings because the parents did not return the forms.

Piers-Harris Children’s Self-Concept Scale (Piers & Harris, 1969; Piers, 1984). This is an 80-item self-report, true/false questionnaire measuring how children feel about themselves, such as the child’s evaluation of his/her popularity with classmates, and self-perceptions of his/her academic abilities. As well as yielding a Total score, this measure also contains six cluster scores (not used in the present study): Behavior, Intellectual/School, Physical Appearance and Attributes, Anxiety, Popularity, and Happiness/Satisfaction. The Piers-Harris can be used
reliably with children over age 8 (Piers, 1984). Since there have not been any systematic attempts to validate the use of this scale with children in grade 3 or below, caution must be used when interpreting results with younger children (Piers, 1984).

Studies that have examined the psychometric properties of the Piers-Harris have found it to be a very reliable and valid measure of self-concept (Piers, 1984). The internal consistency estimates for the total score ranged from .88 to .93, while the cluster scores ranged from .73 (Happiness and Satisfaction) to .81 (Behavior). The test-retest reliabilities for the total score ranges from .42 (8-month interval) to .96 (3-4 week interval), with a median test-retest reliability of .73. However, it has consistently been found that changes in group means on a re-test are in the direction of higher scores (more positive self-concept) even when no treatment has taken place. The Piers-Harris has been found to be sensitive enough to discriminate between various groups, such as between clinic and nonclinic samples.

Research staff administered the questionnaires to the siblings in the group orally both at pre- and post-test (within two weeks after the last group session).

**Autism Knowledge Measure for Young Children** (Perry, 1989). This questionnaire is intended to measure children’s basic knowledge of the characteristics and possible causes of autism (e.g., “Do autistic kids have something wrong in their brain that makes them act that way?”). The questionnaire includes 20 items which are answered with “yes”, “not sure”, or “no” responses (see Appendix). The total score is the number of items the child answers correctly out of 20 questions. To ensure understanding, the questions are stated in simple language suitable for children. This measure was administered orally at both pre-and post-testing. Data were missing for one of the siblings. Internal consistency was computed for this sample of siblings using their pre-test scores on this measure \( N = 30 \). The value for coefficient alpha was .68, indicating fair reliability.
What It’s Like to Have a Brother or Sister With a Developmental Disorder (Perry, 1989).

This questionnaire was developed based on the clinical and experimental literature (e.g., Seligman, 1983), and designed to tap issues deemed important for psychosocial adjustment. It includes 24-items with a verbal 4-point Likert scale as well as two open-ended items intended to measure children’s adjustment (see Appendix). The questionnaire is comprised of six subscales: Competence/Knowledge (e.g., “Are you good at teaching _________ to do something new (like to tie his/her shoelaces or order a meal in a restaurant)?”); Chores/Expectations (e.g., “Do you have to “babysit” or help to take care of your autistic brother or sister?”); School/Friends (e.g., “Do kids at school or in your neighbourhood ever tease you because you have a brother/sister like _________?”); Anger/Resentment (e.g., “Do you get mad at your parents for always paying attention to _________ more than you?”); Mental Health (e.g., Do you think it is normal to have the feelings you do about _________?”); and Future Concerns (e.g., “Do you worry that you might have a child like _________ when you grow up?”). Only the total score will be used in the present study. Since this measure was constructed for the purposes of the present study, internal consistency was computed for this sample of siblings using their pre-test scores on this measure (N = 31). The value for coefficient alpha was .49, indicating unacceptable reliability. Due to the poor internal consistency of the total score, it was decided post-hoc (based on clinical grounds) that the anger/resentment subscale would be used for all analyses examining siblings’ maladjustment. It has been suggested that siblings’ anger and resentment may be an important factor relating to psychosocial adjustment (McHale & Gamble, 1989; Seligman, 1983). The value for coefficient alpha was then computed for this 4-item subscale and found to be .61, indicating fair reliability for so brief a measure.

Procedure

Families expressing interest were informed by a letter that a sibling support group would be held for all siblings of families in the TRE-ADD program. Siblings were selected based on
parents’ agreement to have their child participate in the sibling group as well as the child's willingness to participate. However, an age range was set for each round of the sibling groups to ensure similar ages, interests, and common needs in participants. A member of the TRE-ADD Research staff met with the parent(s) and sibling at the family’s home within two weeks of the first session of the group (pre-test). Parents signed a consent form, agreeing to the sibling’s participation in the sibling support group, as well as for the research component and access to the clinical files of the child with autism. Parent(s) were given the CBCL to complete while the siblings were given the Piers-Harris Children’s Self-Concept Scale, the Autism Knowledge Measure, and the questionnaire “What it’s Like to Have a Brother or Sister With a Developmental Disorder”.

