# ASSESSING MATERNAL FUNCTIONING IN FAMILIES OF CHILDREN WITH AUTISM

## DISSERTATION

Presented to the Graduate Council of the
University of North Texas in Partial
Fulfillment of the Requirements

For the Degree of

DOCTOR OF PHILOSOPHY

Ву

Joelle J. Oizumi, B.A., M.A.

Denton, Texas

August, 1996

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Oizumi, Joelle, J., <u>Assessing maternal functioning in</u> families of children with autism. Doctor of Philosophy (Psychology), August, 1996, 226 pp., 20 tables, 1 illustration, references, 33 titles.

Mothers and siblings of children with autism incur stressors that impact their well-being more adversely than mothers of children with ADHD or normally developing In Study 1, twenty-six mothers of children with children. autism (Group 1) were compared to 24 mothers of children with ADHD (Group 2) and 24 mothers with normally developing children (Group 3). All families included a normally developing child (ages 4 to 12). Measures to delineate levels of maternal functioning were administered. Results for Study 1 indicated that mothers of children with autism had higher levels of psychological symptomatology, higher parenting stress, poorer perceptions of their family environment and their ability to parent the siblings, and higher perceptions of internalized problems of the siblings than mothers with normally developing children. findings support the literature stating that mothers of children with autism may experience increased levels of maternal stress. The reciprocal nature of the parent-child relationship suggests that parents should be involved in meeting the needs of siblings in these families. A subgroup of Group 1 mothers participated in a parent group that occurred simultaneously with a sibling group. Mothers were randomly assigned to participate in a parent/sibling group, a sibling only group, or a wait-list group. Intervention efficacy was assessed using Study 1 measures plus measures designed specifically for the intervention. Overall results of study 2 indicated that mothers in the deluxe intervention perceived their parenting of the siblings to have improved after the intervention when compared to the standard and wait-list groups. This suggested that concurrent mother/sibling intervention provided the mothers with beneficial information and contributed to their enhanced sense of competence about parenting the siblings. addition, mothers in the deluxe intervention perceived their family environment and the behaviors of the sibling to get worse at post-intervention, but return to baseline over This suggests that the intervention may have initially brought some difficulties to the surface that were resolved over time. Results will be discussed with their implications for further research and clinical intervention.

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#### CHAPTER I

#### INTRODUCTION

The parent-child relationship is a very powerful and reciprocal relationship where parents affect childrens' well-being and children, in turn, affect the well-being of their parents. Literature suggests that parents of children with autism experience effects of stressors associated with autism that make them particularly vulnerable to problems with family functioning such as poor psychological adjustment, marital discord, and poor coping strategies (e.g., Fishman & Wolf, 1991; Gallagher, Beckman, & Cross, 1983; Moes, Koegel, Schreibman, & Loos, 1992). It, therefore, becomes important to assess the effects of stressors encountered by parents of children with autism as compared to parents of children with other disorders, as well as parents of normally developing children.

Children with psychological disorders and disabilities have also been shown to affect siblings in areas of stress, psychological well-being, level of responsibility in the family, and emotional adjustment. In addition, parental adjustment may also have an effect on these siblings, as well as the child with the disability. As in the case of the parent-child relationship, the sibling relationship is

also quite powerful. One only needs to consider the vast amount of time and space shared by siblings to appreciate the strong influence that they can have upon each other. Therefore, it becomes important to address the needs of all family members, including siblings.

Many researchers have developed methods of enhancing the functioning of children with disabilities within the family unit. Parent and sibling training programs have been developed to address behavior problems and other needs (e.g., self-help skills) of children with disabilities. However, the literature lacks empirical investigation of interventions that address the myriad needs of siblings of children with disabilities. Therefore, empirical interventions designed specifically for siblings of children with disabilities are an important area of study. As will be discussed later, These interventions should involve the parents because of the influential role they can play in the functioning of siblings of children with disabilities.

# Effects of Children with Disabilities on Parents

A parent-child relationship is one where the parent has an important caretaking role and incurs responsibility for the child's behaviors, development, and his or her well-being. The reciprocal nature of this relationship is such that the characteristics and behaviors of the child also have a strong influence on parenting itself, as well as various aspects of the parents' lives. When a child has a

disability, the impact on the parent is greater because the caretaking role becomes more difficult, effortful, and worrisome.

Parenting children with disabilities is a great source of stress for the family unit and often has a significant impact on family functioning (Beckman, 1983; Donenberg & Baker, 1992; Fishman & Wolf, 1991; Friedrich & Friedrich, 1981; Gallagher et al., 1983; Kazak & Marvin, 1984; Powers, 1984; Wolf, Noh, Fishman, & Speechley, 1989). The literature examining the effects of parenting children with disabilities has implicated several factors that are important to consider. Some of the difficulties parents may experience include: added stress, reliance on less effective coping strategies, lower sense of parental competence, poor psychological well-being, less marital satisfaction, and less social support.

Increased stress has been shown to have a number of negative ramifications on family functioning (Margalit, Raviv, & Ankonina, 1992) including: poor psychological wellbeing (Fishman & Wolf, 1991), less marital satisfaction (Friedrich & Friedrich, 1981), and less social support (Gallagher et al., 1983). Margalit, Raviv and Ankonina (1992) compared the coping, family coherence, and family interrelatedness of 78 couples of children with disabilities and 83 couples with nondisabled children. Results indicated that families having children with disabilities tended to

use more avoidant coping strategies (e.g., eating or doing other things to avoid problems), reported a lower sense of family coherence, and displayed less family relatedness than did families of children without disabilities.

Some research has looked specifically at the maternal relationship. Friedrich and Friedrich (1981) examined 34 families of children with disabilities and 34 families with nondisabled children. Results indicated that marital satisfaction was lower for families of children with disabilities than for families with nondisabled children. In a related vein, Rodrigue, Morgan and Geffken (1990) compared mothers of children with autism to mothers of children with Down's Syndrome and a control group. They examined the effects of parenting these children on mothers. Results indicated that parents of children with autism reported less parenting competence, less marital satisfaction, and less family adaptability or flexibility than the other two groups.

Stress associated with parenting children with disabilities has been suggested to have a negative effect on psychological well-being (Esman & Klebanoff, 1958; Fishman & Wolf, 1991; Kazak, 1987; Marcus, 1977). Fishman and Wolf (1991) attempted to address some of the methodological problems associated with earlier research that linked parenting stress with psychological distress in families of children with disabilities (e.g., limited age-span of

subjects, biased samples of only intact families, lack of comparison groups, and mothers as the sole respondent). Fishman and Wolf (1991) compared both mothers and fathers of 31 children with autism, 31 children with mental retardation, and 62 children determined to be developing at a normal rate. Results indicated that the psychological well-being of mothers of children with autism was most affected, that is, they scored highest on measures of parenting stress and depression. Similar findings were indicated by Moes et al. (1992) when they compared mothers and fathers of children with autism. Their results indicated that mothers experienced more stress related to parent and family problems than fathers.

Research suggests that there are several factors that may predict and mediate levels of stress experienced by parents of children with disabilities (Beckman, 1983; Friedrich & Friedrich, 1981; Gallagher et al., 1983).

Predictors often include: age of the disabled child (Beckman, 1983; Gallagher et al., 1983); diagnostic category of the child (Ferrari, Matthews, & Barabas, 1983; Fowle, 1968; Gallagher et al., 1983; Holroyd & McArthur, 1976); children's characteristics such as behavior problems, temperament, social responsiveness, and rate of progress (Beckman, 1983); parent characteristics such as socioeconomic class, intelligence, personality, past experience, and marital satisfaction (Friedrich & Friedrich,

1981); and social support (Fishman & Wolf, 1991; Friedrich & Friedrich, 1981; Gallagher et al., 1983; Ingram, 1973; Marcus, 1977).

The age of the child with the disability is often a predictor of the amount of stress experienced within the family unit. Gallagher et al (1983) suggested that as age of the child increases, stress experienced by the family increases. This was proposed to occur because older children may pose more difficulties to their parents in terms of behavior management due to their physical strength and their social interactions with others. In addition, parents may perceive the older, school-age children as unmanageable because the differences between older children and their normally developing peers would likely become more salient (Gallagher et al., 1983).

Behavioral characteristics of children with disabilities, apart from their actual diagnoses, can also be a significant source of stress for the family unit. Beckman (1983), in his study of 31 disabled infants and their mothers, found that less social responsiveness, more difficult temperament, presence of stereotyped behaviors, and unusual care-giving demands are associated with significantly more stress for the mothers of these children. Similarly, Gallagher et al. (1983) reported that children with disabilities who have difficult personality characteristics (e.g., behavior problems or aggressiveness),

higher levels of dependency, and a high degree of physical incapacity significantly contribute to problems experienced by mothers.

Characteristics of parents of children with disabilities also predict amount of stress experienced by the family unit. Gallagher et al. (1983) examined factors like socioeconomic status, age, income, intelligence, and poor psychological adjustment. They found that these factors contribute to parental stress in general. They also suggested that these factors have an even greater effect on stress experienced by parents of children with disabilities.

Social support is a factor that is consistently reported to have a stress buffering effect on parents and siblings of children with disabilities. Because amount of social support tends to decrease due to the attitudes of others and the social withdrawal of the parents because of embarrassment or perceived lack of understanding from others (Gallagher, et al., 1983), it becomes important to assess existing support and to provide conditions for new support for families with children with disabilities.

Crnic, Greenberg, Robinson and Ragozin (1984) utilized 105 mother-infant pairs to examine the stress-buffering effects of social support on these mothers. Results indicated that negative life stress had an impact on maternal satisfaction. Results also indicated a relationship between social support and parents'

satisfaction, such that more social support was associated with more satisfaction. This finding suggests that social support may buffer the effects of maternal stress.

It appears that children with various disabilities have differential effects on the family unit. For example, Ferrari et al. (1983) compared families of children with epilepsy and families of children with diabetes. They found that families of children with epilepsy perceived themselves as less close than families of children with diabetes. They suggested that this finding is likely due to parents' perception that the children with epilepsy are more behaviorally immature and resistive which may result from the unpredictability of epilepsy as compared to diabetes.

It is also reported that parents of children with autism tend to incur greater amounts of stress than parents of children with other disorders such as mental retardation (Fishman & Wolf, 1991; Gallagher et al., 1983; Holroyd & McArthur, 1976; Powers, 1984; Wolf et al., 1989). As mentioned above, Beckman (1983) suggested that less social responsiveness, more difficult temperament, stereotyped behaviors, and unusual care-giving demands in children with autism can lead to greater maternal stress. This profile is consistent with the typical behavior problems associated with children with autism.

However, one recent study did not replicate this finding. Donenberg and Baker (1993) compared groups of

children with externalizing behaviors (hyperactivity and aggression) to children with autism and nondisabled children. They found that parents of children with externalizing behaviors experienced as much stress as parents of children with autism and less stress than parents of nondisabled children. However, their focus was on preschool aged children. This similarity in level of stress for parents with young children found by Gallagher et al. (1983) and difference in level of stress for parents of older children found in other studies may suggest that parental stress experienced by parents of children with autism may increase as the child gets older (Gallagher et al., 1983).

#### Difficulties Associated with Autism

To some extent having a child with autism may be stressful for family members because these children display maladaptive behaviors and disciplinary challenges that are often seen among other children with disabilities such as Conduct Disorder, and ADHD. Furthermore, they display other behaviors such as social withdrawal that compound the difficulty of raising and interacting with these children. These difficulties are reflected in the current DSM-IV criteria (American Psychiatric Association, 1994) which indicate that children with autism typically have symptoms from three categories including social interaction,

impairments in communication, and restricted and repetitive patterns of behavior.

Social interaction is typically manifested by: (a) marked impairment in the use of nonverbal behaviors; (b) failure to develop peer relationships appropriate to developmental level; (c) lack of spontaneous seeking to share enjoyment, interests, or achievements with others; and/or (d) lack of social or emotional reciprocity. Qualitative impairments in communication are manifested by: (a) delay in, or lack of development of spoken language; (b) marked impairment in the ability to imitate or sustain conversation in individuals with speech; (c) stereotyped and repetitive use of language or idiosyncratic language; and/or (d) lack of varied, spontaneous make-believe play or social imitative play. Restricted repetitive and stereotyped patterns of behavior, interests, and activities are manifested by: (a) encompassing preoccupation with one or more stereotyped and restricted patterns of interest; (b) apparently inflexible adherence to specific, nonfunctional routines or rituals; (c) stereotyped and repetitive motor mannerisms; and/or (d) persistent preoccupation with parts of objects.

These difficulties likely result in detachment from others and a failure to bond with parents and other family members, making interaction and affection difficult.

Children with autism typically do not cry for attention from

their parents nor do they derive comfort from their parents when received (Schreibman, 1988). Another feature of children with autism is that they can demand environmental sameness which may likely result in more stress on the family. For example, they may have difficulty adjusting to a change in a weekly routine for a family vacation. Because of the profound aforementioned characteristics of autism and the extent to which this disability is different from other behavior disorders, it becomes especially important to delineate differences in parental stress, psychological symptomatology, and family environment in families of children with autism.

Identifying and understanding differences in the effects of stressors associated with parenting children with special needs is important for the development of interventions designed to address the specific needs of families. Although effects of stressors associated with parenting children with special needs can be predicted by previous literature (Beckman, 1983; Fishman & Wolf, 1991; Friedrich & Friedrich, 1981; Gallagher et al., 1983; Kazak & Marvin, 1984; Powers, 1984; Wolf, Noh, Fishman, & Speechley, 1989), it is important to replicate these effects by comparing families of children with different needs. Finally, because families of children with autism are thought to incur additional stressors as a result of the nature of the disability, understanding the effects of these

stressors on family functioning becomes especially important in conceptualizing the unique challenges inherent in these families, as well as in formulating interventions to ameliorate these challenges.

## Effects of Children with Disabilities on Siblings

Literature suggests that children with disabilities have an effect not only their parents, but their siblings as well. The research in this area has yielded conflictual and heterogeneous results. Many researchers suggest that children with disabilities have negative effects on siblings (Jabs, 1992; Lobato, Faust, & Spirito, 1988; Pearson & Sternberg, 1986; Powers, 1984; Slade, 1988; Vadasy, Fewell, Meyer, & Schell, 1984). Others suggest that being a sibling of a brother or sister with a disability can have positive effects on the sibling such as increased sensitivity and compassion towards others (Jabs, 1992; Lobato, Faust, & spirito, 1988; Seligman, 1983a), or will at least not automatically result in negative effects (Lobato et al., 1988; Schwirian, 1976; Stoneman, Brody, Davis, & Crapps, 1987).

Negative effects that siblings may incur as a result of their experiences include: additional stress (e.g., Devereaux, 1979; Fishman & Wolf, 1991; Lobato et al., 1988), poor psychological adjustment (e.g., Gath, 1972; McLinden, Miller, & Deprey, 1991), pressure from added responsibility for the child with special needs and from a heightened

caretaking role in the family (e.g., Caldwell & Pichert, 1985; Jabs, 1992; Powers, 1984; Seligman, 1983a; Stoneman, Brody, Davis, & Crapps, 1988; Vadasy, 1984), feelings of jealousy, anger, and/or embarrassment (e.g., Powers, 1984), increased anxiety (McKeever, 1983), and fear of "catching" the disability from the child (e.g., Seligman, 1983a, 1983b).

McKeever (1983) suggested that being a sibling of a person who is disabled is a complex stressor for the This, in part, may be a function of the sibling sibling. relationship in that siblings spend a significant amount of time with one another. Breslau et al. (1981) examined the psychological functioning of 239 families of normally developing siblings of children with cystic fibrosis, cerebral palsy, myelodysplasia, or multiple handicaps. Results indicated that, although siblings of disabled children did not manifest higher rates of psychological impairment, they did display more acting out and aggressive behaviors than siblings of normally developing children. McKeever (1983) reported that siblings of children with chronic health problems display more adjustment and behavior problems than other siblings.

Seligman (1983a) reported that normal siblings often experience feelings of embarrassment, anger, and guilt towards their brother or sister who is disabled. These feelings often result from being responsible for the child,

being taken advantage of by the child and parents, and having restricted social opportunities because the child with the disability cannot participate. Stoneman et al., (1988) found that siblings' increased responsibility for their disabled brother or sister leads to greater sibling conflict and anger and/or resentment from being socially restricted from activities and friends. San Martino and Newman (1974) suggested that guilt may be the most predominant influence on sibling adjustment because many siblings feel a sense of responsibility for the child and they do not incur the same difficulties as the child with the disability.

Seligman (1983b) suggested that siblings of children with disabilities may be concerned about "catching" the disability. As a result, they will likely experience anxiety and fear when discussing the disability or when caring for the child with the disability. In a related vein, children may have misconceptions about the course of the disorder as well.

Other factors that commonly play a role in the impact of children with disabilities on their siblings include: family income (e.g., Seligman, 1983b; Vadasy et al., 1984), age and gender of the sibling (e.g., Vadasy et al., 1984), and the nature and severity of the handicap (e.g., Gath, 1972; Vadasy et al., 1984). Seligman (1983a) suggested that socioeconomic status may be related to the amount of

responsibility a normal sibling might assume for the child with a disability. Families with a lower income may have fewer resources to care for the disabled child and rely more on the sibling for the role.

Researchers commonly find that an older female sibling is most adversely affected by a child with a disability (e.g., Jabs, 1992; Lobato et al., 1988; Seligman, 1983a; Slade, 1988). Slade (1988) reported that older sisters of children with disabilities may experience additional demands for caring for their sibling which, in turn, may lead to adjustment problems. Seligman (1983a) indicated that older female siblings may overcompensate for the child with the disability by taking on parental duties and feeling responsible for some of the caretaking. Lobato et al. (1988) indicated that older female siblings of children with the disabilities display more behavior problems, specifically anxiety and depression, than younger female siblings of children with disabilities.

Slade (1988) suggested that the nature and severity of the disability may have deleterious effects on siblings. For example, a disability requiring heightened dependence of the child with the disability on the family and siblings will likely result in increased strain and responsibility on the part of the sibling. Also, siblings may lack attention from the parents because the parents devote much of their time to the disabled child.

As mentioned earlier, siblings of children with disabilities may also encounter positive experiences or, at least, experience no negative effects of being the sibling of a child with a disability. Seligman (1983a) found that, overall, normal siblings reported a positive adaptation to having a retarded brother or sister. Researchers often find that poor psychological well-being does not automatically result from having a sibling with a disability (Lobato et al., 1988; Schwirian, 1976; Stoneman et al., 1987).

Literature examined by Lobato et al. (1988) suggested that siblings of children with disabilities are often more compassionate, sensitive, and understanding of others). Seligman (1983a) described research that suggested siblings of children with mental retardation felt comfortable bringing their friends into the home, had healthy relationships with their siblings, and were accepting and tolerant of their sibling's disability. In addition, literature suggests that the sibling relationship is particularly influential on children with disabilities because much of the child's time is spent with his/her sibling and peer interactions of the disabled child are often facilitated by the sibling (Tiedemann & Johnston, 1992).

Given the potentially wide range of effects that children with disabilities can have on their siblings, a growing body of research has attempted to enhance the

experiences that siblings encounter as a result of being the brother or sister of a child with special needs.

Researchers have conducted sibling training programs that are generally behavioral in nature and attempt to facilitate the sibling relationship of children with developmental disabilities and their normally developing brothers and sisters. In addition, a small amount of research has examined the effects of support groups for siblings of children with disabilities.

## Sibling Training

Sibling training programs typically utilize siblings of children with developmental disabilities (e.g., mental retardation, autism). The interventions are geared towards teaching the sibling to function as an agent of change to positively facilitate the sibling relationship and to have a beneficial impact on the child with special needs. These programs generally teach behavior skills to siblings to enhance the functioning and interaction of the children with disabilities. For example, Colletti and Harris (1977) demonstrated that siblings could acquire skills to modify the behavior of children with autism. Other researchers have enhanced the role of siblings as "teachers" of academic skills (e.g., Schreibman, O'Neil, & Koegel, 1983), self-care skills (e.g., Lobato & Tlaker, 1985), and domestic skills (Swenson-Pierce, Kohl, & Egel, 1987).