The sibling support group met weekly for eight consecutive weeks. The goals of the sibling support group included: increasing knowledge and understanding of autism and related developmental disorders; providing the siblings an opportunity to discuss their feelings in an accepting environment; helping siblings share ways of coping with difficult situations unique to having a sibling with a developmental disorder; enhancing self-concept; and encouraging siblings to have fun in a supportive environment. These goals were addressed throughout the eight sessions by focusing on exercises, games, and activities that are fun and promote group cohesion, information sessions on autism and related disorders, and discussions relating to feelings and attitudes in living with a brother or sister with developmental disabilities.

During the two weeks following the last group session (post-test), information was obtained from the siblings at the family’s home or at Thistletown Regional Centre, by a TRE-ADD Research staff member. The siblings were re-administered the Piers-Harris Children’s Self-Concept Scale, the Autism Knowledge Measure, and the questionnaire “What it’s Like to Have a Brother or Sister With a Developmental Disorder”, as well as completing for the first time the Satisfaction Evaluation Form anonymously.
CHAPTER 3: RESULTS

To control for Type 1 error, a conservative alpha level of .01 was used for all statistical tests.

For addressing Hypothesis 1, the Internalizing, Externalizing, and Total mean T scores of the CBCL for the present sample of siblings were compared to an average T score of 50 by computing three one-sample t tests (one-tailed) (see Table 1). In addition, a one-sample t test (one-tailed) was also conducted on the sample siblings’ Total scores on the Piers-Harris Children’s Self-Concept Scale, to evaluate whether their mean was significantly different from 51.84, the mean reported in the Piers-Harris manual for the standardization sample (see Table 1). For Internalizing behaviours, the sample mean of 57.31 (SD = 11.67) was significantly different from 50, t(28) = 3.37, p < .01. The results indicate that the siblings of children with autism were exhibiting more internalizing problems than the average t score of 50. However, there were no significant differences found for the siblings in the current study on Externalizing behaviours or the Total problem score in comparison to an average score of 50. For self-concept, the sample mean of 55.13 (SD = 8.27) was marginally significantly different from the mean of 51.84 reported for the standardization sample, t(30) = 2.21, p = .02. Therefore, the siblings in the current study reported having marginally higher self-concepts in comparison to the general population.

To test Hypothesis 2, Pearson product-moment correlations were computed on the siblings’ pre-test scores in order to examine the relationships among the severity of the child’s disability (severity of autism and IQ) and the siblings’ internalizing, externalizing, and
total problem behaviours. First, the CARS scores were correlated with the CBCL, Piers-Harris, and Anger/Resentment subscale of the maladjustment measure ("What It's Like to Have a Brother/Sister with a Developmental Disorder"). As shown in Table 2, there were no significant correlations. The results suggest that there was no linear relationship between severity of autism and siblings' psychosocial adjustment as measured by the CBCL (internalizing behaviours, externalizing behaviours, and total problem score), the Piers-Harris total self-concept score, or the Anger/Resentment subscale.

Second, correlations were computed between IQ and the siblings' pre-test scores of the CBCL, Piers-Harris, and the Anger/Resentment subscale of the maladjustment measure ("What It's Like to Have a Brother/Sister with a Developmental Disorder"). There were no statistically significant correlations found among these variables (see Table 2). The results of the correlational analyses indicate that there was no linear relationship between level of cognitive functioning for the child with autism and siblings' psychosocial adjustment as measured by the CBCL (internalizing behaviours, externalizing behaviours, and total problem score), the Piers-Harris total self-concept score, or the Anger/Resentment subscale.

It was decided post-hoc to investigate whether there was a nonlinear relationship among CARS scores and IQ with the outcome measures examined above (as reported by Tew & Laurence, 1973). A total of ten simple scatterplots were created with either the CARS or IQ
scores on the x-axis and the dependent variable on the y-axis. There were no clear nonlinear relationships evident from the scatterplots. Therefore, the results indicated that severity of disability (based on severity of autism and level of cognitive functioning) was not related to siblings' psychosocial adjustment.

Table 2. The Relationship Between Severity of Disability and Siblings' Psychosocial Adjustment (Pearson r)

<table>
<thead>
<tr>
<th>Measures</th>
<th>CARS</th>
<th>IQ</th>
</tr>
</thead>
<tbody>
<tr>
<td>CBCL</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Internalizing</td>
<td>-.28b</td>
<td>.09c</td>
</tr>
<tr>
<td>Externalizing</td>
<td>-.26b</td>
<td>.06a</td>
</tr>
<tr>
<td>Total</td>
<td>-.21a</td>
<td>.22d</td>
</tr>
<tr>
<td>Piers-Harris</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>-.09c</td>
<td>-.03r</td>
</tr>
<tr>
<td>Coping/Adjustment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anger/Resentment</td>
<td>.07e</td>
<td>.06f</td>
</tr>
</tbody>
</table>

Note. CARS = Childhood Autism Rating Scale; IQ = Intelligence Quotient; CBCL = Child Behavior Checklist.

\(^{a}n = 17. ^{b}n = 18. ^{c}n = 20. ^{d}n = 22. ^{e}n = 23. ^{f}n = 25\)

With respect to Hypothesis 3, Pearson product-moment correlations were calculated on the siblings' pre-test scores in order to investigate the relationships among siblings' knowledge of autism, siblings' age and psychosocial adjustment. The siblings' total score on the Knowledge of Autism Measure was not significantly related to their age, \(r(29) = -.17, p > .01\).

Similarly, siblings' knowledge of autism was not significantly related to their scores from the CBCL (internalizing behaviours, externalizing behaviours, and total problem score), Piers-Harris total self-concept score, and the Anger/Resentment subscale of the maladjustment measure ("What It's Like to Have a Brother/Sister with a Developmental Disorder") (see Table 3). Therefore, there were no linear relationships between siblings' knowledge of autism and their chronological age or psychosocial adjustment.
To evaluate the sibling support groups systematically, thereby testing the remaining three hypotheses, three paired t tests were computed. One paired t test was conducted in order to determine whether siblings improved their self-concepts on the Piers-Harris Children’s Self-Concept Scale from pre-test to post-test (see Table 4). The findings indicated that siblings’ mean self-concept score at post-test ($M = 58.77$, $SD = 8.92$) was significantly higher than the mean self-concept score at pre-test ($M = 54.35$, $SD = 8.56$), $t (25) = -2.84$, $p = .005$. Therefore, the results indicated that the siblings significantly increased their self-concept from the beginning of the sibling group to the end of the group.

Another paired t test was performed in order to determine whether siblings improved their knowledge of autism on the Knowledge of Autism Measure from the beginning to the end of the sibling group (see Table 4). The results suggested that the siblings’ mean knowledge of autism score at post-test ($M = 13.20$, $SD = 3.04$) was significantly higher than the mean score at pre-test ($M = 11.40$, $SD = 3.49$), $t (24) = -2.45$, $p = .01$. Therefore, siblings’ knowledge of autism improved significantly from the beginning of the group to the end.

The third paired t test was conducted in order to investigate whether the siblings decreased their maladjustment scores (indicating better adjustment) on the questionnaire, What It’s Like to Have a Brother/Sister with a Developmental Disorder. It was found that the siblings’ mean score for the Anger/Resentment subscale at post-test ($M = 7.62$, $SD = 2.32$) was not significantly different from the mean score at pre-test ($M = 8.00$, $SD = 2.62$), $t(25) = .95$, $p > .01$. The results showed that the siblings did not decrease their maladjustment score on the Anger/Resentment subscale.
Table 3. The Relationship Between Siblings’ Knowledge of Autism and Their Psychosocial Adjustment (Pearson r)

<table>
<thead>
<tr>
<th>Measure</th>
<th>Knowledge of Autism</th>
</tr>
</thead>
<tbody>
<tr>
<td>CBCL</td>
<td></td>
</tr>
<tr>
<td>Internalizing</td>
<td>.22&lt;sup&gt;b&lt;/sup&gt;</td>
</tr>
<tr>
<td>Externalizing</td>
<td>-.11&lt;sup&gt;b&lt;/sup&gt;</td>
</tr>
<tr>
<td>Total</td>
<td>.04&lt;sup&gt;a&lt;/sup&gt;</td>
</tr>
<tr>
<td>Piers-Harris</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>-.02&lt;sup&gt;c&lt;/sup&gt;</td>
</tr>
<tr>
<td>Coping/Adjustment</td>
<td></td>
</tr>
<tr>
<td>Anger/Resentment</td>
<td>.13&lt;sup&gt;c&lt;/sup&gt;</td>
</tr>
</tbody>
</table>

Note. CBCL = Child Behavior Checklist
<sup>a</sup>n = 27. <sup>b</sup>n = 28 <sup>c</sup>n = 30