Schreibman et al. (1983) investigated the effectiveness of a program designed to teach behavior skills to three siblings of children with autism. Results demonstrated that siblings could learn to use behavior skills effectively and generalize those skills to other settings, resulting in behavioral improvements of the children with autism. Celiberti & Harris (1993) assessed the effectiveness of a treatment program designed to teach specific behavioral skills to siblings of children with autism that would assist them in play interactions. Three sibling dyads participated in the study which included a child with autism and a normally developing sibling. Results indicated that specific skills were easily attained and maintained over time by the siblings. James and Egel (1986) investigated the effects of sibling training on children with handicaps and their siblings. Three siblings were trained to use direct prompting and modeling when interacting with their brothers or sisters with disabilities. Results indicated that these procedures were effective in increasing sibling interaction, increasing the initiation of responses, and generalizing to children who were not directly trained.

Although it is important to involve siblings in assisting children with disabilities, sibling training programs often fail to address the full range of needs of the siblings, rather they tend to focus on ultimately improving the functioning of the children with disabilities.

In addition, many of these studies involved very small samples of children (e.g., Celiberti & Harris, 1993; James & Egel, 1986; Schreibman et al., 1983). Another limitation of sibling training interventions is that skills learned by the siblings, although helpful in facilitating the sibling relationships, may result in the siblings bearing the brunt of increased parental expectations (e.g., parents may place more demands upon the sibling because of their newly developed skills). It thus becomes important for service providers to address other needs of siblings that are often ignored in sibling training programs. These needs may be more comprehensively targeted through the use of sibling support groups.

### Sibling Groups

Research in this area is surprisingly sparse given the amount of research devoted to group interventions for parents. Well controlled studies are lacking; however, studies that do exist suggest that sibling groups enhance sibling interactions (e.g., learning to feel comfortable discussing the disability, expressing their emotions) and increase the social interaction of the siblings with their peers (Clark, Cunningham, & Cunningham, 1989; McLinden, Miller, & Deprey, 1991). Sibling groups can also help to enhance the sibling's understanding of their brother or sister's disability (Chinitz, 1981; Lobato, 1985; Schreiber & Feeley, 1965; Slade, 1987).

Schreiber and Feeley (1965) conducted a demonstration program for siblings of children with mental retardation to help them identify, clarify, and understand their role as a sibling of someone with a disability. They reported that, as a function of participation in the group, siblings learned to express and maintain more positive feelings towards the child with mental retardation, build more healthy family relationships, and rely on support from their peers. Similarly, Kaplan and Fox (1968) demonstrated that siblings were able to talk about similarities and differences between themselves and their disabled brother or They were also able to empathize with their brother or sister's view of the world which enhanced their understanding of the disability. This early research laid the groundwork for more empirical research in the area of sibling group interventions.

Clark et al. (1989) evaluated a group sibling training program designed to enhance sibling interaction through the use of role play, problem solving, homework assignments and contingency management procedures. Three children with autism and their siblings participated in the program.

Results indicated that siblings' social behavior and communication were enhanced as a result of the intervention.

McLinden et al. (1991) evaluated the effectiveness of a 6-week support group for siblings of children with special

needs. Six siblings of children with mental retardation, physical handicaps, or multiple handicaps participated in the group intervention to provide peer support and coping strategies for living with a child with a disability.

Results indicated that siblings reported having more social support as a result of the group. There was not, however, a significant effect on the participating siblings' knowledge, attitudes, and behavior.

Group interventions have been considered to be somewhat effective for siblings of children with special needs; however, there are several limitations to the existing literature. Although early literature prompted further inquiry in the area of sibling support groups, these studies were not empirically based (Schreiber & Feeley, 1965). Unfortunately, there have been only a few subsequent empirical studies that have examined the effects of support groups on siblings of children with disabilities (Clark et al., 1989; Lobato, 1985; McLinden et al., 1991). studies that do exist often use a small sample of children (e.g., Clark et al., 1989 utilized 3 subjects; Lobato, 1985 utilized 6 subjects; McLinden et al., 1991 utilized 6 subjects), or report high drop-out or poor attendance due to vacation plans or transportation difficulties (Kaplan & Fox, 1968; McLinden et al., 1991). The studies often used children with different disabilities making generalizability difficult (e.g., Chinitz, 1981; Lobato, 1985; McLinden et

al., 1991). A heterogenous subject sample also makes an educational component more cumbersome because it needs to explain a broader range of disorders, which may differ significantly in cause, course, and manifestations.

Finally, these studies fail to include a control group to distinguish group effectiveness from other possible intervening variables (e.g., Lobato, 1985; McLinden et al., 1991).

Most relevant to the intervention component of this investigation, is that literature suggests that some of the negative effects of children with disabilities on siblings may be secondary to parental factors. For example, the parents' attitude about the disabled child can directly impact the sibling (Lobato et al., 1988; Slade, 1988). As discussed earlier, siblings may incur added responsibilities for the child with the disability (e.g., Caldwell & Pichert, 1985; Powers, 1984; Seligman, 1983a; Stoneman et al., 1988; Vadasy et al., 1984); they may feel taken advantage of due to this added responsibility and/or they may feel resentment due to restrictions on their social opportunities (Seligman, 1983a); or parents may not give the sibling the attention he or she wants because of the attentional demands of the child with special needs (Slade, 1988).

As seen above, there is a small amount of literature that examines the impact of "parent effects" on sibling functioning. However, other bodies of literature do exist

that suggest that parents' behaviors and attitudes have an impact on children in general. Most of the literature examines effects of parents on children in general (Goodman, & Brumley, 1990; Orvaschel, Mednick, Schulsinger, & Rock, 1979; Reider, Broman, & Rosenthal, 1977; Walker & Emory, 1983), or on children with behavior problems (Dadds, Schwartz, & Sanders, 1987; Fendrich, Warner, & Weissman, 1991; Walter, Downey, & Bergman, 1989) and disabilities (Atkins, 1989; Howlin, 1988; Trevino, 1979; Tritt & Esses, 1988). As will be seen in the next section, one can turn to this literature to support the need to examine the role of parents in addressing the many challenges of siblings of children with disabilities. In addition, parents of children with autism are likely to be especially influential on siblings in the family and may not be in a position to meet the needs of siblings because of the high demands of the child with autism.

### Parents Influence on Children's Functioning

Researchers suggest that parents have a strong effect on their children's well-being. The impact is most often studied in the context of families in which a parent has some form of psychopathology. It has been shown that parents who suffer psychological disorders such as schizophrenia and depression tend to have deleterious effects on their children (e.g., Goodman, & Brumley, 1990; Orvaschel, Mednick, Schulsinger, & Rock, 1979; Reider,

Broman, & Rosenthal, 1977; Walker & Emory, 1983). Some of these effects may include: more behavior problems displayed by the children (Fendrich, Warner, & Weissman, 1991; Walter, Downey, & Bergman, 1989) and higher risks for antisocial behavior (Silverton, Harrington, & Mednick, 1988). However, it is difficult to delineate whether or not the parents' problems caused these behaviors, or the children's behaviors caused the parents' problems.

Another problem the children may encounter is higher risks for incurring the disorder (Fendrich et al., 1990; Goodman & Brumley, 1990; Mednick, 1973; Rieder et al., 1977; Walker & Emory, 1983). For example, Fendrich, Warner and Weissman (1990) found that risk factors common in families of parents with major depression such as: marital discord, divorce, parent-child discord, and family cohesion were predictors for depression, conduct disorders, and any other diagnoses in offspring.

Other, less severe, parental problems have also been found to affect the well-being of children. For example, marital adjustment tends to have effects on children (Doherty & Needle, 1991; Emery, Weintraub, & Neale, 1982). Doherty & Needle (1991) examined the well-being of adolescents before and after parental divorce. They found that boys demonstrated ill effects after the divorce and girls showed negative reactions prior to separation. Emery et al. (1982) examined the effects of parent psychopathology

and marital discord on children. They found that the presence of both these variables negatively affected their children's school behavior.

Research also suggests that parents have an especially strong influence on children with behavior problems or other related disorders, as these children already experience stressors and difficulties uncommon to normally developing children. Dadds, Schwartz and Sanders (1987) found that marital discord has an effect on children with conduct disorders such that the level of maternal aversiveness towards those children was higher in groups of parents who were experiencing marital discord.

In addition, parents have an effect on siblings of children with disabilities as a result of dealing with difficulties associated with parenting a child with special needs (Atkins, 1989; Howlin, 1988; Trevino, 1979; Tritt & Esses, 1988). Atkins (1989) suggested that siblings can be strongly influenced by their parents' attitudes and expectations of children with disabilities. Trevino (1979) suggested that parental anxiety or depression and guilt resulting from giving birth to a disabled child can have deleterious effects on the siblings, such as altering social roles, increased expectations by the parents, and lack of attention from parents. Also, there may be parental inconsistencies in attitudes and behaviors towards the disabled child and the normally developing sibling that

result in difficulties for the sibling. Since Howlin (1988) found that parents' ability to convey positive attitudes towards the child with special needs and open communication in the family enhances siblings' adjustment, one may assume that the absence of those abilities may have a negative effect on siblings.

The impact that parents have on siblings of children with disabilities prompts researchers and clinicians to devise means of enhancing parenting skills and improving parent and sibling relationships. This process entails reducing the negative effects (e.g., decreasing stress, family conflict) and enhancing the positive effects (e.g., increasing parental competence, problem solving skills, coping skills) of parents on siblings and children with disabilities. Recent parent training literature suggests that parents can play an important role in the functioning of children; therefore, it is beneficial to include them in the change process.

It is important to examine the literature on parent training as it represents the most frequent method of including parents in the process of change (e.g., Adesso & Lipson, 1981; Brightman et al., 1982; Eyeberg & Matarazzo, 1980; Mash & Terdal, 1973; Webster-Stratton et al., 1990). These interventions are typically geared towards parental involvement to enhance the functioning and behavior of children with special needs and not the siblings of those

children. Therefore, the following discussion of parent training will not be exhaustive. However, it is hoped that this literature can serve as a springboard for research that would demonstrate that parents can not only improve the functioning of the children with special needs, but learn to enhance the adjustment of siblings as well.

# Parent Training

Research examining the efficacy of parent training suggests that it is frequently used to enhance parenting skills, especially for parents of children with special needs (Dadds & McHugh, 1992; Diament & Colletti, 1978; Karoly & Rosenthal, 1977; Mash & Terdal, 1973; Rinn, Vernon & Wise, 1975). It is suggested that parent training enhances family cohesiveness, reduces family conflict, and reduces the number of deviant behaviors displayed by children (Adesso & Lipson, 1981; Karoly & Rosenthal, 1977; Mash & Terdal, 1973). Parent training programs more frequently involve teaching parents behavior skills in a group (e.g., Karoly & Rosenthal, 1977), individual parent training (e.g., Adesso & Lipson, 1981; Hornby & Singh, 1983; Mash & Terdal, 1973), or interaction-oriented interventions through modeling, practice and feedback (Eyeberg & Matarazzo, 1980). Parent training using behavioral interventions is said to have beneficial effects on the family as a whole. Some of these benefits include: decreased deviant behavior patterns of their children

(Adesso & Lipson, 1981), less psychologically stressful home environments (Karoly & Rosenthal, 1977), and increased knowledge of parents' behavior skills (Diament & Colletti, 1978).

Parent training in behavioral skills is most commonly used with children with special needs including: behavior problems (e.g., Eyberg & Matarazzo, 1980), conduct disorders, mental retardation (e.g., Baker, & Brightman, 1984; Dadds & McHugh, 1992; Mash & Terdal, 1973), ADHD (e.g., Pisterman, McGrath, Firestone, Goodman, Webster, & Mallory, 1989), and autism (Handleman & Harris, 1986; Moran & Whitman, 1991).

A limited amount of research has been conducted which suggests that parent training can have positive effects on parents as well as the children targeted for training.

Baker, Landen and Kashima (1991) examined 49 families of children with mental retardation in a parent-training program focused on self-help and behavior skills. They reported that parents showed decreased levels of depression, less parent and family problems, less family stress, and more satisfaction with family adaptability and cohesion.

Parent training studies for parents of children with autism have reported positive results in light of the difficulties associated with parenting a child with autism. Moran and Whitman (1991) designed an educational program to assist parents of children with autism in teaching adaptive

skills. Results indicated that the program was effective in modifying maternal teaching behaviors, child play, and inappropriate behavior of the children with autism. Harris (1987) examined the long-term maintenance of a behavioral intervention for parents of preschool children with autism. Results indicated that behavioral techniques taught in the intervention were still being used by most parents four to seven years after the training program. Although this particular study indicated positive maintenance of the behavioral techniques, it is an exception to the common difficulties with maintenance of other techniques frequently found in the literature.

## Limitations of Parent Training

Although parent training using behavior skills has been deemed quite effective (Adesso & Lipson, 1981; Brightman et al., 1982; Karoly & Rosenthal, 1977; Hornby & Singh, 1983; Rinn, Vernon, & Wise, 1975), many of the parent behavior training studies have methodological problems as indicated by Hornby and Singh (1983). Studies often fail to mention adequate descriptions of the client population, do not supply enough information on the recruitment procedures, and fail to mention specifics of the trainers and training sessions and they utilize mothers and do not include fathers (e.g., Eyeberg & Matarazzo, 1980; Mash & Terdal, 1973). Also, many of the studies failed to explicitly define the content of the training sessions, the goals of the

intervention, and procedural descriptions. The measures employed are often inadequate and reliability checks are often not conducted on the measures (Hornby & Singh, 1983). This lack of information impedes replication of the studies by other investigators.

Another area of concern for behaviorally informed researchers is the common finding that follow-up data on the behavioral interventions reveal poor maintenance effects over long periods of time (Harris, 1984). This suggests that behavioral parent training may have less than optimal long-term effects on parenting skills, on parent-child interactions, and on family functioning as a whole. Therefore, it is important to refine interventions to address areas that maintain the skills obtained through behavioral interventions over extended periods of time.

Of particular relevance to the present investigation is the notion that traditional parent training should be expanded to address areas that surpass management of child behavior. Some of these areas may include parental and sibling stress, sibling relations, and marital satisfaction (Harris, 1984). Only a sparse amount of research has been conducted that attempts to address areas other than behavior management and functioning of the disabled child. One important area of research that attempts to expound on behavior management and functioning of children with

disabilities is parents' management and facilitation of sibling relationships.

## A Family Systems Perspective

The importance of understanding siblings' influence on each other, parents' effects on children, and children's effects on parents has been illustrated above. However, there is another aspect of these reciprocal relationships that must be considered when studying family relationships. Family systems literature suggests that family members' actions and behaviors are directly linked to the actions and behaviors of every other family member. In other words, a family operates through a series of transactional patterns where each member of the family will react and/or be influenced by an event or situation that occurs within the family (Minuchin, 1974). These patterns, once established, regulate the family members' behavior. With this in mind, it makes sense that having a child with a disability in the family would lead to certain reactions or behaviors by each of the other family members which, in turn, influence the child with the disability (Vadasy et al., 1984). Because of the everyday interactions that occur between parents and children, it becomes important to consider the functioning of the family as a unit, as well as the functioning of the child with the disability, the parents, and the siblings as separate entities.

exchange theory in relation to families with children with autism. His theory suggests that parents and children inadvertently end up reinforcing maladaptive behaviors in one another, bringing the role of the entire family to the forefront. For example, acting-out behavior of a child with autism elicits attention from parents because the parents want to decrease or diminish that behavior. In other words, a child's action leads to a parental action. In turn, the parental action may influence the behavior of the child with the disability, as well as other members of the family who are involved in the interaction.

Because of the severe nature of autism, it becomes important to understand the impact of the disorder on the family unit and the potential reactions of the family members to the manifestations of autism. In order to gain this understanding, it may be beneficial to involve as many family members as possible in an intervention that focuses on family interactions, as well as individual behaviors and needs. In addition, interventions should present information at a level appropriate to each member.

# Parents' Management of Sibling Problems

The few studies that have examined the special role of parents as a facilitator of sibling relationships also provide indirect support for the role of mothers in enhancing the functioning of siblings of children with

autism (Adams & Kelley, 1992; Glogower & Sloop, 1976; Leitenberg, Burchard, Burchard, Fuller, & Lysaght, 1977; O'Leary, O'Leary, & Becker, 1967; Olson & Roberts, 1987; Tiedemann & Johnston, 1992). Although most of the research in this area is focused on using behavioral interventions, the notion that parents, particularly mothers, can play a facilitative role in improving the sibling relationship, by understanding and intervening in the relationship, is important to the current investigation.

O'Leary et al. (1967) utilized parents to apply a set of procedures (prompting, shaping, and instructions to increase cooperative behavior) to improve the behavior of two siblings. They found that parental facilitation of sibling interaction decreased the amount of problem behaviors displayed by the siblings. Olson and Roberts (1987) compared three parent training interventions (Social Skills training, Timeout, and Combination) to facilitate the relationship between aggressive pairs of siblings. found that children in the timeout and combination groups displayed significantly less aggressive behavior following the intervention. Adams and Kelley (1992) conducted a similar study comparing parents' use of timeout (i.e. isolating the child for a specific period of time) and overcorrection methods to reduce sibling aggression (i.e. having the child correct the results of the behavior and practice the correct behavior). They also found that both

training procedures resulted in decreased aggression among siblings.

Tiedemann and Johnson (1991) compared an individual parent-training format and a group format for teaching parents skills to facilitate sibling sharing, a behavior deemed important in promoting positive sibling relationships. Forty-eight families participated in one of the two training programs. Results indicated that both programs demonstrated increased sharing in the siblings when compared to a wait-list control group.

The above bodies of research demonstrate that parents can play a role in enhancing children's functioning and facilitating sibling relationships. The research suggests the potential value of including parents in the process of addressing the needs of siblings of children with disabilities. It is, therefore, important to develop a means of addressing the siblings' needs through the direct involvement of parents. One way that this may be accomplished is through the use of concurrent sibling and parent support groups. Very little literature addresses the parent management of sibling relationships when one child has a severe disorder such as autism. Therefore, it also seems important to examine parents' roles in the facilitation of sibling relationships of this sort, as they are potentially strained by stressors associated with the disability.

### Rationale

Study 1. Parents of children with autism were targeted for this study because they may endure additional stress and difficulties due to the nature of autism. A comparison group of mothers of children with ADHD was utilized because children with ADHD exhibit behavioral challenges much like those of children with autism and their mothers also endure stress related to parenting these children. In addition, there are differences between children with autism and ADHD in terms of sociability which may affect the parenting of these groups of children differently. These two groups were compared to a third group of mothers with normally developing children to delineate perceptions of sibling functioning between these groups and to examine differences in maternal functioning as a result of having a child with a disability in the family. This delineation is important for determining target areas for future interventions and designed to address the needs of siblings of children with disabilities, as well as the needs of the mothers who care for these children. It can also help to determine differences in functioning as a result of parenting children with different disabilities (i.e., autism or ADHD), or no disabilities (i.e., control group).

Maternal functioning for this study was defined as level of psychological symptomatology, level of stress from parenting, and parenting sense of competence. Maternal

functioning was assessed using specific standardized measures of these constructs including the Hopkins Symptom Checklist (HSCL); the Parenting Stress Index (PSI); and the Parenting Sense of Competence Scale (PSOC).

The HSCL is a measure of psychological symptomatology that is often helpful in identifying symptoms that may indicate poor psychological well-being (Derogatis, Lipman, Rickels, Uhlenhuth, & Covi, 1974). Symptoms suggesting anxiety, depression, somatization, obsessive-compulsive tendencies, and interpersonal sensitivity are measured with this scale. Such information is useful in determining if stressors related to parenting children with disabilities lead to some of these symptoms. Although this instrument is not commonly used in this body of literature, it may assist in understanding the relationship between mothers' psychological symptomatology and parenting a child with a disability.