Table 4. The Mean Difference in Siblings’ Scores on the Outcome Measures

<table>
<thead>
<tr>
<th>Sibling Outcome</th>
<th>Pre M</th>
<th>Pre SD</th>
<th>Post M</th>
<th>Post SD</th>
<th>t</th>
<th>df</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Piers-Harris Knowledge</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>54.35</td>
<td>8.56</td>
<td>58.77</td>
<td>8.92</td>
<td>-2.84</td>
<td>25</td>
<td>.005</td>
</tr>
<tr>
<td>Coping/Adjustment</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anger/Resentment</td>
<td>11.40</td>
<td>3.49</td>
<td>13.20</td>
<td>3.04</td>
<td>-2.45</td>
<td>24</td>
<td>.01</td>
</tr>
<tr>
<td>Anger/Resentment</td>
<td>8.00</td>
<td>2.62</td>
<td>7.62</td>
<td>2.32</td>
<td>.95</td>
<td>25</td>
<td>.18</td>
</tr>
</tbody>
</table>
CHAPTER 4: DISCUSSION

Research examining the psychosocial adjustment of siblings of children with autism is plagued with inconsistent findings, making interpretation difficult. In an attempt to clarify research findings to date, the present study explored the psychosocial adjustment of siblings of children with autism (e.g., internalizing and externalizing behaviours, self-concept). Another goal was to examine the relationships of siblings’ psychosocial adjustment with severity of the children’s disability and siblings’ knowledge of the disability, two factors relatively unexamined in the area of autism. The present study also contributes to the literature by systematically and empirically evaluating changes in siblings’ self-concept, knowledge of autism, and anger and resentment after participation in a sibling support group.

As predicted, the siblings in the current study were reported by their mothers to exhibit significantly more internalizing behaviours than average. Although inconsistent findings are prevalent, the current findings are consistent with results from other studies indicating that parents reported significantly more internalizing behaviours for siblings of children with PDD in comparison to siblings of control children (Fisman et al., 1996; Gold, 1993; Rodrigue et al., 1993). In contrast, siblings were not found to present with significantly more externalizing or total problem behaviours than average. While consistent with findings by Gold (1993), these findings are contrary to results from previous studies in which parents reported more externalizing behaviours in siblings of children with PDD than for a control group (Fisman et al., 1996; Rodrigue et al., 1993), and exhibited more inattention/hyperactivity and conduct problems than siblings of children with mental retardation (Bagenholm & Gillberg, 1991). Although siblings were found to exhibit more internalizing behaviours than average, their mean score did not fall in the clinical range. However, when examining individual scores, 9 of the 29 siblings had internalizing scores that fell in the clinical range. Clinical follow-up was
provided for individuals experiencing significant internalizing problems. Since the participants in the present study were composed of a clinical sample, they may have been experiencing more internalizing problems than a random sample of siblings of children with autism. Therefore, a limitation of the current study includes possible sampling bias. The siblings' parents may have identified their problems, and as a result, had them participate in the sibling support group.

The findings for the CBCL also may be a result of potential rater bias, a further limitation of the current study due to the reliance on parent reporting of internalizing and externalizing symptoms. On one hand, some siblings may be experiencing more internalizing and externalizing problems than reported because the parents do not want to admit that their "healthy" child is having any difficulties. On the other hand, parents may over-report the number of behavioural problems (e.g., internalizing and externalizing) siblings are exhibiting. For example, mothers' perceptions of the siblings' adjustment may be strongly influenced by the amount of stress they are experiencing rather than the siblings' actual behaviour (Lobato et al., 1987). Using self-report measures in addition to parent and teacher ratings when examining siblings' internalizing behaviours would help compensate for this limitation.

The siblings' self-concepts were also examined as a measure of psychosocial adjustment. Interestingly, these siblings of children with autism had marginally higher self-concept scores than the normative sample, findings consistent with Mates (1990). However, this finding is somewhat in contrast to past studies, which found no differences in self-concept for siblings of children with autism in comparison to siblings of children with Down Syndrome/Mental Retardation or no disability (Bagenholm & Gillberg, 1991; Rodrigue et al., 1993). Of the total sample, 13% of the siblings had Total scores that were 1.5 standard deviations higher than the mean of the standardization sample. Although these scores may accurately reflect the child's positive self-evaluation, they may actually reflect the need to appear extremely self-confident (Piers, 1984). The need to appear self-confident may be particularly relevant in the current study
because the questions were read to the siblings aloud in order to ensure understanding.
Therefore, the siblings may have presented themselves in a more positive light.

Also important to note are the siblings’ scores on the Response Bias and Inconsistency Indices of the Piers-Harris Children’s Self-Concept Scale. The Response Bias Index measures the tendency to respond in a positive or negative direction (Piers, 1984). While only 3.7% of the standardization sample scored 2 standard deviations or more from the mean, 6.5% and 15.4% of the siblings in the present sample scored more than 2 standard deviations from the mean at pre-test and post-test, respectively. The Inconsistency Index measures the degree to which an individual responds in a random manner (Piers, 1984). Once again, only 3.7% of the standardized sample received scores 2 standard deviations or more from the mean, 25.8% and 34.6% of the siblings in the present sample received such scores at pre-test and post-test, respectively. While these results must be interpreted cautiously due to the small sample size in the present study, these scores on both indices may be a result of having read the questions aloud to the siblings. The higher percentage of siblings responding inconsistently and with a positive or negative response bias calls into question the reliability of the mean total self-concept score, and it’s relationship with other variables, including severity of disability and knowledge of autism.

In summary, the current findings suggest that as a group, these siblings were exhibiting more internalizing problems than average, but in general were not experiencing any significant psychosocial adjustment difficulties. Conclusions must be drawn cautiously though, due to the limitations previously discussed. However, the majority of the siblings may be well adjusted, having developed good coping skills for the unique situations they encounter as a sibling of a child with autism.

The present study was the first to investigate the influence of severity of disability on siblings’ adjustment, using both severity of autism and cognitive functioning as indicators of
overall severity. Consistent with findings from earlier studies with other disabilities (Breslau et al., 1981; Tew & Laurence, 1973), no significant linear relationships were found between severity of autism or IQ with measures of siblings’ psychosocial adjustment. Therefore, the siblings of children with less severe disabilities (mild autism or higher cognitive functioning) did not experience more psychosocial adjustment difficulties than siblings of children with moderate or severe disabilities. In addition, contrary to findings by Tew and Laurence (1973), the present study did not support the presence of a nonlinear relationship.

These findings suggest that siblings’ psychosocial adjustment may not be affected by the severity of their brother or sister’s autism or level of cognitive functioning. However, certain limitations need to be considered before drawing any conclusions. First, CARS scores were not available for 35% of the children with autism. Therefore, the correlations were conducted with a small sample of siblings, which may have resulted in insufficient power. Second, there was limited variability in the severity of autism scores. Therefore, mild, moderate, and severe autism were not equally represented in this sample. This limitation also pertains to the children’s IQ scores. The majority of IQ scores were at the lower end of cognitive functioning, representing severe mental retardation. Since this is the only study known to examine the relationship between severity of disability and siblings’ psychosocial adjustment in the area of autism, other studies should seek to corroborate these findings using the same standardized measures with a more heterogeneous sample.

It was also predicted that siblings’ knowledge of autism would be related to their age and psychosocial adjustment. Siblings’ knowledge of autism was not related to their age. Consistent with the one other study examining this issue, siblings did not gain more information about autism as they got older (Roeyers & Mycke, 1995). This finding is disconcerting because it may indicate that open communication is not taking place in families. Either siblings are not asking
their parents questions about their brother or sister’s behaviours or parents are not providing age-relevant information to siblings.

Findings also indicate that for siblings in this sample, internalizing, externalizing, and total problem behaviours, self-concept, and anger/resentment were not related to the amount of knowledge they had about autism. However, these findings are difficult to interpret given that their overall knowledge of autism was poor. It would be interesting to investigate whether siblings’ knowledge of autism is related to psychosocial adjustment at post-test, when siblings attain higher scores, thereby demonstrating more knowledge of autism. The CBCL scores were not collected at post-test in the current study. Given that the CBCL measures behaviour over a six-month period and the current study took place over three months, information obtained at post-test would have included siblings’ behaviours before the sibling support group was implemented. Consequently, more research is needed before concluding that it is not necessary to provide siblings with information about autism for improving adjustment.

In addition, the present study, as well as the study by Roeyers and Mycke (1995), examined knowledge of autism with measures created for the purposes of the study based on DSM-III-R criteria. While the current study reported fair internal consistency, the analysis was based on a small sample size. Therefore, standardized measures with good psychometric properties and up-to-date criteria (e.g., DSM-IV) are needed for examining knowledge of autism and its relation to siblings’ psychosocial adjustment in a reliable and valid way.