The PSI is an instrument designed to identify areas of the parent-child dyad where stress may be incurred and where there is a risk for dysfunction. This instrument examines the parent domain (which identifies facets of parents' functioning that may be leading to stress in the relationship) and the child domain (which identifies times where children may engage in behaviors that bring stress into the relationship) (Loyd & Abindin, 1985). In this study, the PSI was administered to mothers in regards to the

sibling, as opposed to the child with autism. Previous researchers have utilized this measure to assess parenting stress (e.g., Donenberg & Baker, 1993; Fishman & Wolf, 1991; Kazak & Marvin, 1984; Webster-Stratton, 1992; Webster-Stratton et al., 1988; Wolf et al., 1989).

The PSOC measures mothers' perceptions of their ability to competently parent their children in a number of basic areas. This scale is important in gaining an understanding of mothers' views of their own parenting skills and abilities. Self-perceptions of parenting competence is important in this context because parents with difficult parenting roles (such as parenting a child with autism) may perceive their own parenting skills as less adequate than parents with normally developing children. Above mentioned researchers have used this measure to examine parenting competence (e.g., Donenberg & Baker, 1993; McBride, 1991; Rodrigue et al., 1990; Tiedemann & Johnston, 1992).

Maternal perceptions of the family environment and maternal perceptions of the siblings' behavior and social competence were also assessed. To measure these constructs the Family Environment Scale (FES) and the Child Behavior Checklist (CBCL) was utilized. The FES is one of the Social Climate Scales designed to gain an understanding of an individual's vast environmental settings and their effects on functioning and well-being. The FES focuses specifically on the important aspects of family roles and relationships.

In this study, mothers completed the FES. It is important to measure mothers' perceptions of their family to see if mothers who have children with disabilities perceive their family environment as being different than mothers of normally developing children. Previous researchers have utilized the FES to assess family environment (e.g., Billings & Moos, 1981; Friedrich et al., 1985; Karoly & Rosenthal, 1977; Margalit et al., 1992)

The CBCL is a measure of parents' perceptions of the children's behavior and social competence. The CBCL was administered to mothers in order to gain an understanding of the different perceptions of the siblings of children with autism (Group 1); siblings of children with ADHD (Groups 2); and siblings of normally developing children (Group 3).

Above mentioned researchers have used the CBCL to assess parents' perceptions of children's behavior (e.g., Margalit et al., 1992; McLinden et al., 1991; Tiedemann & Johnston, 1992; Webster-Stratton, 1992; Webster-Stratton & Hammond, 1990; Webster-Stratton et al., 1988).

As mentioned, measures of parenting stress and mothers' perceptions of children's behaviors, competence, and expectations, focused on the siblings of children with autism, ADHD, and other children, as opposed to the children with the disability or comparison children. This approach has not been applied in previous literature.

It is necessary to assess the differences in maternal functioning and maternal perceptions between these groups for a number of reasons: 1) Differences in parenting stress and psychological functioning between parents of children with autism and parents of children with other difficulties has been suggested by the literature; however, it is important to delineate where these differences lie so that specific problems in maternal functioning can be addressed; 2) It is important to determine if mothers are also experiencing stress and difficulties with other children in the family (i.e. the sibling) and not just the child with autism. One might speculate that the negative effects of raising a child with autism would have an impact on parenting other children in the family. This study examined this possibility empirically.

Study 2. The intervention component of this investigation (Study 2) attempted to address some of the limitations of previous sibling interventions by directly involving mothers in an intervention, by providing an empirical study with a larger sample of mothers and siblings (N=16), and including a wait-list control group. This investigation took precautions against high drop-out rates and/or poor attendance by screening out subjects with prior commitments, maintaining a transportation fund for travel problems, providing baby sitting services for the children with autism, providing a brief intervention (6 sessions),

and removing potential financial hardships by not charging families for participation. A homogeneous sample of subjects (mothers and siblings of children with autism) was utilized so that results would generalize to other interventions designed for this specific population of families. Maternal involvement in the intervention likely decreased the siblings' responsibility to make positive changes in their relationships with the children with autism. It also likely buffered some of the deleterious effects parents have on siblings that result from parenting a child with autism. Parent training literature attempts to involve parents in the process of enhancing the functioning of children with autism; however, it fails to address the needs of the siblings.

As described earlier, parent training programs have limitations that should be addressed. This study addressed these limitations by describing the client population and recruitment procedures in more detail than much of the literature (see methods section). In addition, measures were chosen based on their use in previous literature and their sound psychometric properties. Attempts were made to sustain the effects of the intervention over time by extensively discussing methods to maintain and generalize skills, knowledge, and coping strategies with mothers. This study did not address the use of fathers in the change process as their inclusion in the study would have

drastically reduced the number of the families that would be able to participate, as sessions were offered on weekday afternoons.

In addition to attempting to avoid the methodological shortcomings of sibling and parent training programs and support groups, this investigation attempted to address the needs of the siblings by involving the mothers in the intervention. It also likely met some of the needs of the parents, both directly through the parent groups and indirectly through the sibling groups (parents who filled out questionnaires, but did not participate in a parent group). The effects of the actual intervention were better delineated by including a wait-list control group.

The objectives of this intervention were to address the stress, psychological well-being, and other difficulties associated with parenting a child with autism. The intervention attempted to: 1) assess the effects of a concurrent parent-sibling intervention on the parents' knowledge, attitudes and functioning; 2) compare these effects with a group that derived indirect benefits from participation; and 3) monitor these changes over time (via a 4 week follow-up) to examine continuing intervention effects. This parent intervention served as a source of social support for parents of children with autism. It is hoped that the intervention served the following functions: alleviated some parental stress, particularly as it relates

to parenting; improved psychological well-being; enhanced parents' perceptions of their children; and taught parents behaviors that facilitate the sibling relationship and enhance sibling functioning.

# Hypotheses for Study 1

## Differences in maternal functioning between groups.

Hypothesis 1: Group 1 (mothers of children with autism), Group 2 (mothers of children with ADHD), and Group 3 (mothers of children in the community) will differ in reported degree of psychological symptomatology reported as measured by the HSCL. Mothers of siblings of children with autism will report the most psychological symptomatology, followed by mothers of children with ADHD, followed by mothers of normally developing children.

Hypothesis 2A: Groups 1, 2, and 3 will differ in reported parental stress level. Mothers of siblings of children with autism will report experiencing the greatest amount of parenting stress on the Parent Domain of the PSI.

Hypothesis 2B: When completing the Child Domain of the PSI with respect to the sibling, mothers of children with autism will report experiencing less parenting stress than mothers of children with ADHD or normally developing children. This predicted direction is based on the idea that siblings are considered to be less of a source of stress than the children with autism because they are less demanding of parental attention.

Hypothesis 3: Groups 1, 2 and 3 will differ on the measure of maternal sense of parenting competence as measured by the PSOC, such that mothers in Group 1 will display a lower level of parenting competence than mothers in Group 2 who will display a lower sense of parental competence than mothers in Group 3.

Hypothesis 4: Groups 1, 2 and 3 will differ in their perceptions of the family environment as measured by the FES. Mothers in Group 1 will perceive their family environment more negatively than mothers in Group 2 who will perceive their family environment more negatively than mothers in Group 3.

Hypothesis 5: There will be differences between Groups 1, 2, and 3 on the measure of maternal perceptions of siblings' behaviors and social competence as measured by the CBCL. Mothers in Group 1 will display more positive perceptions of the siblings' behaviors and social competence when compared to mothers in Groups 2 and 3. This predicted direction differs from the other hypotheses because the entire measure is completed with the sibling without autism in mind who may be viewed as an overachiever in families of children with autism. This may be due to a need for the sibling to compensate for the difficulties inherent in raising a child with autism or it may be due to decreased parental attention to the sibling.

Hypothesis 6: Mothers in Groups 1, 2, and 3 will differ in their perceptions of their parenting skills of the siblings as measured by the Mother's Report Card. This measure asked mothers to rate their skills in parenting the sibling by assigning grades for themselves from "A" to "F." Mothers of children with autism will perceive their parenting skills of the sibling as less adequate than mothers of children with ADHD, who will perceive their skills as less adequate than mothers of children from the community. Therefore, mothers of children from the community will assign themselves higher grades than mothers of children with ADHD who will assign themselves higher grades than mothers of children with autism.

#### Hypotheses for Study 2

Prior to delineating the hypotheses for Study 2, it is necessary to provide an overview of the subject breakdown. The mothers of children with autism (Group 1) were assigned to one of four subgroups in order to compare a standard intervention (where only siblings participated in a group intervention) with a deluxe intervention (where mothers and siblings participated concurrently in a group intervention), and to compare these interventions to a wait-list control group (where mothers and siblings participated immediately following the first intervention) (see Figure 1). All siblings in Study 2 participated in sibling the

intervention; however, only about half of the mothers participated in the group intervention for mothers.

For clarification, the mothers who participated in the intervention along with their children are in the "deluxe intervention." Mothers who did not participate in the intervention, but whose children did participate, are in the "standard intervention." Group 1A included mothers who completed paperwork only and whose children participated in the first sibling group. Group 1B included mothers and their children who participated in the first concurrent parent/sibling group. Group 1C included mothers and siblings who were initially assigned to a wait-list control group and who then participated in the second concurrent parent/sibling group. Group 1D included mothers and their children who were initially assigned to a wait-list control group followed by mothers who completed paperwork only and siblings who participated in the second sibling group.

Effects of the Intervention for Mothers of Children with Autism. Hypothesis 7A: Mothers in the deluxe intervention will report less psychological symptomatology then mothers in the standard intervention at post-intervention, as measured by the HSCL. Mothers in the standard intervention will report less psychological symptomatology at post-intervention than mothers in the wait-list control group. This finding is expected due to the elements of the intervention designed to directly

address the needs and concerns of the mothers in the deluxe groups and to indirectly address the needs of the mothers in the deluxe and standard conditions by addressing the siblings' needs.

Hypothesis 7B: Mothers in the deluxe intervention will report a decrease of psychological symptomatology over time, from pre- to post- to follow-up data collection, when compared to mothers in the standard intervention. Given the indirect nature of this intervention, it is not likely that this decrease will approach statistical significance.

Hypothesis 8A: Mothers in the initial deluxe intervention will show less parenting stress as measured by the PSI, at post-intervention than mothers in the initial standard condition at post-intervention. Mothers in these two conditions will show less parenting stress than mothers in the wait-list control condition at post-intervention data collection.

Hypothesis 8B: Mothers in the deluxe intervention will report a decrease in parenting stress over time, from predata collection to post-data collection to follow-up data collection, when compared to mothers in the standard intervention.

Hypothesis 9A: Mothers who initially participated in the deluxe or standard interventions will display higher levels of parenting sense of competence, as measured by the PSOC, when compared to mothers in the wait-list control condition immediately following the intervention.

Hypothesis 9B: The group intervention for mothers in deluxe condition will result in an increase in mother's perception of parenting competence over time (when comparing pre-, post- and follow-up data) when compared to mothers in the standard condition.

Hypothesis 10A: Mothers in the deluxe intervention will perceive their family environment as more cooperative and favorable, as measured by the FES, than mothers in the standard intervention at post-intervention data collection. Also, mothers in the deluxe and standard interventions will perceive their family as more cooperative and favorable than mothers in the wait-list control group at post-intervention data collection.

Hypothesis 10B: Mothers in the deluxe intervention will perceive their family environment to be more favorable than mothers in the standard intervention from pre- to post- to follow-up data collection.

Hypothesis 11A: Mothers in the initial deluxe condition will show a more positive perception of the sibling's behaviors and social competence, as measured by the CBCL, than mothers in the initial standard condition at post-data collection. Mothers in both these conditions will show a more positive perception of the sibling's behaviors and

social competence than mothers in the wait-list group as measured by post data.

Hypothesis 11B: Mothers who participated in the deluxe intervention will perceive the sibling's behaviors and social competence to be greater over time, from pre- to post- to follow-up data collection than mothers who participated in the standard intervention.

Hypothesis 12A: Mothers in the deluxe intervention will show more positive perceptions of their parenting skills of the siblings, as measured by the Mother's Report Card, than mothers in the standard intervention at post-intervention. Mothers in the standard intervention will show more positive perceptions of their parenting skills of the siblings than mothers in the wait-list control condition at post-intervention.

Hypothesis 12B: Mothers in the deluxe intervention will rate themselves higher than mothers in the standard intervention on their parenting skills of the siblings over time, from pre- to post- to follow-up data collection.

Hypothesis 13: Mothers in the deluxe intervention will rate themselves lower on the Retrospective Report Card, which asks them to re-evaluate their perceptions of their sibling parenting by giving themselves the grade they believe they should have received prior to the intervention, then they did on the pre-test Mother's Report Card. This would suggest that they over-estimated their abilities prior

to the intervention based on parenting skills and knowledge of sibling issues learned in the intervention. However, mothers in the standard intervention would rate themselves the same on the Retrospective Report Card and the pre-test Mother's Report Card because they did not have an intervention to prompt evaluation of their parenting skills.

Hypothesis 14A: On the Report Card for the Group, the supplemental portion of the Post-treatment Consumer Satisfaction Scale, and the Follow-up Consumer Satisfaction Scale, mothers in the deluxe intervention will rate the overall intervention experience as positive and beneficial.

Hypothesis 14B: Mothers in the deluxe and standard interventions will rate the sibling groups positive, in terms of meeting the needs of the siblings on the Posttreatment Consumer Satisfaction Scale and the Follow-up Consumer Satisfaction Scale.

#### CHAPTER II

#### METHOD

### Study 1

Participants. Twenty-six mothers (Group 1) of children with autism who also have a normally developing child participated in the study. The normally developing sibling was between the ages of 4 and 12 and no more than 6 years older or younger than their brother or sister with autism.

Twenty-four mothers (Group 2) of children who were reported by their mothers to have Attention Deficit Hyperactivity Disorder (ADHD) also participated in the study. The presence of this diagnosis was specifically reported by the mother in each family. At least one sibling in each of these families was between the ages of 4 and 10 and no more than 6 years older or younger than their brother or sister. There were no other siblings in the family with developmental delays and/or other serious physical illnesses or conditions, as confirmed by the mother.

Twenty-four mothers (Group 3) of children from the community with no prior history of psychiatric, medical, or learning problems participated in the study. At least one sibling of the children from the community was between the ages of 4 and 12 and no more than 7 years older or younger than their brother or sister. Siblings and children with

autism (Group 1), children with ADHD (Group 2), and children from the community (Group 3) resided in the same home and had no known psychiatric diagnoses or learning disabilities that might contribute unique sources of stress to their families. This information was confirmed by the mother.

Subject Recruitment. Several means of recruiting subjects were utilized to obtain the three groups of mothers. Subjects in Group 1 were recruited through professionals involved with programs for children with autism and their families in the Dallas-Fort Worth metroplex area. Professionals were contacted by mail and/or These programs included: independent school districts, special education facilities, parent support groups, and other parent organizations. Professionals in the community who had considerable involvement with this population were contacted. In addition, editors of autism newsletters were asked to print an announcement about the study. Announcements indicated that any interested parent should call for more information. Recruitment was also conducted through newspaper and radio public service announcements. Follow-up phone calls were often conducted in order to make an exhaustive effort at gaining a sufficient number of subjects for the study.

Interested parents received an introductory letter briefly explaining the intervention and a consent form to sign. The siblings also received an introductory letter and

an assent form to sign (see Appendix A). In exchange for the families' participation in the study, the families recruited during the summer (n=18) were offered a cost-free, sibling or mother/sibling intervention designed to address siblings' and mothers' issues and concerns. families who participated in the study in October, 1994 were offered a half-day sibling support group and parent workshop. The sibling support group was a condensed version of the intervention offered during the summer. The parent workshop was offered for both mothers and fathers and consisted of a brief overview of the information presented in the summer intervention. In order to acquire additional families, presidents of the local chapters of the Autism Society of America were contacted and asked to pass out flyers at their monthly meetings. Three additional families were acquired through this method of recruitment.

Subjects in Group 2 were recruited through clinicians at the UNT Psychology Clinic who are responsible for providing services to children being seen at the clinic. Flyers were distributed throughout the clinic to elicit participation from student clinicians (see Appendix A). Other clinic directors and psychologists working in clinics throughout the metroplex and leaders of ADHD support groups were also contacted and asked to distribute information about the study to members of the groups. Interested

parents were asked to complete a consent form prior to participating in the study (see Appendix A).

Researchers attended three ADHD support group meetings in an attempt to recruit subjects through direct contact. Flyers were given to recruiters explaining the study and requesting that interested families contact the researchers for more information (see Appendix A). Finally, press releases were placed in several local newspapers in an attempt to recruit the families of children with ADHD. Researchers then called those families to provide further information about the study and to determine whether or not they met the criteria for participation. Subjects in Group 2 were informed that their participation in the study would in no way affect their treatment at the clinic in which they were being seen. As an incentive for participation in the study, siblings were entered in a drawing for fifty dollars.

Subjects in Group 3 were recruited through flyers placed around the University of North Texas campus and other sites including day care centers, schools and churches (see Appendix A). In addition, announcements were made to students in psychology classes providing extra credit for mothers who had at least two children that fit the criteria for the study. Finally, an ad was placed in the University newspaper explaining the study itself and the eligibility criteria. As an incentive for participation in the study, siblings were entered in a drawing for fifty dollars.

Interested families were asked to complete consent and assent form prior to their participation in the study (see Appendix A).

#### Data Collection

Baseline data for Study 1 for Groups 1, 2 and 3 were collected by 4 doctoral students in the clinical and counseling programs. Students were trained in assessment procedures through a two semester graduate assessment sequence and had administered similar measures to students and clients. Upper-level undergraduate research assistants also assisted with data collection after being trained by graduate students and the faculty supervisor. These undergraduate assistants were closely supervised in the data collection process.

After obtaining informed consent, mothers in Groups 1, 2, and 3 were administered a series of pen and pencil measures. A set of standardized instructions was constructed that was read from a protocol in its entirety to each mother. Measures administered included the following: a demographic questionnaire; the Hopkins Symptom Checklist; the Parenting Stress Index; the Parenting Sense of Competence Scale; The Family Environment Scale; the Child Behavior Checklist; and the Mothers' Report Card. The measures were administered in a standardized order and shorter and longer questionnaires were initially interspersed. Data collection for Groups 1, 2, and 3 took

place in the UNT Psychology Clinic and/or in the homes of the participants. It ranged from 1 to 2.5 hours per family. It began in the Summer of 1994 and continued through the Summer of 1995. For the purposes of confidentiality, data were coded, prior to administration, as to not identify subject or group membership.

As mentioned, Group 1 data for Study 2 (those families who participated in the intervention) were collected on three or four occasions (depending on group assignment).

Baseline data were collected prior to the intervention.

Other administrations included: a second baseline administration for the wait-list control group, post-intervention, and follow-up four weeks after the intervention for all families. In addition to the measures described above, subjects participating in Study 2 completed a Retrospective Report Card, Report Card for Group Intervention, Post-treatment Consumer Satisfaction Measure, and a Follow-up Consumer Satisfaction Measure.

Trained undergraduate and graduate research assistants scored the various questionnaires under the supervision of the faculty advisor. All protocols were scored twice and checked for scoring accuracy by at least one graduate student or an advanced undergraduate student. All data were then recorded on data coding sheets by undergraduate research assistants and re-checked for accuracy by different research assistants.

### Measures

Demographic Questionnaire. A questionnaire of basic demographic information was administered which differed slightly for Groups 1, 2 and 3. The questionnaire for Groups 1 and 2 asked more specific information about types of schooling and learning disabilities or other difficulties. Each version contained items regarding age, grade, gender, type of school, activities their child was involved in, racial/ethnic background, family constellation, marital status, education level, income level, and specific questions related to the children's disabilities. a supplemental portion of the demographic questionnaire for Group 1 subjects who participated in the intervention to address prior discussion of the intervention with the siblings and to find out why the parents were interested in participating and to anticipate any concerns they may have about the intervention (see Appendix B).

Hopkins Symptom Checklist. The Hopkins Symptom
Checklist (HSCL) is a 58-item self-report measure assessing symptoms suggesting psychological distress (Derogatis et al., 1974). The HSCL is scored on five underlying dimensions including: Somatization; Obsessive-compulsive; Interpersonal sensitivity; Anxiety; and Depression. Higher scores on this measure indicated higher levels of psychological symptomatology and lower scores indicated lower levels of symptomatology. Internal consistency

reliability for a normative sample of 1,485 psychiatric outpatients and normals ranged from .84 to .87 on each of the dimensions. Test-retest reliability for a sample of 425 anxious neurotic outpatients ranged from .75 to .84. (see Appendix B). The alpha internal consistency reliability coefficient for the entire scale with this sample of families from the metroplex with children with autism, ADHD, or no known disability was  $\alpha = .92$ .

Parenting Stress Index (PSI). The Parenting Stress Index (Abidin, 1986) is a self-report measure. Although this measure has two versions: a short version (36-items) and a long version (120-items), the latter was used in this Items addressed various areas of life stress study. incurred as a result of being a parent. The measure was a Likert-type rating scale with responses ranging from 1 (strongly agree) to 5 (strongly disagree). Higher scores on this measure indicate higher levels of stress related to parenting and lower scores indicate lower levels of parenting stress. Domains addressed in the long version of this inventory include a Child Domain and a Parent Domain. Items on the Child Domain address: Adaptability, Acceptability, Demandingness, Mood, Distraction/ Hyperactivity, and Reinforcement of Parent. Items on the Parent Domain address: Depression, Attachment, Restriction of Roles, Sense of Competence, Social Isolation, Relationship with Spouse, and Parent Health. These domains

are designed to identify areas of parent and child functioning that are at risk due to experienced stress. Questions focus on parental perceptions of the child's behaviors. For this study, mothers focused on the siblings when completing the measure, rather than the child with the disability.

Alpha reliability for the Parent Domain for a sample of 534 parents was  $\underline{\alpha} = .93$ . Alpha reliability on the Child Domain for the same sample was  $\underline{\alpha} = .89$  (Loyd & Abindin, 1985). The alpha internal consistency reliability coefficient for this sample of subjects was  $\underline{\alpha} = .95$ .

Parenting Sense of Competence Scale. The Parenting Sense of Competence Scale is a 17-item self-report measure assessing self-esteem in the parenting role (Gibaud-Wallston & Wandersman, 1978). The measure was a Likert-type rating scale with responses ranging from 1 (strongly agree) to 7 (strongly disagree). Higher scores on this measure indicated higher levels of parenting competence and lower scores indicate lower levels of competence in parenting The scale consists of two subscales: skills. Skill/Knowledge and Valuing/Comfort. The Skill/Knowledge subscale assesses parents' reports of their parenting skills and knowledge. The Valuing/Comfort subscale assesses parents' degree of value and comfort in the parenting role. Alpha reliabilities for the original sample of 132 parents from intact couples were  $\alpha = .82$  for the Skill/Knowledge

subscale and  $\alpha$  = .70 for the Valuing/Comfort subscale (see Appendix B). The alpha internal consistency reliability coefficient for this sample of families with children with autism, ADHD, or no known disability was  $\alpha$  = .74.

Family Environment Scale. The Family Environment Scale is a 90-item self-report measure assessing people's perceptions, conceptions and expectations of their family environment (Moos & Moos, 1986). The measure is in a "True/False" format. The scale consists of three forms: The Real Form, The Ideal Form, and the Expectations Form. The Real Form was utilized in this study in order to explore current issues within the family environment. This measures was designed to measure people's perceptions of their conjugal or nuclear family environment. Higher scores on this scale indicate a more positive perception of the family environment and lower scores indicate a less positive perception of the family environment.

This form consists of three dimensions: Relationship;
Personal Growth; and System Maintenance which collectively
contain 10 subscales. The Relationship dimension assesses
degree of commitment, help, and support family members
provide for one another and their willingness to express
their feelings including anger, aggression and conflict.
These traits are measured on the subscales: Cohesion,
Expressiveness, and Conflict. The Personal Growth dimension
assesses the extent to which family members are assertive,

self-sufficient, achievement-oriented, sociable, and maintain ethnic or religious values. These traits are measured on subscales including: Independence, Achievement Orientation, Intellectual-cultural Orientation, Active-Recreational Orientation, and Moral-Religious Emphasis. The System Maintenance dimension assesses the degree of importance of organization and structure in family activities and responsibilities, and the extent to which rules and procedures guide and facilitate living. traits are measured on the subscales of Organization and Control. Alpha internal consistency reliability for the Form R subscales for a sample of 1,125 normal and 500 distressed families ranged from .61 to .78. Test-retest reliability for this sample ranged from .68 to .86 (Moos & Moos, 1986). The alpha internal consistency coefficient for families with children with autism, ADHD, or no known disabilities was  $\alpha = -.97$ .

Child Behavior Checklist (CBCL). The Child Behavior Checklist is a 120-item self-report measure assessing parents perceptions of children's competencies, problems, and behaviors (Achenbach, 1991). The checklist is free-response and 3 and 4 point Likert-type rating scale with responses ranging from "Not True", "Less Than (trait)", or "Below Average" to "Very True or Often True", "More Than (trait)", or "Above Average".

This measure consists of three subscales. The Internalizing Subscale measures the internal, personality problems that the target child is perceived to be experiencing by the parent (e.g., anxiety, depression, low self-esteem). The Externalizing Subscale measures that external, behavioral problems that the parent perceives the target child to exhibit (e.g., arguing, aggression, impulsivity). The Social Competence Subscale measures the parents' perceptions of the target child's ability to relate well to their peers and to engage in social activities. Social Competence can only be computed for siblings ages 6 or older, thus eliminating 8 subjects from the sample of 76.

Higher scores on the overall measure and on the Internalizing and Externalizing Subscales indicate more negative perceptions of the siblings' behaviors and lower scores indicate more positive perceptions of the siblings' behaviors. However, higher scores on the Social Competence subscale indicate better social competence. Similar to the PSI, this instrument was completed by the mothers regarding the target sibling of the child with autism (in Group 1), of the sibling of the child with ADHD (in Group 2), and of the child from the community (in Group 3). Alpha internal consistency reliability for the total competence scores for non-handicapped boys and girls in the United States (ages 4-11) was .57 and .62 respectively. For boys and girls 12-18 the alpha internal consistency reliability for the total

competence scores was  $\alpha$  = .64. The alpha internal consistency reliability for the total problems score for the same normative sample (boys and girls 4-11 and 12-18) was .96 (Achenbach, 1991). The alpha internal consistency reliability coefficient for this study was  $\alpha$  = .95.

Mother's report card. The Mother's Report Card (Celiberti & Oizumi, 1994) is a 15-item self-report measure assessing mother's parenting competence of parenting the sibling of the child with autism (Group 1), the sibling of the child with ADHD (Group 2), or the sibling of the normally developing child (Group 3). Mother's were asked to rate themselves on a 5-point scale (i.e., A=Excellent, B=Good, C=Satisfactory, D=Needs Improvement, and F=Poor). Therefore, higher scores indicate more positive perceptions of ability to parent the sibling and lower scores indicate more negative perceptions of ability to parent the sibling (see Appendix B). The alpha internal consistency reliability coefficient with this sample of mothers with children with autism, ADHD, or no known disabilities was  $\alpha = .87$ .

### Study 2

Mothers participating in the intervention. Sixteen of the mothers of children with autism from Group 1 also participated in the intervention component of this investigation. Siblings of the children with autism were between the ages of 5 and 12 and no more than 6 years older

or younger than their brother or sister with autism. One or two of the siblings in these sixteen families who met the age criteria participated in a sibling support group. Eight mothers participated in a group and eight mothers served as a control/comparison group. As mentioned previously, siblings and children with autism resided in the same home and the siblings had no known psychiatric or learning disabilities that may have affected their ability to participate in the group or contributed unique sources of stress to their families.

Group leaders. The parent groups were co-led by two doctoral students in clinical psychology under the weekly supervision of a faculty supervisor who had experience providing interventions to families of children with autism. Supervision focused on session content, as well as discussion of prior sessions. Group leaders followed a structured curriculum which was devised by the leaders and the supervisor prior to the intervention.

#### Procedures

Subject assignment. Sixteen mothers in Group 1 who participated in Study 2 were quasi-randomly assigned to one of four treatment groups: 1) Group 1A included 5 mothers who initially participated in the parent support group concurrent to the sibling group, 2) Group 1B included 4 mothers who completed questionnaires at pre- and post-intervention but did not participate in an the support group

concurrent with the sibling group, 3) Group 1C included 3 mothers who were initially assigned to a wait-list control condition and then participated in the parent group following mothers in Group 1A; and 4) Group 1D included 4 mothers who were initially assigned to a wait-list control condition and completed the questionnaires following mothers in Group 1B.

To clarify, five mothers (1A) participated in a three week intervention that coincided with the intervention provided for the sibling of their child with autism. Four mothers (1B) completed the questionnaires during pre- and post-intervention, but did not participate in the group intervention. Eight mothers (1C and 1D) were assigned to a wait-list control group and followed the same format of the first 9 mothers upon completion of the first intervention. Three of the wait-list families participated in an intervention that was identical to those received by mothers in the first group and four completed questionnaires at preand post-treatment, but did not participate in the parent group. All siblings received the intervention either initially, or following the first group. One family was not available to complete Baseline 1 data, but participated in the intervention with the second group after completing Baseline 2 data, therefore they were not included in the wait-list group for the purposes of data analysis.

Attempts were made to randomly assign families to one of the four above-mentioned groups (i.e., 1A, 1B, 1C, or 1D). Families were initially randomized and modifications were made as necessary. Two families who met the selection criteria had scheduling conflicts and were then randomly assigned to one of the remaining groups in which no scheduling conflicts existed. No families were given the option of choosing the parent/sibling or sibling only groups. One family who was originally assigned to the waitlist control group was invited to participate in the initial group in order to take the place of a family who withdrew from the study. Parents were not informed about when the intervention (i.e., deluxe or standard) would be scheduled until they were randomized into a group.

Twenty-six families showed an initial interest in participating in the study. Nineteen of these families provided baseline data prior to the intervention. Three of these 19 families dropped-out prior to the intervention, leaving 16 families who participated in the entire 3-week intervention and follow-up data collection. Two of the three families who dropped-out of the study were assigned to participate in the initial intervention and one of the families was assigned to the wait-list control group. Baseline data from two of these families were analyzed as part of Study 1. Two of the original 26 families agreed to participate in Study 1 at a later date. Data collection was

accompanied by a one-day workshop. This workshop covered some of the material discussed during the intervention. Four additional families, recruited in the Fall of 1994, participated in the shorter intervention offered at this time. Data from the families who participated in the workshop was used for Study 1 only.

Setting. Group sessions were conducted in the Psychology Clinic at University of North Texas. Group rooms had light brown and tan decor and they were equipped with comfortable chairs, large tables, and white boards for conveying information to parents. Large tables were moved against the wall so that parents could sit in a circle. The participating siblings met in similar rooms in the same building, but often used large tables for art projects and other activities. Mothers in the standard intervention generally waited in the waiting room of the clinic. A few of the mothers left during each session and returned to the clinic when the sibling group was over.

Intervention schedule. The intervention consisted of biweekly group meetings of two hours each over a 3 week span. The meeting format for the two parent groups was identical and consisted of group discussion, structured and unstructured activities, perspective-taking exercises, role play, writing activities, and homework. Also, the two parent groups met at the same time on the same days of the week.

Intervention curriculum. The curriculum consisted of information provided and support given to parents of siblings of children with autism during 6 two-hour group sessions. The curriculum for the parent groups closely followed the content of the sibling sessions with five primary objectives: 1) mothers were introduced to the information and skills provided to their son or daughter participating in the sibling group; 2) mothers were provided with information to learn about and understand autism from both the perspective of a youngster and a sibling; 3) mothers were taught strategies and skills to address the myriad stressors faced by siblings of children with autism; 4) mothers were taught some basic skills pertaining to simultaneously parenting children with autism and their siblings, and 5) they were instructed in how to facilitate maintenance and generalization of the skills and knowledge imparted to siblings so that benefits gained from the intervention could be maximized and persistent over time (see Appendix C for a brief description of each session's content).

Data collection schedule. Mothers whose children initially received the intervention were administered a series of pen and pencil measures at three points in time: pre-treatment, post-treatment and follow-up. Subjects assigned to the two wait-list groups completed these measures at four points in time: twice at pre-treatment

(i.e., simultaneous with the initial groups' pre-treatment and post-treatment), post-treatment, and follow-up. Post-treatment data for the wait-list control groups were gathered by scheduling appointments to collect the data from the mothers at their homes or in the psychology clinic.

Follow-up questionnaires were completed by both sets of mothers, those who participated in the parent group (deluxe), and those who did not participate (standard), four weeks following the completion of the interventions. Measures administered at post-data collection were readministered for the follow up data. The purpose of followup administration was to assess the short-term durability of changes that resulted from the intervention and to examine the maintenance of knowledge and skills acquired during the brief intervention. A four week follow-up was chosen so there would be a period of time at least as long as the intervention between post- and follow-up data collection, and so all data collection would be complete by the end of the summer before the children returned to school. leaders contacted participants one week prior to follow-up data collection to remind them of their scheduled appointments. Follow-up data were collected on the day of, but prior to the graduation parties for the siblings who participated in the groups. This assured that mothers in the deluxe and standard interventions completed the followup data at the same time.

# Measures for Study 2

The measures mentioned for Study 1 were among the battery of measures re-administered to Group 1 in Study 2 at post-intervention and follow-up to assess the efficacy of the intervention. They included: The Hopkins Symptom Checklist, the Parenting Stress Index, the Parenting Sense of Competence Scale, the Family Environment Scale, the Child Behavior Checklist, and the Mothers' Report Card. In addition, the Parent Retrospective Report Card, the Report Card for Group Intervention, and the Post-treatment Consumer Satisfaction Scale were administered at post-treatment data collection. The Follow-up Consumer Satisfaction Scale was administered at follow-up data collection.

Parent Retrospective Report Card. The Retrospective Mothers' Report Card is a 15-item self-report measure designed to assess parenting competence of the siblings following the intervention. Unlike the initial Mother's Report Card, mothers were asked to re-evaluate their perceptions of their ability to parent the sibling by giving themselves the grade they believe they should have received prior to the intervention. Therefore, this measure was designed to assess the perceived accuracy of the mothers' initial rating of their sibling parenting skills. However, they were not given access to their original scores on the Mother's Report Card to complete this measure.

Similar to the Mother's Report Card, mothers were asked to rate themselves on a 5-point scale (i.e., A=Excellent, B=Good, C=Satisfactory, D=Needs Improvement, and F=Poor). On this measure higher scores indicate that, prior to the intervention, mothers perceived their parenting of the sibling to be more competent and lower scores indicate that mothers felt their parenting of the sibling prior to the intervention was less competent. This instrument was completed by the mothers from Group 1 who participated in the intervention and by mothers in Group 1 who completed data only and whose children participated in the intervention (see Appendix B). The alpha internal consistency reliability coefficient for this study was  $\alpha = .93$ .

Report Card for Group Intervention. The Report Card for the Group Intervention is a 15-item self-report measure for mothers in the deluxe intervention designed to assess their views of the treatment condition in which they participated. Upon completion of the group, mothers were asked to give a grade to the group leaders on several aspects of the intervention. This measure was designed to assess the extent to which mothers were satisfied with the various components of the mothers' group. Mothers were asked to rate the group leaders on a 5-point scale (i.e., A=Excellent, B=Good, C=Satisfactory, D=Needs Improvement, and F=Poor) (see Appendix B). Therefore, higher scores

indicate more satisfaction with the group leaders and the content of the intervention than lower scores. The alpha internal consistency reliability coefficient for the mothers who participated in the deluxe intervention was  $\alpha$  = .78.

Post-Treatment Consumer Satisfaction Scale. Treatment Consumer Satisfaction Scale was used to examine mothers' satisfaction with the group intervention for themselves (mothers in the deluxe intervention) and for the siblings (mothers in all groups). This measure is a 22-item survey with open- and close-ended questions regarding specific and more general information about the sibling groups with an additional 25 supplemental items for the mothers who participated in the group. Therefore, mothers in the standard intervention completed the sibling-only portion and the mothers in the deluxe intervention completed the sibling and supplemental portions of the questionnaire designed to address issues that occurred in the parent support group, as well as the sibling group. For closeended questions, mothers were asked to rate aspects of the intervention on a scale of 1 to 5 with 1 being the least of the entity (e.g., dissatisfied) and 5 being the most of the entity (e.g., satisfied). Therefore, higher scores on this portion indicated more satisfaction with the intervention (see Appendix B). The alpha internal consistency reliability coefficient for this sample of mothers was  $\alpha$  = .83.

Follow-up Consumer Satisfaction Scale. The Follow-up Consumer Satisfaction Scale was used to examine mothers' satisfaction with the group intervention (Study 2). This questionnaire is similar to the Post-Treatment Consumer Satisfaction Scale and contains information regarding the sibling groups and a supplementary section for mothers who participated in the deluxe intervention. The siblingfocused portion of this measure consisted of 37-items with close- and open-ended questions regarding specific and more general information about the sibling groups. supplemental portion consisted of an additional 14- items of similar format (see Appendix B). Similar to the Posttreatment Consumer Satisfaction Measure, higher scores indicated more satisfaction with the aspects of the intervention. The alpha internal consistency reliability coefficient for this study was  $\alpha = .80$ .

# Internal Consistency Reliabilities for other Measures

For Study 2, the Hopkins Symptom Checklist alpha internal consistency reliability for the pre-test data was  $\alpha$  = .92, For post-test data it was  $\alpha$  = .96, and for follow-up data it was  $\alpha$  = .97. For the Parenting Stress Index, pre-test alpha internal consistency reliability was  $\alpha$  = .93, post-test alpha = .95, and follow-up alpha = .96. On the Parenting Sense of Competence Scale, the alpha internal consistency reliability coefficient for pre-data was  $\alpha$  = .62,  $\alpha$  = .53 for post-data, and  $\alpha$  = .57 for follow-up data.

On the Family Environment Scale, the alpha internal consistency reliability coefficient for the pre-test data was  $\alpha=-.97$ . For the post-test data the coefficient was  $\alpha=.16$ , and for the follow-up data it was  $\alpha=.30$ . For the Child Behavior Checklist, the alpha internal consistency reliability for the pre-data was  $\alpha=.94$ . For the post-data on the CBCL it was  $\alpha=.96$ , and for the follow-up data it was  $\alpha=.93$ . For the Mother's Report Card, the pre-treatment data alpha internal consistency reliability coefficient was  $\alpha=.88$ . For post-treatment data the coefficient was  $\alpha=.99$ , and for follow-up data the coefficient was  $\alpha=.99$ .

#### CHAPTER III

#### RESULTS

# Study 1

Attempts were made to match the siblings, the children with ADHD, and the children from the community to each of the siblings of children with autism and the children with autism themselves in order to minimize the affects of external variables. Children were matched according to the following variables: 1) gender of the sibling; 2) gender of the child with autism; 3) age of the sibling (within one year); and 4) age of the child with autism (within one year). Six of the twenty-four Group 2 children were matched to six of the Group 1 children on all of the above mentioned variables. Four of the Group 2 children were matched to 4 of the Group 1 children on at least 3 of the 4 mentioned variables. The remaining 14 children in Group 2 were matched with the remaining children from Group 1 on at least 2 of the above mentioned variables.

Twelve of the twenty-four Group 3 children were matched to 12 of the Group 1 children on the following variables: 1) gender of the sibling; 2) gender of the child with autism; 3) age of the sibling (within one year); and 4) age of the child with autism (within one year). Six of the Group 3 children were matched to 6 of the Group 1 children on at

least 3 of the above variables. The remaining 6 children in Group 3 were matched to the remaining 6 children in Group 1 on at least 2 of the above mentioned variables.