The second main objective of the current study was to evaluate systematically and empirically the effectiveness of a sibling support group for siblings of children with autism. As hypothesized, the siblings significantly improved their overall self-concept, and knowledge of autism from the beginning to the end of the group. The finding that siblings increased their self-concepts is consistent with Lobato (1985), who found that siblings increased their percentage of positive self-reference statements while simultaneously decreasing negative self-statements.
However, since there was no control group in the present study, it can not be determined whether the positive changes were a direct result of the clinical intervention. Changes in siblings’ self-concepts may be a result of factors external to the group activities, such as the novelty and excitement of simply participating in a group designed just for them (Lobato, 1985) or spending some quality time alone with one of their parents on the drive to the group session.

Another limitation that makes it difficult to determine whether changes in self-concept were a result of the clinical intervention, is the repeated administration of the Piers-Harris Children’s Self-Concept Scale. It has consistently been found that group means often increase (representing a more positive self-concept) upon retest of this measure (Piers, 1984), even when no treatment has been implemented. This places even more importance on including a control group for program evaluation.

As previously mentioned, siblings significantly increased their knowledge of autism by the end of the sibling support group. The siblings scored at a chance level on the knowledge of autism measure before the group began, thereby indicating that they did not possess a lot of knowledge about autism. This finding is consistent with results from other clinical studies indicating that siblings initially had little knowledge of their brother or sister’s disability but became more accurate in describing their brother/sister’s disability after participating in a sibling group (Chinitz, 1981; Howlin & Yates, 1990; Lobato, 1985). Therefore, it appears that the sibling support group in the present study may have been successful in helping siblings understand autism, and as a result, their brother or sister’s behaviours. Once again however, there was no control group with which to compare changes. Furthermore, the siblings’ mean score was still only 65% at post-test, suggesting that there remains considerable room for improvement.

Contrary to what was hypothesized, there were no changes in the siblings’ feelings of anger/resentment by the end of the sibling support group. This may be a direct result of the
questionnaire used to measure this construct. Since it was developed for the purposes of the present study, there were no available psychometric properties. Although internal consistency was computed and found to be fair for the anger/resentment subscale, the sample size used for these purposes was small.

However, another possible explanation is that there was a change from pre- to post-test in socially desirable responding. Siblings may have felt that they had to give the "appropriate" response to the anger/resentment questions at pre-test, but after the group, with feelings of anger/resentment having been normalized, they felt permission to respond more honestly. This would mask any actual changes over time in anger/resentment. On the other hand, the sibling group may have been unable to change the reality that the siblings are angry/resentful.

Although it is difficult to make any conclusive statements on the effectiveness of the sibling support group because a control group was not included, the siblings reported that they really enjoyed their experiences in the group and wished that it would continue past eight weeks. They were given the opportunity to discuss their experiences, express their feelings, problem solve, and learn about autism in a supportive environment, and equally important, have fun as children.

Despite the limitations already discussed, the present study makes some significant contributions to the current research literature. First of all, both mother-report and self-report measures were used in order to examine siblings' overall psychosocial adjustment. Second, some gaps in the research literature with respect to siblings' adjustment when a child has autism are addressed. For example, this study used standardized measures for examining the influence of severity of disability on adjustment, as well as using both severity of autism and cognitive functioning as indicators. Also adding to current research, this study took the first step in attempting to find any evidence for the suggestion that knowledge of a brother or sister's disability leads to better understanding, and therefore adjustment. Third, with respect to
evaluation of the sibling support group, the sample size is large and the research design relatively strong in comparison to other published studies. Finally, the systematic empirical evaluation of the sibling support group showed that one can provide a real clinical service by increasing siblings' understanding of their brother or sister's disability and helping them feel more positive about their abilities. In addition, providing sibling groups can help to identify siblings that may need additional services and provide more long-term clinical support for those exhibiting significant problems (e.g., internalizing and/or externalizing problems, poor self-concepts).

There are several directions to be addressed in future research. Since sibling relationships take place in the context of the family system, it would be useful to evaluate the effects familial variables have on siblings' psychosocial adjustment. One could determine how the presence or absence of particular variables place siblings at increased risk for psychosocial adjustment difficulties, while the presence or absence of other variables protect siblings from experiencing difficulties. For example, Fisman et al. (1996) found that the presence of parent distress (comprised of parent stress and depression) significantly contributed to siblings' internalizing and externalizing behaviours. Moreover, Bristol (1984) found that when mothers of children with autism reported having a social support network, they had lower levels of stress. Therefore, the presence of a social support network for the mother may protect siblings from experiencing adjustment difficulties. Examining familial variables such as social support and parental stress, rather than focusing exclusively on sibling variables (e.g., age and gender) may help account for inconsistent findings across studies, as well as the variability in siblings' adjustment within studies.