Chi-square analyses were used to examine differences between Groups 1, 2 and 3 on gender of sibling, gender of other child (i.e., child with autism for group 1, child with ADHD for group 2, and other child for group 3), birth order of siblings and other children, race of sibling, marital status of parents, and race of mother. No significant group differences were found on any of these variables, except for birth order of sibling and other child. This suggests that birth order is the only external factor that may have had an effect on the findings (see Table 1). Groups 1 (autism) and 3 (control) had more older siblings than Group 2 who had more older children with ADHD. Therefore, significant results between Groups 1 and 2 or Groups 2 and 3 may be partially attributed to the birth order of the two children being considered in the study. Inspection of Table 1 will reveal no such differences between Groups 1 and 3 with respect to the birth order of the siblings.

One-way ANOVA's were used to analyze age of siblings, age of other children, age of mothers and fathers, education of mothers and fathers, and family income. Again, no significant differences were found between the three groups on these variables. See Table 1 for means, standard

deviations, and results of the analyses for the demographic variables for of three groups.

One-way ANOVA's were used to analyze the dependent measures for Study 1. Differences between Group 1 (mothers of children with autism), Group 2 (mothers of children with ADHD), and Group 3 (mothers of children in the community) were compared on each of the following dependent measures: Hopkins Symptom Checklist and the five dimensions of this scale, the Parenting Stress Index with the Child and Parent domains analyzed together and separately, the Parenting Sense of Competence Scale, the Family Environment Scale, the Child Behavior Checklist with the Internal, External and Social Competence scales, and Mother's Report Card. Posthoc analyses were used for measures with significant results to determine where group differences lie.

Hypothesis 1 stated that mothers of children with autism would score higher on this measure indicating higher levels of psychological symptomatology than mothers of children with ADHD who, in turn, would display higher levels of psychological symptomatology than mothers with normally developing children. The Hopkins Symptom Checklist (HSCL), a measure of psychological symptomatology, was utilized to aid in the understanding of maternal symptoms which may indicate depression, anxiety or other ailments. Results of this analysis indicated a significant group difference on the HSCL  $\{E(2,71) = 6.18, p < .0034\}$  supporting this

hypothesis. Post-hoc analyses using Tukey-HSD procedures revealed significant differences between Groups 1 and 3 and Groups 2 and 3. This finding suggests that mothers of children with autism and mothers of children with ADHD have higher levels of psychological symptomatology than mothers of normally developing children (see Table 2).

This scale contains 5 subscales (Somatization, Obsessive-compulsive, Interpersonal sensitivity, Depression, and Anxiety) which were also analyzed. The following dimensions of the HSCL revealed significant differences between these three groups: Obsessive-compulsive  $[\underline{F}(2,71)=5.41,\ p<.0065]$ , Interpersonal sensitivity  $[\underline{F}(2,71)=3.55,\ p<.0340]$ , and Depression  $[\underline{F}(2,71)=5.12,\ p<.0083]$  (see Table 2).

Post-hoc analyses revealed that Groups 1 and 3 and Groups 2 and 3 differed on the Obsessive-compulsive dimension which suggests that mothers of children with autism and mothers of children with ADHD experienced more unremitting thoughts and actions than mothers with normally developing children.

Post-hoc analyses of the Interpersonal Sensitivity dimension of the HSCL revealed significant differences between Groups 1 and 3. This finding suggests that mothers in Group 1 (autism) are more like to feel inadequate and inferior when comparing themselves to others, than are mothers with normally developing children.

Finally, the HSCL dimension of Depression showed significant differences between mothers of children with autism and mothers with normally developing children. This indicates that mothers of children with autism reported more feelings of dysphoria, lack of energy and hopelessness than mothers with normally developing children.

The Somatization [F(2,71)=1.39, p < .2556] and the Anxiety [F(2,71)=2.42, p < .0955] dimensions (which measure physical complaints such as gastrointestinal or respiratory problems, and anxiety symptoms like restlessness and nervousness) did not reveal significant differences between these three groups. However, trends in the data suggest a similar pattern with mothers of children with autism scoring higher than mothers with normally developing children (see Table 3).

Hypothesis 2 stated that Group 1 (mothers of children with autism), Group 2 (mothers of children with ADHD), and Group 3 (mothers of children in the community) will differ on the Parenting Stress Index indicating differences in experienced parental stress level. Results indicated a significant difference between groups [F(2,71)=5.03, p<0.0091] supporting this hypothesis. Post-hoc analyses revealed that mothers of children with autism displayed a significantly higher overall level of parenting stress than mothers of children with normally developing children (see Table 4).

Hypothesis 2 further stated that mothers of children with autism will score the highest and report experiencing the greatest amount of parental stress on the parent domain of the measure, followed by the mothers of the children with ADHD, followed by mothers of normally developing children. However, it also stated the mothers of children with autism will report the least amount of parenting stress on the child domain because it focuses on the non-impaired sibling.

The Parent Domain of the Parenting Stress Index is designed to assess areas of parent functioning that may be perceived as stressful. Questions focus on parental perceptions of the child's behaviors. The Child Domain of the Parenting Stress Index is designed to measure areas of child functioning that may be perceived as stressful to the parent. For this study, mothers from all 3 groups were asked to focus on the sibling when completing the Child Domain in order to gain an assessment of their perceptions of stress related to parenting the sibling, as opposed to the other child (i.e., with autism, with ADHD, or with no disability).

Results revealed significant differences between groups on the Parent Domain  $[\underline{F}(2,71)=4.24,\ \underline{p}<.0182]$  and the Child Domain  $[\underline{F}(2,71)=4.69,\ \underline{p}<.0122]$ . Specifically, mothers of children with autism scored higher than mothers with normally developing children on the Parent Domain, supporting this hypothesis. On the Child Domain, mothers of

children with autism scored higher than mothers with normally developing children, as well, which does not support hypothesis 2. These findings may suggest that mothers with children with autism perceived themselves as experiencing more stress related to both their parenting roles in general and to their parenting of the sibling specifically (see Table 4).

Hypothesis 3 stated that there will be differences between Groups 1, 2 and 3 on the measure of maternal sense of parenting competence. The Parenting Sense of Competence Scale is a self-report measure of assessing parents' perceptions of their competency in their parenting role. No significant differences were revealed between groups 1, 2, and 3 on this measure [F(2,71)=2.11, p <.1282], therefore, this hypothesis was not supported. However, means reveal a trend which suggests that mothers of normally developing children scored higher and feel more competent in a parenting role than mothers of children with ADHD and mothers of children with autism (see Table 5).

Hypothesis 4 stated that Groups 1, 2 and 3 will differ in their perceptions of the family environment, such that mothers in Group 1 would score higher and perceive their family environment more negatively than mothers in Group 2 who would score higher and perceive their family environment more negatively than mothers in Group 3. Again, the Family Environment Scale (FES) is a measure of mothers' perceptions

of the family environment and the interactions among family members. Hypothesis 4 was supported by statistical analyses [F(2,71) = 3.48, p < .036]. Post-hoc analyses revealed significant differences between Groups 1 and 2 and Groups 1 and 3. This suggests that mothers of children with autism perceived their family environment as less favorable than mothers of children with ADHD and mothers of normally developing children (see Table 6).

Hypothesis 5 stated that there will be differences between Groups 1, 2, and 3 on the measure of maternal perceptions of siblings' behaviors and social competence, such that mothers with less positive perceptions would score higher on the measure. This hypothesis was not supported because the overall Child Behavior Checklist (CBCL) did not reveal significant difference between groups 1, 2 and 3 [F(2,71)=2.78, p < .1094]. The Internalizing subscale of this measure revealed significant differences between Groups  $[\underline{F}(2,71)=3.76, \underline{p}<.028]$ . However, this difference was not in the predicted direction. Post-hoc analyses revealed that differences exist between Group 1 and Group 3. subscale measures syndromes that are internal, personality difficulties, as opposed to external, conduct problems. Mean values revealed that mothers' of children with autism scored higher indicating that they perceive the sibling as having more internal, personality problems than do mothers in Group 3 (see Table 7).

Although not significant, mean values for the Social Competence subscale  $[\underline{F}(2,65)=.808,\ p<.450]$  indicated that mothers of children with autism perceived the siblings as having less social competence than mothers of children with ADHD and mothers with normally developing children. In addition, means of the Externalizing score  $[\underline{F}(2,71)=.62,\ p<.5427]$  were in the same direction as those for the Internalizing score suggesting that mothers of children with autism may also perceive the siblings as having more external, conduct related problems than mothers with normally developing children (see Table 7).

Hypothesis 6 stated that differences will exist between Groups 1, 2 and 3 in mothers' perceptions of their parenting skills of the siblings based on the Mothers' Report Card. Results supported this hypothesis and indicated a significant difference between Groups 1, 2, and 3 on this measure [F(2,71)=8.55, p < .0005]. Post-hoc analyses revealed that mothers of children with autism scored significantly lower than mothers of children with ADHD and mothers with normally developing children, that is, they rated their parenting of the sibling as less competent than the other groups. This may indicate that mothers of children with autism perceive their parenting skills of the sibling as less adept than mothers of children with ADHD and mothers of normally developing children. It may also suggest that mothers of children with autism realize that it

is difficult to offer enough attention and/or adequate parenting skills to the siblings when children with autism require extra attention (see Table 8 for ANOVA between Groups 1, 2 and 3 on the overall MRC, Table 9 for ANOVAs for individual item differences between these groups, and Table 10 for individual item Means and SDs).

### Study 2

As mentioned, attempts were made to randomized subjects in one of the three intervention groups (i.e., deluxe, standard, or wait-list). This was done to reduce the influence of confounding variables such as age, gender, and birth order that may be accounting for group differences. Follow-up analyses were conducted to see if there were differences between these three groups using chi-square analyses and Oneway ANOVAs. Results of these analyses did not indicate any significant group differences on the demographic variables listed above with the exception of father's education where father's in the wait-list group had more education overall than fathers in the initial deluxe and standard groups (see Table 11).

Additional chi-square analyses, and t-tests were conducted to test differences between all subjects who participated in the deluxe group and all subjects who participated in the standard group (including those subjects originally assigned to the wait-list control group). Again, there were no significant differences on the majority of

these variables. The only variables indicating significant group differences were mother's age and father's age. For the additive deluxe subjects, mothers and fathers were older than mothers and fathers in the standard condition (see Table 12). Therefore, age of parent may have some influence on results of these analyses. However, the age of all parents was between the mid-thirties and the early forties which is not a wide age-range.

Data for Study 2 Hypotheses 7A-12A were analyzed using One-way ANOVAs for baseline data to test for preintervention differences and determine necessary covariates based on significant differences between the deluxe intervention, the standard intervention, and the wait-list control group. Despite attempts to randomize, there were significant group differences on three of the dependent variables at pre-data collection (the PSOC, the CBCL, and the Mother's Report Card). Therefore, ANCOVAs for those three variables were conducted using the respective preintervention variable as the covariate. Repeated measures ANCOVAS for the other three dependent variables (i.e., the HSCL, the PSI, and FES) were conducted to examine differences between pre-intervention and post-intervention while controlling for these pre-group differences using the above three variables as covariates (see Tables 13 and 14).

Hypotheses 7B-12B analyses included mothers initially assigned to the wait-list group, but who later participated

in either the deluxe or the standard intervention. allowed more subjects to be included in the analyses. hypotheses were also initially analyzed using One-way ANOVAs to determine pre-intervention differences between all subjects who participated in the deluxe intervention or the standard intervention. There were two variables that displayed significant pre-data between groups, the Parenting Stress Index and the Mother's Report Card. Repeated measures ANCOVAs were conducted on these two variables with the respective pre-data as the covariate. For the other four variables, repeated measures ANCOVAS compared pretreatment with immediate post-treatment, pre-treatment with follow-up, and immediate post-treatment with follow-up using the two above variables as covariates to control for preintervention differences (see Tables 15 and 16).

Hypothesis 7A stated that mothers who participated in the deluxe intervention would report less psychological symptomatology than mothers in the standard intervention, indicated by lower scores on the HSCL at post-intervention. Also, mothers in either intervention would report less psychological symptomatology than mothers in the wait-list control group at post-intervention. This hypothesis was not supported. Results did not indicate a main effect of group [E(2,10)=1.79, p<.217] or time [E(1,10)=.20, p<.665], or a significant interaction of group and time [E(2,10)=.12, p<.888] (see Table 13).

Hypothesis 7B for Study 2 stated that mothers in the deluxe intervention, and the standard intervention to a lesser extent, would experience a slight decrease in level of psychological symptomatology across pre-, post- and follow-up data. Results did not indicate a main effect of group [F(1,12)=.00, p < .967], time [F(2,25)=.19, p < .831], or a significant interaction [F(2,25)=.70, p < .507] (see Table 15).

Hypothesis 8A stated that mothers who participated in either the standard or deluxe intervention would report less parenting stress when compared to the wait-list control mothers, indicated by lower scores on the PSI at post-intervention. This hypothesis was not supported, as results did not indicate a significant main effect of group [E(2,10)=1.24, p < .330], time [E(1,10)=.41, p < .535], or a significant interaction of group and time [E(2,10)=.93, p < .427] (see Table 13).

Hypothesis 8B stated that mothers who participated in the deluxe intervention would experience a decrease in level of parenting stress, from pre- to post- to follow-up, as compared to mothers in the standard intervention. The results did not indicate a main effect of group [F(1,13)=.23, p < .640], a main effect of time [F(1,13)=.84, p < .377], or a significant interaction [F(1,13)=.86, p < .370] (see Table 15).

Hypothesis 9A stated that mothers who initially participated in the intervention in the deluxe or standard intervention would display a higher level of parenting sense of competence (i.e., score higher on the PSOC) when compared to mothers in the wait-list control condition at post-intervention. Results of the ANCOVA did not support this hypothesis  $[\underline{F}(3,14)=1.12,\ p<.382]$  (see Table 13).

Hypothesis 9B stated that mothers in the deluxe condition were expected to feel more competent in their parenting skills than mothers in the standard condition over time from pre- to post- to follow-up data collection. There was no significant main effect of group [F(1,13)=.79, p < .391], and no significant interaction [F(2,27)=.16, p < .851]. However, there was a main effect of time [F(2,27)=3.96, p < .031] which indicated that mother's parenting competence decreased between pre-intervention, post-intervention, and follow-up for the deluxe and standard interventions (see Table 15).

Hypothesis 10A stated that mothers who initially participated in the deluxe and standard interventions, would perceive their family environment as more cooperative and favorable than mothers in wait-list control group, indicated by higher scores on the FES at post-intervention. Results revealed a main effect of group [F(2,10)=4.06, p<.051], a main effect of time  $[F(1,10)\approx52.51, p<.000]$ , and a significant interaction [F(2,10)=56.97, p<.000].

Therefore, mothers in the deluxe and standard interventions perceived their family environment as less favorable after the intervention than mothers in the wait-list group (see Table 13).

Hypothesis 10B stated that mothers in the deluxe and interventions would view their family environment as slightly more favorable than mothers in standard intervention from pre- to post- to follow-up intervention. Results indicated a main effect of group  $[\mathbf{F}(2,10)=.07,\ \mathbf{p}<.051]$ , a main effect of time  $[\mathbf{F}(2,27)=4.45,\ \mathbf{p}<.000]$ , and a significant interaction  $[\mathbf{F}(2,27)=.14,\ \mathbf{p}<.000]$ , therefore, this hypothesis was supported. Mothers in the standard intervention had lower overall perceptions of their family environment than mothers in the deluxe intervention. However, bother groups perceived their family environment to worsen just after the intervention, but return to the baseline perceptual level at follow-up data collection (see Table 15).

Hypothesis 11A stated that mothers in initial deluxe or standard interventions will show a more positive perception of the sibling's behaviors and social competence (score lower on the CBCL) at post-intervention, as compared to mothers in the wait-list group. Results of the ANCOVA indicated a significant difference between these groups at post-intervention [f(3,14)=16.81, f(3,14)=16.81, f

in the deluxe group perceived the siblings as having the most difficulty with behavior and social competence, followed by mothers in the standard group. Mothers in the wait-list group perceived the siblings as having the least difficulty with behavior and social competence (see Table 13).

Hypothesis 11B stated that mothers in the deluxe condition would rate the siblings' behaviors and social competence as more positive than mothers in the standard intervention from pre- to post- to follow-up data collection. There was no main effect of group  $\{F(1,13)=.95,$ p < .347, and no significant interaction [F(2,27)=.61, p <.552]. However, there was a main effect of time [F(2,27)=4.45, p < .021]. Means indicated that mothers in both interventions perceived the behavior and social competence of the siblings to improve over time. Means suggested that improvement was perceived from postintervention to follow-up. Because these findings are inconsistent with the findings of Hypothesis 11A comparing the deluxe, standard, and wait-list groups at postintervention only, this may indicate that the lasting effects of the intervention were evidenced on this measure of parents' perceptions of the siblings' behaviors and social competence (see Table 15).

Hypothesis 12A stated that mothers in the deluxe intervention will score higher on the Mother's Report Card,

showing more positive perceptions of their parenting skills, specific to the siblings, than mothers in the standard intervention at post-intervention. In addition, mothers in the standard intervention will show more positive perceptions of their parenting skills of the siblings than mothers in the wait-list control condition at post-intervention. Although there was no significant group differences based on an ANCOVA [E(3,14)=3.44, p<.055], mean values indicated a trend suggesting that mothers in the deluxe intervention perceived themselves to have better parenting skills of the sibling at post-intervention than mothers in the standard intervention (see Table 13). In addition, mothers in the standard intervention perceived themselves to have better parenting skills of the sibling than mothers in the wait-list group.

Hypothesis 12B stated that mothers in the deluxe intervention would perceive their parenting skills of the sibling as more competent than mothers in the standard intervention over time from pre- to post- to follow-up. A repeated measures ANCOVA indicated a main effect of group  $[\underline{F}(1,13)=9.61,\ \underline{p}<.008]$ . However, there was no main effect of time  $[\underline{F}(1,13)=.65,\ \underline{p}<.435]$ , and no significant interaction  $[\underline{F}(1,13)=.04,\ \underline{p}<.841]$ . The main effect of group suggested that mothers in the deluxe group perceived their parenting skills of the siblings to be more adequate than mothers in the standard condition at some point after

the intervention. Tables 15 and 16 indicate the specific areas of parenting of the sibling that changed the most from pre- to post-intervention for mothers in the deluxe and standard interventions.

Hypothesis 13 stated that mothers in the deluxe intervention would rate themselves lower on the Mother's Retrospective Report Card than on the pre-test Mother's Report Card. The Mothers' Retrospective Report Card is a measure designed to reassess parents' views of their competence and parenting skills prior to the intervention. Mothers in the deluxe condition rated their sibling parenting skills as somewhat lower than they originally rated them prior to the intervention (i.e., their scores went down). Mothers in the standard intervention rated their parenting skills the same (i.e., their score was the same) (see Table 17).

Hypothesis 14A stated that mothers in the deluxe intervention would rate the overall intervention as positive and beneficial. Totals and means were computed for the Report Card of the Group Intervention which was designed for mothers in the deluxe intervention to provide the opportunity to grade the group leaders on several aspects of the intervention. Results suggested that overall, mothers rated the intervention between good and excellent (Total=65.14 of 75 possible and mean=4.34 of 5 possible). Areas of the intervention that received high grades

consistently included spending time with the sibling, enhancing their self-esteem and individuality. Areas that received slightly lower grades included sibling and peer-interactions and family togetherness (see Table 18).

Hypothesis 14A also stated that the supplemental portion of the Post-treatment Consumer Satisfaction Scale would indicate a positive and beneficial experience in regard to the deluxe intervention by mothers who participated. Overall, mothers who participated in the group intervention believed their experience to be positive and beneficial (Mean=3.6 of 5 possible) and the hypothesis was supported.

Intervention components that were rated highest by mothers were, group discussions and the overall sessions (Means = 4.38 and 4.5, respectively). The intervention component that they rated lowest overall was the homework assignments (Mean = 2.5 of 5) which is slightly below "somewhat helpful and enjoyable." On the subjective portion of this section, most of the mothers wrote a statement suggesting that the group gave them an opportunity to affiliate with others mothers and learn about siblings' needs through this process. Some participants also wrote that they appreciated knowing specifically what the sibling was doing and learning in his or her group.

A t-test was used to assess the results of the initial portion of the Post-treatment Consumer Satisfaction measure

(which focused on the benefits of the group for the siblings). There were no significant differences on this portion of the measure between mothers in the deluxe intervention and mothers in the standard intervention [F(1,14)=3.12, p < .157]. However, the means suggest that both groups rated the intervention as more helpful, positive and/or enjoyable than not helpful or negative (Standard Intervention, Mean=4.56 of 5 possible; Deluxe Intervention, Mean=4.46 of 5 possible).

Hypothesis 14A indicated that mothers in the deluxe intervention would rate their experience in the intervention as positive after four weeks had elapsed. The supplemental portion of the Follow-up Consumer Satisfaction Measure supported this hypothesis (Mean = 3.83 of 5 possible). This finding suggests that, overall, mothers continued to view the intervention as beneficial after four weeks.

Intervention components that were rated highest by most mothers were the overall helpfulness of the group, using skills learned in the group to communicate with the siblings, and continuing to use knowledge and skills addressed in the group. (Means = 4.75, 4.13, 4.25, respectively).

Intervention components that were rated the lowest by most mothers, but were still above the mid-point of the scale were being better able to deal with sibling issues (Mean = 3.71 of 5). On the subjective portion of this

measure many mothers mentioned that the most helpful parts of the intervention were having the opportunity to communicate with other mothers, and begin able to communicate and understand the needs of the siblings. The least helpful part was, again, the homework.

Hypothesis 14B stated that mothers in the deluxe and standard interventions would rate the sibling groups as positive in terms of meeting the needs of the siblings. A t-test was used to analyze the results of the initial portion of the Follow-up Consumer Satisfaction Measure. Again, there were no significant differences between the deluxe and standard interventions on this portion of the measure [F(1,14)=3.41, p < .128]. Both groups rated the intervention as positive and beneficial overall (Mean=3.7 for deluxe and 3.5 for standard of 5 possible). Individual item analyses revealed that only two items were significantly different between these two groups. mothers in the deluxe intervention stated that they agreed more with the item "The sibling gains the attention of the child with autism when interacting with him as a result of my family's participation in the sibling project" than mothers in the standard intervention [ $\underline{F}(1,14)=5.27$ ,  $\underline{p}<.047$ ]. Mothers in the deluxe intervention also agreed more with the item "The sibling praises the child with autism when appropriate as a result of my family's participation in the

intervention" than mothers in the standard intervention  $[\underline{F}(1,14)=4.00, \ \underline{p}<.033]$ .

### CHAPTER IV

### DISCUSSION

## Study 1

Findings. This study attempted to assess differences in maternal functioning and mothers' perceptions of siblings' functioning in families of children with autism, children with ADHD, or children with no disabilities. Several measures were administered to evaluate various aspects of maternal functioning and perceptions of siblings functioning. These included: The Hopkins Symptom Checklist, the Parenting Stress Index, the Parenting Sense of Competence Scale, the Family Environment Scale, the Child Behavior Checklist, and the Mother's Report Card. Overall findings suggest that mothers of children with autism have more difficulties in some areas of maternal functioning than mothers of children with ADHD and mothers with normally developing children. In addition, mothers of children with disabilities perceived the siblings as having more problems than siblings of normally developing children on some of the indicators.

Mothers of children with autism and mothers of children with ADHD scored significantly higher on the Hopkins Symptom Checklist than mothers of normally developing children.

This finding is consistent with literature which suggests

that parenting children with disabilities is a source of stress for the family (e.g., Fishman & Wolf, 1991; Friedrich & Friedrich, 1981; Margalit, Raviv, & Ankonina, 1992).

However, these studies did not measure psychological symptomatology using the HSCL. Therefore, this finding may be unique to this study. In addition, these studies did not utilize the same comparison group (i.e., ADHD) which may also have affected these results.

High levels of psychological symptomatology may be a function of the demanding nature of dealing with disabled children (e.g., presence of behavior problems, increased need for attention, additional expenditures needed to manage the child). Another plausible explanation for the difference between mothers of children with autism and mothers of children with ADHD on the HSCL may be that mothers of children with autism were seeking help for their stress and symptomatology (they participated in an intervention or workshop to gain information or assistance) and mothers of children with ADHD completed questionnaires only and were not specifically seeking assistance. Although not formally measured in the current study, it is possible that subjects in Group 1 may represent a more impaired subpopulation of mothers of children with autism.

When examining the dimensions of the HSCL, significant differences between these groups of mothers were indicated on the Obsessive-compulsive, Interpersonal sensitivity, and

Depression dimensions. The Obsessive-compulsive dimension focused on thoughts, impulses or actions that are unremitting and distressing. On this dimension, mothers of children with autism scored significantly higher than mothers of children with ADHD, similar to the findings of Fishman and Wolf (1991). This indicated that the severity of autism and the diverse aspects of the disorder may lead to unwanted thoughts or preoccupations for those mothers. This may be due to the nature of the disorder such that the prognosis for autism is poor and mothers may have a limited number of resources available to deal with the severity of the disorder resulting in feeling stressed or overwhelmed. As a result, mothers may ruminate over the problems they experience in the parenting role.

The Interpersonal sensitivity dimension focused on feelings of inadequacy or inferiority and the Depression dimension focused on depressed affect, dysphoric mood, loss of energy, and feelings of hopelessness or futility. On these dimensions mothers of children with autism scored significantly higher than mothers with normally developing children. This may signify that mothers who raise children with autism experience negative feelings toward themselves in regard to the parenting role. They may also experience depressive feelings as a result of the demanding nature of autism and the excessive needs of the children with autism which mothers may perceive as partially unmet.

The Somatization and Anxiety dimensions of the HSCL revealed no significant differences between groups, but trends suggested that mothers of children with autism exhibited higher rates of somatization and anxiety than mothers of children with ADHD who also displayed more somatization and anxiety than mothers of normally developing children. This finding suggests that having a child with a disability may cause stress that manifests itself as physical symptoms for some of the subjects.

The overall Parenting Stress Index indicated that mothers of children with autism experienced higher levels of stress related to the parenting role than mothers with normally developing children. This finding supports the literature which indicates that parents of children with autism incur greater amounts of stress than parents of children with other disorders (e.g., Beckman, 1983; Donenberg & Baker, 1992; Fishman & Wolf, 1991; Gallagher et al., 1983; Holroyd & McArthur 1976; Wolf et al., 1989). Although, some of these studies (e.g., Donenbery & Baker, 1992; Fishman & Wolf, 1991; Wolf et al., 1989) utilized the Parenting Stress Index and were measuring the same construct as this study, other studies (e.g., Beckman, 1983; Holroyd & McArthur, 1976) utilized different measures of stress and available resources which may have led to different results if utilized in this study.

As mentioned, the Parenting Stress Index consisted of a Child Domain and a Parent Domain. Again, the Parent Domain measured stress based with meeting the demands of the general parenting role. The Child Domain measured behaviors and attitudes of children which make it difficult for parents to fulfill their parenting role. For this study, the Child Domain was completed with the siblings in mind to assess stress related to parenting the sibling, rather than the child with the disability. The Parent Domain and the Child Domain of this measure revealed that mothers of children with autism rated the siblings and the general parenting role as contributing to higher levels of parenting stress than were reported by mothers with normally developing children. This may suggest that mothers of children with autism not only experience more stress as a result of their parenting role, but they also experience stress related to the behaviors and attitudes of the siblings. This may be due to parents attributing stress to the general parenting role, regardless of the child they are focusing on.

On the other hand, parents may also be recognizing their own shortcomings in parenting and meeting the needs of other siblings in the family. Still, it could be that the siblings' behavior is actually worse than the literature indicates because of the siblings' competition for attention from their parents or because of their family environment.

In other words, the siblings may act-out in an attempt to receive attention from their parents, even if it is negative, or they may act-out because their family environment is less stable and resistant to problematic behaviors.

Although no significant differences were found on the Parenting Sense of Competence Scale, there were trends in the data suggesting that parents of normally developing children feel slightly more competent in the parenting role than mothers of children with autism and mothers of children with ADHD. This finding is consistent with the above results of the Parenting Stress Index and with previous research which indicates that parents of children with autism report less parenting competence than mothers of children with Down's Syndrome and children with no disabilities (Rodrique, Morgan, & Geffken, 1990). Although these authors used the same measure of parenting competence (i.e. the PSOC), it is notable that they utilized a different comparison group (i.e., families of children with Down's Syndrome) than was used in this study (i.e., families of children with ADHD). Therefore, these findings may be unique to this study.

It is suggested by this finding that raising a child with a disability such as autism or ADHD may lead mothers to question their parenting competence and skills, and therefore, incur stress related to the parenting role. On

the other hand, it may be that parents of children with autism require more parenting competence, making it more difficult to achieve competency in the parenting role.

Whatever the case, this lower sense of parenting competence may be a result of mothers' seemingly ineffectual effort to teach children with disabilities new skills and show them how to behave, as they do not learn as quickly, and may not behave as well as the other children in the family.

The Family Environment Scale is a measure of the mother's perceptions of the family environment as a whole. This study demonstrated that mothers of children with autism perceived their family environment as less favorable than mothers of children with ADHD and mothers with normally developing children. This is consistent with Rodrique, Morgan, and Geffken's (1990) research which states that parents of children with autism reported less family adaptability or flexibility than families of children with other disabilities. This may be due to the inevitable stress and demandingness incurred by having a child with autism in the family which may disrupt or deleteriously impact upon many aspects of family interactions.

The overall Child Behavior Checklist, based on the siblings, did not reveal any significant differences between groups of mothers. However, the Internalizing Subscale which measured the internal, personality functioning of the siblings indicated that mothers of children with autism

perceived the siblings to have more internal difficulties than mothers of siblings with normally developing children. This may be due to the stressful family environment that is common in families of children with a disability (e.g., Beckman, 1983; Gallagher, Beckman, & Cross, 1983; Kazak & Marvin, 1984). This finding may suggest that mothers feel as though the siblings' anxiety and depression increased because of the decreased attention the siblings commonly receive from parents of children with autism and because of the stressors associated with being the sibling of a child with autism. This finding is consistent with research suggesting that being a sibling of a child with autism can result in problems with depression, anxiety and social competence (e.g., Fishman & Wolf, 1991; Stoneman, et al., 1988; Vadasy, 1984). This perception may be a result of the siblings' actual problems, or it may be a mere perception based on the mothers' ideas of how the siblings must feel growing up with a brother or sister with autism.

This finding may also suggest that mothers of children with autism merely perceive the siblings as being adversely affected by the children with autism. On the other hand, this finding may be a direct result of the sample of mothers of children with autism who participated in this study. Their siblings may have had problems with anxiety and depression, which may have led the mothers to participate in the study in order to gain assistance for the siblings.

As mentioned, trends suggested that mothers of children with autism perceived the siblings to have less social competence then mothers of children with ADHD or normally developing children. This finding may suggest that the siblings are missing out on social activities due to the confinements of caring for a child with autism. It may also be that the siblings of children with autism are actually less socially competent then other siblings because their activities are restricted and they may not have a normally developing companion to affiliate with for long durations of Finally, trends in the data indicated that mothers of children with autism perceived the siblings to have more problems with externalizing behaviors than mothers from Groups 2 and 3. This may indicate that parents perceive the siblings as being difficult to handle behaviorally, or the siblings may actually act-out in response to decreased attention from their parents, or they may be attempting to affiliate with their brother or sister with autism.

The Mothers' Report Card was a measure designed to evaluate mothers' perceptions of the parenting skills of the sibling of the child with autism (Group 1), the sibling of the child with ADHD (Group 2), or the other normally developing child (Group 3). Significant differences were indicated between mothers of the children with autism and mothers of children with ADHD and no disability. Mothers of children with autism felt that their parenting skills were

less adequate in all content areas of the intervention. This finding is related to other literature indicating that parents of children with autism feel less adequate in their parenting skills (Rodrigue et al., 1990). However, other literature did not utilize a measure that was designed to tap into parenting skills that were specific to the sibling and based on a group intervention.

Specific items that indicated a larger discrepancy between mothers of children with autism and mothers in the other groups were "Giving the sibling individualized attention", "Doing things to take care of my relationship with my spouse", and "Enhancing the sibling's self-esteem." (see Table 10). This finding suggests that difficulties and stressors related to parenting a child with autism may affect a mother's own perception of her parenting skills. It may also suggest that mothers of children with autism feel their parenting of the siblings is less adequate because they are focusing more of their attention on the child with autism or that the parents may be encountering stressors that have a direct effect on their abilities to parent the siblings.

Overall, these findings support the literature which states that parenting and being the sibling of a child with a disability, especially autism, can be stressful and result in difficulties like psychological symptoms, a perceived lack of competence in parenting skills, and perceived poor

social competence of the siblings (e.g., Beckman, 1983; Donenberg & Baker, 1992; Lobato et al., 1988; Mclinden et al., 1991; Powers, 1984; Wolf et al., 1989). Therefore, there is a need to address problems associated with parenting and being the sibling of a child with autism or Disabilities are difficult to manage and they add stress to lives of family members, individually and as a Therefore, it is important to focus on the needs of whole. the siblings and the parents in order to improve family functioning and to provide strategies for meeting family members' needs. To gain an understanding of these needs, difficulties associated with particular disorders must be compared and delineated. Once these are better understood, interventions and programs can be designed to address these issues and be responsive to the specific needs of family members of children with different disabilities.

## Clinical Implications of Study 1

The above findings support the previous literature indicating that parenting a child with a disability is difficult (e.g., Gallagher et al., 1983; Kazak & Marvin, 1984; Wolf et al., 1989). This supports the need for programs designed to address stressors and symptoms that may result from parenting a child with a disability. According to the Child Behavior Checklist in this study, it appears that siblings experience difficulties as a result of having a child with a disability in the family. This finding is

consistent with literature which states that there are negative effects of being the sibling of a child with a disability (e.g., Pearson & Sternbery, 1986; Powers, 1984; Slade, 1988; Vadasy et al., 1984). In addition, parents seem to perceive the siblings as having problems associated with being the sibling of a child with a disability and likely feel responsible for dealing with those difficulties and meeting the siblings' needs. Therefore, there is a need for developing interventions designed to meet the needs of siblings or clarify the parents' perceptions of the siblings' problems. This need is also recognized in the literature (e.g., Clark et al., 1989; McLinden et al., 1991; Schreiber & Feeley, 1965). Concurrent support groups for various family members appear to be a means of addressing some of these needs on multiple levels.

Although it seems intuitive that parents of children with disabilities may perceive siblings as less difficult to raise, there are still apparent stressors associated with raising them. Therefore, treatment should be generalized and focus, not only on meeting the siblings' needs, but also on assisting parents in dealing with maladaptive behaviors or problems exhibited by the siblings, as well as the child with the disability.

<u>Limitations</u>. One of the limitations of Study 1 is that mothers who participated in the research study were likely not a representative sample of the population of families in

the United States. Most of the mothers in Group 1 participated in an intervention (Study 2) or attended a one-day work shop geared toward meeting the needs of the siblings. Therefore, they are likely more representative of mothers who generally participate in programs for their children or who seek out ways to help meet the needs of the siblings. In addition, they may have agreed to participate in the study because they were experiencing difficulties related to the child with autism and noting challenges incurred by the siblings. Therefore, their ultimate motivation was to seek help with these issues. On the other hand, they may represent families who are sufficiently insightful to be sensitive and responsive to the needs of siblings.

Mothers in Groups 2 and 3 were also not likely a representative sample of the general population. These mothers were probably among those mothers who do not mind donating their time and who are somewhat interested in research. In addition, the siblings of the families who participated in these groups were placed into a drawing for \$50.00 and this may have been a motivation for some of the mothers to participate in the study. Therefore, it was difficult to discern the motivation for participation in one of these groups. The recruitment methods likely impacted upon the representativeness of the participants which may, in turn, limit the generalizability of the findings. The

sample may have been more representative were each group offered the same incentive for participation (e.g., providing interventions or workshops for all subjects, or only collecting baseline data from all subjects).

Another limitation of this study is that fathers were not utilized. Although a sample of fathers may be difficult to obtain because they are frequently working full-time, and may be less accessible, their opinions are very important in understanding family relationships, sibling functioning and the effects of having a child with a disability in the family. Fathers may further support what the mothers have already reported about family relationships, sibling functioning and the effects of having a child with a disability in the family. However, it is quite possible that fathers have a different view than mothers on these matters. Our understanding of family functioning should be informed by both maternal and paternal reports.

Although attempts were made to match the siblings and the other children on several variables, some differences between groups were still noted. The birth order of Groups 1 and 3 differed from that of Group 2. The siblings in Groups 1 and 3 were older, on average, than the other children, and the other children in Group 2 were older, on average, than the siblings. This may have had some influence on the results as several researches have indicated that being an older sibling, specifically a

female, of a child with a disability can have deleterious affects on well-being. This may be due to additional demands for caring for the child with the disability and overcompensation for the shortcomings of the child with the disability (Jabs, 1992; Lobato et al., 1988; Seligman, 1983a; Slade, 1988).

Another limitation of Study 1 is that children in Group 1 (siblings of children with autism) and Group 2 (siblings of children with ADHD) were not matched by time since diagnosis and length or type of treatment. Mothers were asked if their children were diagnosed with autism or ADHD. If they reported that the children had been diagnosed by a doctor, another mental health professional, or the school, they were allowed to participate in the study. Therefore, the accuracy of the children's diagnoses may be questionable in some cases.

The time since diagnosis and age at diagnosis were different for some of the families which may have had some effect on the results. For example, families with children diagnosed with autism several years ago may be more adjusted to dealing with the needs and demands of those children than families with children diagnosed with autism recently. Also, age of diagnosis may affect the family's ability to cope with the issues associated with raising a child with autism.

In addition, some of the children with autism in Group 1, and ADHD in Group 2, were involved in treatment and others were not. Those children who were involved in treatment were in individualized programs where type, length, and intensity of treatment was different for each family. Therefore, the treatment variable may have had an effect on maternal functioning. For example, a mother with a child who is in treatment 5 hours a day, 5 days a week, may experience less stress due to relief from the demands of the child and time to herself, than a mother whose child is in treatment for only 1 hour a week.

Another, more specific limitation is the lack of information about severity of the diagnosis of the children with autism. Autism can range from mild to severe. It is quite likely that the level of severity would affect siblings differently. For example, a child with severe autism would probably require more attention from parents than a child with mild autism, in turn decreasing the attention received by the sibling in that particular family. Also, the sibling's relationship with a child with severe autism would likely be different than that of a child with mild autism, such that their interactions would be less frequent and the amount of fighting or level of frustration between them would be higher.

<u>Directions for future research</u>. Future research should incorporate a larger sample size to address some of the

research issues raised above. A larger N may result in more statistically sound analyses. In addition, a larger sample size would have likely improved the contribution of this study and led to more reliable and/or significant results. Finally, a larger number of subjects would allow more confidence in generalizability to other families with similar problems.

Future studies should compare families who have children with difficulties other than autism and ADHD to see how the siblings and others family members are affected. For example, it may be beneficial to compare children who have a medical problem to children with autism or ADHD in order to delineate differences in necessary coping skills and potential stressors related to the disease or disorder. This information could provide more specific information about the problem. For example, a child with a lifethreatening medical problem (e.g. cancer) may induce worry in the parents and siblings regarding the child's health which are not inherent to children with autism or ADHD. On the other hand, this information may demonstrate similarities inherent in taking care of and living with a child with a disease or disability. There should also be delineations made with regard to the severity of the disability under study. This factor is likely to have an impact on family functioning and should be addressed in

interventions or programs designed to assist families of children with disabilities.

Future research for Study 1 should also address variables other than those investigated in this study in order to gain a more thorough perception of the differences between the three groups and to gain specific information about areas to target for treatment or to develop interventions designed to address the needs of mothers, siblings and other family members. Previous literature indicated some potential difficulties in families of children with disabilities aside from parenting stress, parenting sense of competence, psychological symptomatology, family environment, and sibling functioning. Such variables may include: marital satisfaction, parental conflict, and social support. There may also be variables that have not been addressed in previous literature that can be examined. For example, general mental health, and stress or symptoms experienced by other family members could be explored. need for the investigation of variables other than those commonly found in the literature has been expressed by other researchers as well (e.g., Donenberg & Baker, 1993; Gallagher et al., 1983).