Examining the relationship between the family environment and the quality of sibling relationships over time would also make a significant contribution to the literature. McHale et al. (1986) found that while siblings of children with disabilities did not differ from a control group in the quality of their sibling relationships, there was a large discrepancy within the group.
While some siblings reported very positive relationships, others reported very negative ones. Status variables, including siblings' age and gender, were not related to the quality of the sibling relationships. Since a positive sibling relationship may affect siblings' psychosocial adjustment, it becomes necessary to determine the factors that may enhance or prevent this from occurring. More specifically, the level of family conflict (e.g., between parents, parents and children, and siblings) may be one factor that impacts on the quality of the sibling relationship. This may be truer in families of children with disabilities as a result of the additional stressors associated with caring for a child with special needs. One could gather information through self-report measures as a way of gaining family member's perceptions of conflict within the home. However, a further contribution would include corroborating self-reports with direct observations of parent, parent-child, and sibling interactions. It would be important to examine the sibling relationships over time and determine whether changes in perceived and/or observed family conflict parallel changes in the quality of sibling relationships.

Finally, more systematic and empirical research is needed on the contributions of sibling support groups for siblings' overall adjustment. Researchers should measure changes in specific factors that are important goals of the group, such as changes in siblings' knowledge of autism and coping abilities. It could then be determined whether this impacted on siblings' psychosocial adjustment (e.g., emotional and behavioural problems, and self-concept). To most effectively accomplish this, a control group needs to be incorporated as a major component of the study. Any changes could then be attributed to the intervention itself. Moreover, it is important to use measures which are reliable, valid, sensitive to change, and clinically meaningful, to ensure that the sibling group being implemented is clinically helpful and based on empirical research.
References


Perry, A. (1989). *What it’s like to have a brother or sister with a developmental disorder*. Unpublished manuscript, Toronto: Thistletown Regional Centre.


Appendix

AUTISM KNOWLEDGE MEASURE FOR YOUNG CHILDREN

I AM GOING TO READ YOU SOME QUESTIONS ABOUT AUTISM. I WANT YOU TO ANSWER AS BEST YOU CAN, EITHER YES OR NO. IF YOU DON'T KNOW, TRY TO GUESS WHAT YOU THINK IS THE RIGHT ANSWER. IF YOU CAN'T GUESS, YOU CAN SAY YOU'RE NOT SURE.

1. Are autistic kids (like your brother/sister) different from other kids?  
   YES  NOT SURE  NO

2. Can autistic kids think and talk the same way as other kids?  
   YES  NOT SURE  NO

3. Do autistic kids do funny things like jiggling a piece of string or spinning things, for a long time?  
   YES  NOT SURE  NO

4. Do autistic kids like to show love, like by smiling at you or giving you a hug?  
   YES  NOT SURE  NO

5. Do autistic kids need to have special classes at school so they can learn?  
   YES  NOT SURE  NO

6. Do autistic kids have lots of friends they like to play games with?  
   YES  NOT SURE  NO

7. Do autistic kids have something wrong in their brain that makes them act that way?  
   YES  NOT SURE  NO

8. Is it right that most autistic kids are girls?  
   YES  NOT SURE  NO

9. Will most autistic kids still be different when they grow up?  
   YES  NOT SURE  NO

10. Are parents who have autistic kids different from parents of normal kids?  
    YES  NOT SURE  NO

11. Are autistic kids usually mentally retarded too?  
    YES  NOT SURE  NO

12. Do autistic kids look at you when you talk to them?  
    YES  NOT SURE  NO

13. Do autistic kids like to be by themselves a lot?  
    YES  NOT SURE  NO

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14. Are autistic kids usually born into rich families? | YES | NOT SURE | NO
---|---|---|---
15. Have autistic kids been that way since they were very young? | YES | NOT SURE | NO
---|---|---|---
16. Is autism common enough that there are lots of people on your street (or in your building) with an autistic kid in the family? | YES | NOT SURE | NO
17. Do autistic kids sometimes hit themselves or bite their hand? | YES | NOT SURE | NO
18. Do autistic kids get that way because of the way their parents treat them? | YES | NOT SURE | NO
19. Do autistic kids do funny things like flapping their hands or bouncing up and down in their chair? | YES | NOT SURE | NO
20. If a kid has an autistic brother or sister does that mean there's something wrong with him/her too? | YES | NOT SURE | NO

TOTAL CORRECT ___
WHAT ITS LIKE TO HAVE A BROTHER OR SISTER
WITH A DEVELOPMENTAL DISORDER

THIS IS A QUESTIONNAIRE ABOUT WHAT IT'S LIKE TO HAVE A BROTHER OR SISTER WITH AUTISM (OR A DEVELOPMENTAL DISORDER). WHEN YOU SEE A BLANK IN THE QUESTION YOU CAN PRETEND YOUR BROTHER OR SISTER'S NAME IS THERE.