Additional research should focus on using measures that delineate more specific differences between various disorders. Measures should be less global and examine interactions that occur specific to the characteristics of

the disorder under study. Measures such as the HSCL and PSI that measure global functioning may not be specific enough to gain an understanding of the unique difficulties experienced by mothers as a result of parenting a child with autism. A measure designed to delineate specific differences between families of children with autism and families of children with ADHD would likely be beneficial. The measure should assess specific behaviors and parental perceptions of the children with disabilities.

Another area of research that should be investigated is the effects of parental characteristics (e.g., personality traits, disciplinary methods, age, marital status) on children. Targeting parental differences may lead to a greater understanding of the parental role in families of children with disabilities. This information would likely supplement the research on the stress buffering effects of parental characteristics.

## Study 2

Findings. In the initial part of study 2, the following three groups were compared: the deluxe intervention group, the standard intervention group, and the wait-list control group. There were no significant differences between these three groups on the HSCL, PSI, PSOC or the Mother's Report Card. Comparisons across time were also conducted to compare all the subjects in the deluxe condition to all subjects in the standard condition. These analyses included

subjects initially assigned to the wait-list control group who were later assigned to one of the two treatment groups. Again, there were no significant group differences between these two conditions from pre- to post- to follow-up data collection on the HSCL, the PSI and the Mother's Report Card. This lack of difference on these measures may have been due to the small number of subjects in each of these groups, resulting in lack of variability. On the more global measures (i.e., HSCL, PSI, PSOC), the lack of difference may have also been due to the imprecise nature of these measures when considering the specific topic areas included in the intervention. In other words, the measures may be more sensitive to large numbers of subjects because of the general nature of most of the items.

The Parenting Sense of Competence Scale indicated that there was a significant difference in the measure over time from pre-intervention to post-intervention to follow-up. However, there was no difference between the deluxe and standard interventions. Mothers in both interventions perceived their general parenting skills as less adequate immediately after the intervention and at follow-up data collection. This suggests that reports from the siblings in regard to the sibling group may have indirectly introduced the needs of the siblings to the parents. For example, the siblings may have pointed out things they learned or explained behaviors of other siblings in the group leading

mothers in the standard intervention to question some of their parenting skills or ability to deal with the sibling's needs. In addition, the parents may have perceived themselves as needing to address those issues. Therefore, they may have perceived their current skills as less effective than they previously thought they were. This finding does not provide information specific to the effects of the parent intervention in terms of general parenting competence, as there were no group differences delineated for this particular measure.

The Family Environment Scale revealed significant differences of group, time and a significant interaction of group and time when comparing the deluxe, standard, and wait-list control groups. Means indicated that mothers in the deluxe intervention and standard interventions rated their family environment less positive than mothers in the wait-list control group immediately following the intervention. This may suggest that, between pre- and postintervention, the interventions led mothers to evaluate their situation more closely, bringing difficulties in their family situation to the forefront. This may have resulted in a negative evaluation of the family environment when compared to mothers who were not currently participating in an intervention and dealing as closely with such issues. the other hand, mothers in interventions may have rated their family environment prior to the intervention as more

positive than it actually was, and changed their evaluations after participating or having their siblings participate in the group. This suggests that the parent and/or sibling intervention may have provided unique information about the sibling issues that were not available to the wait-list group, suggesting some lack of insight into the problems that may exist in all families.

Another explanation may be that families in the waitlist group were responding to the questions on the FES in a socially desirable manner. Because they were not currently participating in one of the interventions, they were not scrutinizing their family environments and may have, instead, been more concerned with how their families would be viewed by others.

The interaction between group and time suggests that both the type of intervention and time of evaluation played a role in how the family environment was perceived. When all mothers who participated in the deluxe and standard interventions were compared, the same findings were present. There were significant main effects of group and time, and a significant interaction. Immediately following the intervention the mothers in both groups rated their family environment as less favorable than they did prior to the intervention. Again, this may have been due to issues of family interactions and effects on siblings being brought to the forefront. However, at follow-up mothers' perceptions

of the family environment in both interventions improved and were comparable to their perceptions prior to the intervention. Therefore, this negative perception of the environment appeared to be temporary.

The Child Behavior Checklist was completed by mothers in regard to the siblings. When comparing mothers in the deluxe intervention, mothers in the standard intervention, and mothers in the wait-list group immediately following the intervention, there was a significant difference between these groups. Mothers in the deluxe intervention rated the siblings as having the most difficulty with behavior and social competence. Mothers in the standard intervention rated the siblings as having less trouble with behavior and social competence than mothers in the deluxe intervention, but more difficulty than mothers in the wait-list group. This suggests that the intervention brought the problems of the siblings to the surface such that they perceived them as particularly salient.

When comparing all mothers in the deluxe intervention to all mothers in the standard intervention over time there were no differences between these groups. However, there was an effect of time suggesting that all mothers perceived the siblings' behavior and social competence to improve over time. Therefore, time was a mediating factor in resolving some of the problems that were recognized immediately after the intervention. Therefore, the intervention, on the

whole, may have highlighted some of the difficulties experienced by the siblings such that mothers felt more tolerant of the siblings' behaviors once they had the opportunity to utilize the skills and knowledge gained from the parent group. In addition, the sibling group may have taught the siblings how to deal with the children with autism in a more effective manner, resulting in better behavior and more social competence over time.

The Mother's Report Card mean values revealed a trend indicating that mothers in the deluxe intervention graded themselves highest after the intervention when compared to mothers in the standard intervention and mothers in the wait-list control group. Mothers in the wait-list group graded themselves higher than mothers in the standard intervention immediately following the intervention. This finding suggests that the intervention for the mothers provided them with knowledge and skills that improved their ability to parent and to meet the needs of the siblings of children with autism. Specific areas of sibling parenting that mothers in the deluxe intervention rated as excellent immediately following the intervention included: being able to recognize when something is troubling the sibling, being available to the sibling, enhancing the siblings' selfesteem, doing activities with just the sibling, and taking care not to place too much responsibility on the sibling. Therefore, the intervention was impressionable in terms of

knowledge and skills related to parenting the sibling and that parents felt competent in these areas after the intervention (see Table 19 and Table 20).

Mothers in the wait-list group rated their parenting of the siblings as more adequate than mothers in the standard intervention. Therefore, mothers in the standard intervention may have learned, through the siblings, about the difficulties siblings experience as a result of having a child with autism in the family. However, these mothers were not provided with skills to deal with these problems which may have left them feeling as though their parenting of the sibling was less adequate than the other mothers.

When comparing all participants in the deluxe and standard interventions over time on the Mother's Report Card from pre- to post- to follow-up, there was a main effect of group indicating a significant difference between mothers in the deluxe intervention and mothers in the standard intervention. Mothers in the deluxe intervention rated their parenting skills of the sibling higher than mothers in the standard intervention at post-data collection and at follow-up data collection. Specific areas of sibling parenting that mothers in the deluxe intervention rated as most improved from pre- to post-intervention included: doing things to take care of their own needs, doing things to take care of their spouse, helping the siblings learn to get along with the other child, taking

care not to place too much responsibility on the sibling, doing activities with just the sibling, and promoting a sense of family togetherness. This suggests that mothers gained knowledge and skills which will meet some of their own needs, as well as the needs of the siblings. Again, the mothers in the standard intervention likely recognized areas of need, but may have felt these needs were not addressed.

The group difference on the Mother's Report Card indicated that mothers who participated in the group had a greater influence on the siblings' progress. In addition, they were able to meet some of their own needs through affiliation with other mothers in similar situations. Therefore, this finding further supports a need to combined mother and sibling participation in attempting to meet the needs of the siblings through a deluxe intervention. This is consistent with family systems literature which suggests each family member has a direct influence on every other family member (e.g., Harris, 1983; Minuchin, 1974), and would, therefore be able to recognize and partially address the needs of each other member. It also further illustrates the limitations of sibling groups that do not incorporate participation of other family members (e.g., Clark et al., 1989; Lobato, 1985; McLinden et al., 1991; Schreiber & Feeley, 1965). Because of the positive benefits that the intervention provided for the mother-sibling relationship, there is indirect support for developing interventions that

involve multiple family members so that everyone is working together to target and address specific areas of need.

The Retrospective Report Card suggested that mothers in the deluxe intervention may have overestimated their parenting skills prior to the beginning of the intervention. That is, they may have gained information from the intervention that enhanced their previous knowledge of parenting the siblings which resulted in lower ratings of their pre-intervention skills on this measure upon the second administration. On the other hand, information from the intervention may have helped them recognize deficiencies in parenting the sibling that they had prior to the intervention (see Table 17). This finding may also explain declines from pre- to post- intervention on other measures (e.g., FES and CBCL). Therefore, it may be that the intervention facilitates a more realistic evaluation of maternal and family functioning; that may render comparisons of pre- and post-functioning problematic.

The Report Card of the Group Intervention allowed mothers to rate the group leaders and the content of the group intervention. As mentioned, overall ratings of the intervention were positive and mothers appeared to enjoy the intervention. There were no aspects of the intervention that were rated below satisfactory by any mother and most aspects were rated good to excellent. General areas that were rated high by mothers in the group included: spending

esteem and individuality. This suggested that mothers may have learned about the importance of giving siblings individualized, quality attention, since quantity of attention is frequently required by the children with the disabilities. Mothers also appeared to agree that information derived from the group will later help them bolster the self-esteem and individuality of the siblings by providing them with more attention and by helping them gain an understanding of the important role they play in the family (see Table 18).

Areas that were only rated as satisfactory by some mothers included: helping the sibling get along with the other child and peers, promoting a sense of family togetherness, and mother's relationship with her spouse. This suggests that mothers may have desired additional or different information in these areas, as they were smaller foci of the intervention. However, in each of these areas, only one or two mothers rated them as satisfactory. Other mothers rated these, and all other areas, as good or excellent.

The supplemental section of the Post-treatment Consumer Satisfaction Scale for mothers in the deluxe intervention was also favorable overall. Areas that the mothers found most helpful during the group was the opportunity to affiliate with other mothers in similar situations and the

chance to discuss problems and issues in a group setting.

Activities listed by several mothers as least helpful were takeing notes on psycho-education material presented in lecture format and completing homework assignments, suggesting that they prefer interaction over individualized writing activities.

The initial portion of the Post-treatment Consumer Satisfaction Scale indicated an overall, positive evaluation by the mothers in the deluxe intervention and the standard intervention. It is notable that there were no differences between the mothers in standard and deluxe interventions on their ratings of the sibling group. Both groups rated the sibling group as helpful, positive and enjoyable for the sibling. More specifically, all mothers tended to perceive the siblings' opportunity to get to know other children in the same situation as very helpful. They also seemed to feel that the siblings enjoyed art activities and meeting friends the most. Some mothers believed that the least helpful part of the sibling group was that the duration was too short and others believed that some of the content of the group was obvious or too simplistic for their child.

The supplemental section of the Follow-up Consumer Satisfaction Scale, for mothers in the deluxe condition, yielded similar results to the Post-treatment Consumer Satisfaction Scale in terms of the evaluation of the group intervention. Mothers continued to rate the overall

intervention as beneficial and were most pleased with the opportunity to talk with other mothers and discuss important issues related to the siblings. Areas of the intervention that the mothers listed as most beneficial included: helping siblings interact better with the child with autism and having the opportunity to talk about issues with other mothers. Again, they found the least helpful part of the intervention to be homework.

The initial portion of the Follow-up Consumer Satisfaction Scale was similar to the Post-treatment Consumer Satisfaction Scale in that there were no significant differences between the deluxe and the standard interventions. Both groups rated the intervention as positive overall. There was one item on the questionnaire that revealed differences between the two groups. Mothers in the deluxe intervention said that the siblings asked more questions about autism as a result of the family's participation in the sibling project than mothers in the standard intervention. This is likely a result of more exposure to attempts to meet the needs of the siblings (i.e., mothers and siblings were focused on siblings' needs). It may also be that mothers in the deluxe intervention were talking more about autism in general which resulted in the asking of more questions by the siblings.

Limitations. One limitation is that

the intervention was a brief 6 session, three week intervention. An intervention that entailed a larger number of sessions and longer sessions may have led to more salient and robust results. Booster sessions following the intervention could have increased use of knowledge and skills gained during the intervention and would have likely improved follow-up results as well. Also, the intervention did not directly target the constructs measured by some of the dependent variables (i.e., the HSCL, the PSI and the FES) which may have contributed to the lack of significant results on some of those measures.

Another limitation of Study 2 is that a sample size of only 16 mothers was utilized. A larger sample size may have made the randomization process more effective such that pregroup differences were not found on any other dependent variables. Also, this small N made it difficult to do adequate data analyses and find significant results. Much of the data were better understood by examining means and making tentative statements about the data. Were the number in each group larger, other more general measures may have provided significant results.

Some of the measures utilized to assess the efficacy of the intervention were too broad. The content of the intervention provided specific information to the mothers regarding siblings' issues and needs. Some of the measures were general and assessed a broad range of clinical

phenomena that were not specifically related to the sibling (e.g., the HSCL assessed overall psychological symptomatology and the PSOC assessed overall parenting competence). Other, specific measures may have yielded more significant results. For example, a measure that asked mothers to log the frequency of interactions they had with the siblings on a daily basis, before and after the intervention, may have been helpful. A subjective measure requesting information about content of conversations between mothers and siblings may have also been beneficial. Other means of measuring the efficacy of the intervention could have been used as well. Behavioral observations of the interactions between mothers and siblings, before and after the intervention, may have been useful in detecting differences in communication or interactions as a result of the intervention. Videotaping interactions between the siblings and the children with autism, in conjunction with mothers' facilitation, before and after the intervention, may have been useful in illustrating changes that occurred as a result of the intervention.

Again, representativeness of the sample of mothers of children with autism was questionable. Mothers who participated were very motivated to help the siblings, as well as the children with autism, through interventions such as this. The sample of mothers that participated in this intervention were likely representative of those mothers who

generally volunteer to be involved in programs for any of their children. They were probably especially motivated to participate in this program because there are not many programs designed to meet the needs of the siblings.

Therefore, they may be more likely to improve their well-being and the well-being of the siblings as a result of participation. On the other hand, they may have participated because they saw the siblings as less healthy and in more need of help. Whatever the case, there is likely something qualitatively different about mothers who chose to involve their children and themselves in the program. In addition, these mothers were not working full-time, as the intervention took place mid-afternoon, two days a week; therefore they do not represent mothers who do work full-time and who are not available for such interventions.

As mentioned for Study 1, a limitation of this study is that fathers were not asked to participate in the intervention because of the frequent difficulties of finding fathers who are available to participate. Fathers are often working full-time and would have difficulty attending such a time-consuming activity. More mothers of children with disabilities seem to stay home with the children or have only part-time jobs. It is important to involve fathers in interventions, as they influence sibling functioning in a different way that is likely complementary to the mother's influence. In addition, literature suggests that mothers

and fathers of children with autism experience different levels of stress and depression. Finally, from a family systems perspective, members of a family share dynamics and interactions that are based on each member of the family. Therefore, fathers' participation may be necessary to gain a more thorough understanding of the family process in order to assist in meeting the sibling's needs.

Another limitation of Study 2 is that the setting and information sharing of mothers who participated in the standard intervention was not controlled. Therefore, information they shared informally was not standardized and may have resulted in inconsistent influence of mothers' responses to the questionnaires. In addition, some of the mothers left the building during the sibling group and were not exposed to the other mothers for this informal exchange of information.

Participants in the study were not completely randomized. As mentioned, attempts to randomize subjects were made initially, but due to drop-outs and scheduling problems, a few of the families had to be randomized into one of the remaining groups. However, no subjects were given a choice between the deluxe and the standard interventions.

There was a significant demographic difference in father's education when comparing the deluxe, standard and wait-list participants. The education level of the father

was higher for the wait-list group than the other two groups. When comparing the total deluxe participants to the total standard participants, there were significant demographic differences noted on mothers' age and fathers' age where mothers and fathers in the deluxe intervention were older than mothers and fathers in the standard intervention.

The content of the intervention could have been improved by initially surveying other families of children with autism about information and skills they would like to gain in such a program, and implementing their ideas into the curriculum. Also, the curriculum could have been piloted on families prior to the actual intervention in order to refine the structure and content of the intervention. However, because of the difficulty in getting subjects for such an intervention and because of the rarity of autism, these procedures were not utilized.

From a clinical perspective, it may have been more beneficial to provide a less structured curriculum so that the mothers could identify issues and areas of focus that were more personally relevant during the 3 weeks. However, from a research perspective, this would have made it difficult to make comparisons between groups. It may have been helpful to decrease the amount of information that was provided during the intervention so that information could be learned more thoroughly and implemented more extensively.

There were aspects of the intervention that mothers rated only as satisfactory on the Consumer Satisfaction Scale including: helping the sibling get along with the other child and peers, promoting a sense of family togetherness, and mothers' relationship with spouse. These areas were only briefly addressed during the intervention. It may have been beneficial to address such areas in more detail and have more activities related to these specific content areas. There were also a couple of issues that mothers stated they would have liked to address including: more information about the nature and severity of autism, and opportunities to practice interacting with the siblings and the children with autism.

Another limitation is that the follow-up assessment for this study took place four weeks after the intervention. In order to assess long-term effects of the intervention more effectively, a longer period between the intervention and the follow-up assessment could have been implemented. For example, a 6-month follow-up would be more informative of the lasting effects of the intervention because it may have taken some time for the skills and knowledge to be understood and utilized by the parents. However, it would have been difficult for all 16 families to return to Denton for an additional assessment at a later date.

<u>Directions for future research</u>. Future research should include studies that provide more extensive interventions in

terms of length and amount of material covered to see if there are stronger affects on the families. It may also be advantageous to add other comparison groups to delineate more specific differences (e.g., a mothers' group with no concurrent sibling group). This would allow researchers to see if mothers still benefit without indirect information from the siblings.

It may proliferate the existing literature on siblings of children with disabilities to conduct interventions with families of children with different disabilities. Mothers of children with disabilities and problems other than autism may be functioning at a different level, experience unique stressors, and have unique perceptions of their children. Although some of the results of this study may generalize to families of children with other disabilities, there are likely aspects of the study that are specific to families of children with autism.

Future research should implement interventions that involve as many family members as possible. Family dynamics and interactions are important to the positive functioning of the siblings and of the children with autism (e.g., Harris, 1983; Minuchin, 1974). Inventions that involve several family members would likely increase the efficacy of those interventions. The knowledge and skills addressed in the interventions would be understood from various perspectives and would be more likely to be reiterated in

family interactions as a result of having members cue each other to remember and implement the information.

The above findings indicate that mothers of children with autism experience more stress and have more difficulty with maternal functioning than mothers of children with ADHD or mothers with normally developing children. As a result, some researchers have focused on meeting the needs of the siblings though sibling training and sibling groups. However, they have done so by intervening with siblings without parental involvement. This study provided preliminary data suggesting that mothers play a role in meeting the needs of siblings via a concurrent mother/sibling support group. It also indicated that it may be stressful raising normally developing siblings, as well as children with disabilities. Therefore, interventions should include multiple family members in order to address parent and sibling needs in a sufficient and thorough manner.