THERE ARE NO RIGHT OR WRONG ANSWERS TO THESE QUESTIONS. WE JUST WANT TO FIND OUT YOUR REAL FEELINGS. THE ANSWERS YOU GIVE ARE CONFIDENTIAL, AND YOU DO NOT HAVE TO PUT YOUR NAME ANYWHERE ON THIS PAPER.

PLEASE READ EACH QUESTION CAREFULLY AND THEN CIRCLE THE WORDS WHICH BEST DESCRIBE YOUR ANSWER.

***************

1. Are you good at teaching ___________ to do something new (like to tie his/her shoelaces or order a meal in a restaurant)?
   - yes, very good
   - usually quite good
   - not usually not very
   - no, not at all

2. Do you find it hard to understand what ___________ wants or what he/she says or how he/she is feeling?
   - yes, all the time
   - sometimes not usually
   - no, never

3. Do you know a lot about autism or ___________'s disorder?
   - yes, a lot
   - some only a little
   - no, not much at all

4. Is it hard for you to make ___________ stop doing something weird (like licking toys or repeating TV commercials)?
   - yes, very hard
   - sometimes not usually
   - no, not hard at all

5. Do you think you have more chores to do around the house (like setting the table or cleaning up) than your friends?
   - yes, more than all
   - yes, more than most
   - about the same
   - no, less than others

Sib#_____
6. Do your parents help you with your homework? (or, if too young, do your parents read stories to you and help you learn numbers and letters?)
   yes, a lot  sometimes  hardly ever  never

7. Do you have to "babysit" or help to take care of your autistic brother or sister?
   yes, a lot  sometimes  hardly ever  never

8. Do you think it's fair what your parents expect from you (like at school, and at home, and with ________, and when you grow up)?
   yes, very  mostly  not very  no, not fair
   fair  fair  fair  at all

9. Do your friends at school know about ________?
   yes, all  some  only one  no, none
   of them  of them  friend  of them

10. Are you embarrassed to bring friends home after school or for sleep-overs?
   definitely  sometimes  a little  not at all
   (don't ever  (rarely or  (do bring  (do bring
   bring any)  only 1)  friends)  friends)

11. Do kids at school or in your neighbourhood ever tease you because you have a brother/sister like ________?
   yes, often  sometimes  hardly ever  no, never

12. Do your friends understand what ________ is like?
   yes, all  some of them  hardly any  no, not
   of them  sometimes  hardly ever  at all

13. Do you sometimes think it's not fair that you should have a brother/sister like ________?
   yes, all  sometimes  not really  no, never
   the time
14. Is it easy to have __________ for a brother/sister?

yes, very easy
usually easy
not usually easy
no, not easy
at all

15. Do you get mad at your parents for always paying attention to __________ more than you?

yes, a lot
sometimes not really
no, never

16. Are you happy and proud to have __________ for a brother/sister?

yes, very sometimes not usually no, not at all

17. Do people think you are a good kid?

yes, everyone
yes, most people
no, not
no, nobody

18. Do you sometimes feel like doing something you know you're not supposed to (like lying or stealing or swearing or fighting)?

yes, a lot
sometimes not really
no, never

19. Is it OK in your family to get mad at your parents, or get mad at __________?

yes, definitely
yes, sometimes
no, not really
no, not at all

20. Do you think it's normal to have the feelings you do about __________?

yes, definitely
yes, most of the time
not really
no, not at all

21. Are you worried that you might have to look after _______ when your parents get too old to look after him/her?

yes, very worried
a little worried
not really
no, not at all
22. Do you think it is best for your family if ______ stays living at home (instead of somewhere else like a group home)?

   yes, much    probably    not really    no, definitely
   better

23. Do you think that having a brother/sister like _______ will make you a better person (more understanding, etc.)?

   yes,    probably    not really    no, definitely
   definitely

24. Do you worry that you might have a child like ________ when you grow up?

   yes, very    a bit    not really    no, not
   worried    worried    worried    at all

25. What do you want to do when you grow up?

26. Is there anything else that you want to tell us about having ________ for a brother/sister?