APPENDIX A
TABLES

Table 1

Demographic Variables for Study 1

Demographic Variables for Study 1								
	GROUP							
ANOVAs	Autis M	m SD	AD M	HD SD	Cont M		<u>F Sig</u>	
Sibling's Age	8.08	1.94	7.75	2.17	8.67	2.51	351	
Other Child's Age	7.15	2.68	8.71	2.54	7.71	3.67	7 .188	
Mother's Age	36.50	4.40	37.17	4.04	35.25	4.71	313	
Father's Age	39.73	3.87	39.71	5.65	39.11	5.08	.322	
Mother's Education	4.58	1.10	4.71	1.97	4.79	1.25	.812	
Father's' Education	5.31	1.23	4.50	1.50	4.71	1.49	.114	
Family Income <sup>b</sup>	6.08	1.96	5.00	2.59	5.70	1.84	.156	
CHI-SQUARES			FR	<b>EQUEN</b> CI	ES			
		<u> </u>	utism	ADHE	<u>Co</u>	ntrol	<b>X</b> <sup>2</sup>	
Gender of Sibling Male Female			10 16	6 18		8 16	.582	
Gender of Other Ch Male Female	ild		25 1	22 2		20 4	.294	
Birth order of Sib	ling							

Birth order of Sibling and Other Child .027\* Sibling Older Other Child Older Race of Sibling .603 Caucasian (White) African American (Black) Hispanic American Asian American Native American Other 

## CHI-SQUARES

#### PREQUENCIES

	<u>Autism</u>	<u>ADHD</u>	Control	χ²
Race of Mother				.575
Caucasian (White)	23	20	23	
African American (Black)	1	0	0	
Hispanic American	0	0	0	
Asian American	1	1	0	
Native American	0	0	0	
Other	1	3	1	
Marital Status				.238
Single	0	0	0	
Married	25	20	22	
Divorced	1	4	1	
Separated	0	0	1	
Widowed	0	0	0	

Note. \* Grade School=1; Some High School=2; High School

Diploma=3; Some College Courses=3; Four Year Degree=5; Some
Graduate Courses=6; Graduate Degree=7

Note. b \$0-\$9,999=1; \$10,000-\$19,999=2; \$20,000-\$29,999=3; \$30,000-\$39,999=3; \$40,000-\$49,999=4; \$50,000-\$59,999=5; \$60,000-\$69,999=6; \$70,000-or more=7

p \* <.05

Table 2 Group Differences on HSCL Subscales

Group	Mean	SD	N	F Value	F Prob.
Autism (Group 1)	101.69,	(14.95)	26	6.18	.0034**
ADHD (Group 2)	99.21	(16.84)	24		
Control (Group 3)	87.58 <sub>b</sub>	(12.98)	24		
Obsessive-Compulsi	ve Dimensi	on of HSCL			
Group	Mean	SD	N	F Value	F Prob.
Autism (Group 1)	14.08 <sub>a</sub>	(3.45)	26	5.41	.0065**
ADHD (Group 2)	14.46 <sub>a</sub>	(4.58)	24		
Control (Group 3)	11.25 <sub>b</sub>	(2.92)	24		
Interpersonal Sens	itivity Di	mension of	HSCL		
Group	Mean	SD	N	F Value	F Prob.
Autism (Group 1)	11.58,	(2.53)	26	3.55	.0340*
ADHD (Group 2)	11.08	(2.93)	24		
Control (Group 3)	9.75₅	(1.89)	24		
Depression Dimensi	on of HSCL				
Group	Mean	SD	N	F Value	F Prob.

Group	Mean	SD	N	F Value	F Prob.
Autism (Group 1)	19.04.	(5.48)	26	5.12	.0083**
ADHD (Group 2)	17.13	(4.03)	24		
Control (Group 3)	14.92,	(3.83)	24		

Table 3

Non-significant Dimensions of the HSCL

Somatization Dimension of HSCL

Group Prob.	Mean	SD	N	F Value	F
Autism (Group 1)	17.62	(4.10)	26	1.39	.2556
ADHD (Group 2)	16.96	(3.84)	24		
Control (Group 3)	15.63	(4.30)	24		
Anxiety Dimension	of HSCL				
Group Prob.	Mean	SD	N	F Value	F

Prob.

Autism (Group 1) 7.77 (2.39) 26 2.42 .0955

ADHD (Group 2) 7.79 (2.19) 24

Control (Group 3) 6.67 (1.34) 24

p \* <.05, \*\* <.01, \*\*\* <.001

Table 4

Parenting Stress Index (PSI)

Group	Mean	SD	N	F Value	F Prob.
Autism (Group 1)	244.46 <sub>a</sub>	(41.80)	26	5.03	.0091**
ADHD (Group 2)	228.50	(43.77)	24		
Control (Group 3)	207.92,	(36.27)	24		

## Parent Domain

Group	Mean	SD	N	F Value	F Prob.
Autism (Group 1)	134.35 <sub>a</sub>	(22.37)	26	4.24	.0182*
ADHD (Group 2)	130.21	(26.47)	24		
Control (Group 3)	116.25 <sub>b</sub>	(19.08)	24		

## Child Domain

Group	Mean	SD	N	F Value F P	rdb.
Autism (Group 1)	110.12	(24.20)	26	4.69 .0122*	+ *
ADHD (Group 2)	98.29	(20.62)	24		
Control (Group 3)	91.58 <sub>b</sub>	(19.89)	24		

Table 5

Parenting Sense of Competence (PSOC)

Group	Mean	SD	Ŋ	F Value	F Prob.
Autism (Group 1)	77.04	(9,94)	26	2.12	.1282
ADHD (Group 2)	76.92	(11.81)	24		
Control (Group 3)	82.67	(11.66)	24		

p \* <.05, \*\* <.01, \*\*\* <.001

Table 6

Family Environment Scale (FES)

Group	Mean	SD	N	F Value	F Prob.
Autism (Group 1)	504.54.	(44.05)	26	3.48	.0363*
ADHD (Group 2)	533.96 <sub>b</sub>	(55.91)	24		
Control (Group 3)	533.33ь	(36.50)	24		

Table 7

Child Behavior Checklist (CBCL)

Group	Mean	SD	N	F Value	F Prob.
Autism (Group 1)	56.15	(10.90)	26	2.78	.1094
ADHD (Group 2)	51.92	(10.57)	24		
Control (Group 3)	49.68	(11.31)	24		
Internal Subscale					
Group	Mean	SD	N	F Value	F Prob.
Autism (Group 1)	57.39,	(10.46)	26	3.76	.0280*
ADHD (Group 2)	51.88	(9.71)	24		
Control (Group 3)	49.79 <sub>b</sub>	(10.26)	24		
External Subscale					
Group	Mean	SD	N	F Value	F Prob.
Autism (Group 1)	54.19	(11.26)	26	.62	.5427
ADHD (Group 2)	52.38	(11.57)	24		

## Social Competence Subscale (For Siblings Ages 6 and Above)

Control (Group 3) 50.54 (12.03) 24

Group	Mean	SD	N	F Value	F Prob.
Autism (Group 1)	45.72	(8.43)	25	.808	.450
ADHD (Group 2)	48.58	(6.99)	19		
Control (Group 3)	47.20	(7.68)	22		

Table 8

Mothers' Report Card (MCR)

Group	Mean	SD	N	F Value	F Prdo.
Autism (Group 1)	50.85	(7.56)	26	8.55	.0005***
ADHD (Group 2)	56.83 <sub>b</sub>	(8.46)	24		
Control (Group 3)	59.58 <sub>b</sub>	(6.92)	24		

Table 9

Items for Mother's Report Card - Study 1

Items	F Prob.	F Value	Post-hoc
Giving the sibling individualized attention		.008**	Groups 1 & 2 Groups 1 & 3
Helping the sibling learn to get along with			
Helping the sibling resolve peer-related pro		.024*	Groups 1 & 3
Being available to the sibling	2.11	.129	
Taking care not to place too much responsibility			Groups 1 & 3
Recognizing when something is troubling t	4.10 the sibling	.021*	Groups 1 & 3
Doing activities with just the sibling	.919	.404	
Enhancing the sibling's individuality	7.38	.001**	Groups 1 & 2 Groups 2 & 3
Helping the sibling cope with stress	3.44	.038*	Groups 1 & 3
Enhancing the sibling's self-esteem	11.61	.000***	Groups 1 & 2 Groups 1 & 3
Doing things to take care of your own needs	.673	.513	
Doing things to take care of my relationship	4.01 with my sp	.023* ouse	Groups 1 & 3
Promoting a sense of family togetherness	3.27	.044*	Groups 1 & 3
Promoting interactions between the sibling and	the other	.786 child	

p \* <.05, \*\* <.01, \*\*\* <.001</pre>

Table 10

Means and Standard Deviatiosn for Items of the Mother's

Report Card - Study 1

Items	Auti	<u>5m</u>	ADHD	······································	Conti	rol
	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>
Giving the sibling individualized attention		1.08	3.79	.78	3.96	.91
Helping the sibling learn to get along with				. 61	4.08	1.02
Helping the sibling resolve peer-related pro			3.96	.75	4.13	.74
Being available to the sibling	3.54	1.03	4.00	. 83	4.00	.88
Taking care not to place too much responsibility				. 83	4.04	.81
Recognizing when something is troubling the			4.33	.82	4.58	. 58
Doing activities with just the sibling	3.23	1.31	3.75	1.57	3.38	.97
Enhancing the sibling's individuality	3.65	. 94	4.29	. 75	4.42	.50
Helping the sibling cope with stress	3.31	. 97	3.71	1.00	4.00	.83
Enhancing the sibling's self-esteem	3.50	.86	4.25	.68	4.38	.49
Doing things to take care of your own needs	2.65	. 93	3.00	1.64	3.04	1.27
Doing things to take care of my relationship				2.13	3.63	1.01
Promoting a sense of family togetherness	3.58	.90	3.88	1.11	4.25	.74
Promoting interactions between the sibling and	3.81 the ot	1.39 ther chi	4.08 ld	1.38	4.08	.93

Table 11

Demographic Variables for Study 2 (Deluxe v. Standard v. Waitlist)

GROUP

			G.F.	.005			
ANOVAs	Delux	<del></del>	Star	ıdard	Cont	rol	
	M	SD	M	SD	M		<u>F Sig</u>
Sibling's Age	7 40	1.14	7 75	1.71	7.81		_
SIDITING & AGE	7.40	1.17	7.75	1.71	7.01	1,72	.099
Other Child's Age	7.60	2.30	8.50	2.65	7.25	2.49	.364
Mother's Age	39.80	3.56	35.75	3.50	35.57	3.95	.157
Father's Age	42.60	4.10	38.00	2.58	38.57	4.12	.156
Mother's Education	4.00	.82	4.40	1.14	5.29	1.11	.157
Father's* Education	4.25。	.96	5.20	1.09	6.14 <sub>a</sub>	1.07	.038*
Family Income <sup>b</sup>	4.75	2.50	6.20	1.79	7.43	.90	.112
CHI-SQUARES			FF	EQUENC:	IES		
		Delux	e <u>St</u>	andard	Wai	<u>t-lis</u>	t χ²
Gender of Sibling Male Female		1 3		2 3		2 5	.872
Gender of Other Ch Male Female	nilđ	4 0		5 0		7 0	N/A
Birth order of Sil and Other Child Sibling Older Other Child Olde	Ū	3 2		2 2		2 5	.413
Race of Sibling Caucasian (White African American Hispanic American Asian American Native American Other	n (Black	3 k) 0 0 0 0		5 0 0 0 0		6 1 0 0 0	.504

(table continues)

#### CHI-SQUARES

#### FREQUENCIES

1	<u>Deluxe</u>	<u>Standard</u>	<u>Wait-list</u>	$\chi^2$
Race of Mother				349
Caucasian (White)	4	5	6	
African American (Black	) 0	0	1	
Hispanic American	0	0	0	
Asian American	0	0	0	
Native American	0	0	0	
Other	0	0	0	
Marital Status				N/A
Single	0	0	0	
Married	4	5	7	
Divorced	0	0	0	
Separated	0	0	0	
Widowed	0	0	0	

Note, "Grade School=1; Some High School=2; High School

Diploma=3; Some College Courses=3; Four Year Degree=5; Some
Graduate Courses=6; Graduate Degree=7

Note. b \$0-\$9,999=1; \$10,000-\$19,999=2; \$20,000-\$29,999=3; \$30,000-\$39,999=3; \$40,000-\$49,999=4; \$50,000-\$59,999=5; \$60,000-\$69,999=6; \$70,000-or more=7

Note. Groups with different subscripts are significantly different using a Tukey-HSD range test.

p \* < .05

Table 12

Demographic Variables for Study 2 (Deluxe v. Standard)

		GRO	JP				
T-Tests <u>Standard</u> <u>SD</u> F Sig	Delux	<u>:e</u>		*******	<u>M</u>	SD	M
Sibling's Age	7.50	. 93	8.13	1.81		.404	
Other Child's Age	7.13	2.30	7.38	2.83		.849	
Mother's Age	39.13	3.00	34.75	3.81		.024*	•
Father's Age	41.75	4.00	37.63	3.20		.040*	•
Mother's	4.38	. 92	5.00	1.31		.289	
Father's <sup>a</sup> Education	4.88	1.13	5.88	1.25		.115	
Family Income <sup>b</sup>	6.00	2.20	6.50	1.51		.605	
CHI-SQUARES			FRI	EQUENCI	ES		
		<u>D</u>	<u>eluxe</u>	<u>Star</u>	ndard		χ²
Gender of Sibling Male Female			2 6		3 5		600
Gender of Other Ch Male Female	ild		8		8		N/A
Birth order of Sib and Other Child Sibling Older Other Child Olde	_		5 3	2	5		.600
Race of Sibling Caucasian (White African American Hispanic American Asian American Native American Other	(Black	c)	7 1 0 0 0		8 0 0 0 0		.302

#### CHI-SQUARES

#### FREQUENCIES

	<u>Deluxe</u>	Standard	χ²
Race of Mother Caucasian (White)	6	8	.319
African American (Black)	1	0	
Hispanic American	0	0	
Asian American	0	0	
Native American	0	0	
Other	1	0	
Marital Status			N/A
Single	0	0	
Married	4	5	
Divorced	0	0	
Separated	0	0	
Widowed	0	0	

Note. \*Grade School=1; Some High School=2; High School

Diploma=3; Some College Courses=3; Four Year Degree=5; Some
Graduate Courses=6; Graduate Degree=7

Note. b \$0-\$9,999=1; \$10,000-\$19,999=2; \$20,000-\$29,999=3; \$30,000-\$39,999=3; \$40,000-\$49,999=4; \$50,000-\$59,999=5; \$60,000-\$69,999=6; \$70,000-or more=7

Table 13

Study 2 Analyses Comparing Deluxe, Standard, and Wait-list

Groups

ANCOVAS			
Measure	<u>df</u>	F Prob.	F Sig.
PSOC Group (Between Subjects)	3,14	1.123	.382
CBCL Group (Between Subjects)	3,14	16.809	.000***
Mother's Report Card Group (Between Subjects)	3,14	.814	.055
Repeated Measures ANCOVAs			<del></del>
<u>Measure</u>	<u>df</u>	F Prob.	F Sig.
HSCL Group (Between Subjects) Time (Pre-, Post-) Interaction (Group & Time)	1,10	1.79 .20 .12	.217 .665 .888
PSI Group (Between Subjects) Time (Pre-, Post-) Interaction (Group & Time)	1,10	1.24 .41 .93	.330 .535 .427
FES Group (Between Subjects) Time (Pre-, Post-) Interaction (Group & Time)	2,10 1,10 2,10	4.06 52.51 56.97	.051* .000*** .000***

<sup>&</sup>lt;u>p</u> \* <.05, \*\* <.01, \*\*\* <.001

Table 14

Means and Standard Deviations for Study 2 (Deluxe v.

Standard v. Wait-list)

Meas	ures	Pre-Data		Post-Dat	:a
	Group	<u>M</u>	<u>SD</u>	M	<u>SD</u>
HSCL			,		
	Deluxe Standard Wait-List	102.40 95.25 94.83	20.31 15.20 13.01	97.80 83.50 95.17	19.33 13.00 24.74
PSI					
	Deluxe Standard Wait-List	223.40 263.75 221.50	49.37 34.51 32.17	228.40 252.00 217.33	64.52 40.74 47.77
PSOC	Deluxe Standard Wait-List	Covariat	e	63.80 66.50 62.33	
FES					
	Deluxe Standard Wait-List	530.00 531.25 499.67	39.66 75.28 41.88	334.80 339.50 503.67	
CBCL		Covariat	.e		
	Deluxe Standard Wait-List			56.20 52.75 44.33	
Moth	er's Report Card	Covariat	.e		
	Deluxe Standard Wait-List			67.80 49.25 56.17	

Table 15

Study 2 Analyses Comparing Deluxe and Standard Interventions

from Pre- to Post- to Follow-up

Repeated Measures ANCOVAs			
Measure	<u>df</u>	F Prob.	<u>F Sig.</u>
PSI (Covariate)			
Group (Between Subjects)	1,13	.23	.640
Time (Post-, Follow-up)	1,13	.84	.377
Interaction (Group & Time)	1,13	. 86	.370
Mother's Report Card (Covariate)			
Group (Between Subjects)	1,13	9.61	.008
Time (Post-, Follow-up)	1,13	.65	.435
Interaction (Group & Time)	1,13	.04	.841
HSCL			
Group (Between Subjects)	1,12	.00	.967
Time (Pre-, Post-, Follow-up)	2,25	.19	.831
Interaction (Group & Time)	2,25	.70	.507
PSOC			
Group (Between Subjects)	1,13	.79	.391
Time (Pre-, Post-, Follow-up)	2,27	3.96	.031*
Interaction (Group & Time)	2,27	.16	.851
FES			
Group (Between Subjects)	2,10	.07	.051*
Time (Pre-, Post-, Follow-up)	2,27	8.12	.000 <del>***</del>
Interaction (Group & Time)	2,27	.14	.000***
CBCL			
Group (Between Subjects)	1,13	.95	.347
Time (Pre-, Post-, Follow-up)	2,27	4.45	.021*
Interaction (Group & Time)	2,27	.61	.552

<sup>&</sup>lt;u>p</u> \* <.05, \*\* <.01, \*\*\* <.001

Table 16

Means and Standard Deviations for Study 2 (Deluxe v. Standard)

Measures	2	Pre-Dat	э	Post-Da		Follow-	110
Measure	2	LIC DAY	<u>. Ç.A.</u>	tost Da	<u>ua</u>	FOITOW	<u>up</u>
Grou	2	<u>M</u>	SD	M	SD	<u>M</u>	<u>SD</u>
HSCL	******						
Delu: Stand		96.75 96.63	17.58 13.91	88.88 96.63	19.14 19.89	89.12 100.57	19.58 38.49
PSI		Covaria	ite				
Deluz Stand				211.63 250.63	58.55 29.38	201.38 227.00	53.48 66.32
PSOC							
Delu: Stand		73.25 67.88	9.02 12.19	65.50 63.00	7.76 9.33	67.00 62.88	10.15 10.16
FES							
Deluz Stand	_	528.50 507.63	34.98 60.00	409.00 405.50	110.62 74.41	523.25 518.88	47.22 51.51
CBCL							
Delu: Stand		50.75 55.13	15.53 8.11	50.12 52.00	13.94 10.43	46.50 48.50	16.61 10.73
MRC		Covaria	te				
Deluz Stand	_			64.37 51.12	15.32 5.46	62.50 45.00	7.15 18.79

Table 17

Mother's Report Card Pre-test Compared with Mother's Retrospective Report Card

Type of Intervention	Pre-test Means	Pre-test SDs	Retro. Means	Retro. SDs	n
Deluxe	56.25	(5.63)	52.38	(11.45)	8
Standard	47.00	(8.40)	46.36	(14.31)	8

Table 18

Report Card for Group Intervention

Items Mean Frequencies						
Items	Mean	A	requ B	ienc: C	les D	F
Doing activities with just the sibling	5.00	7	0	0	0	0
Giving the sibling individualized attention	4.57	4	3	0	0	0
Being available to the sibling	4.57	4	3	0	0	0
Enhancing the sibling's individuality	4.57	4	3	0	0	0
Enhancing the sibling's self-esteem	4.57	4	3	0	0	0
Recognizing when something is troubling the sibling	4.43	3	4	0	0	0
Doing things to take care of your own needs	4.43	3	4	0	0	0
Talking to the sibling about the nature of autism/PDD	4.43	3	4	0	0	0
Promoting interactions between the sibling and the child with autism/PDD	4.43	3	4	0	0	0
Taking care not to place too much responsibility on the sibling	4.29	2	5	0	0	0
Helping the sibling cope with stress	4.14	1	6	0	0	0
Helping the sibling learn to get along with other children	4.00	2	3	3	0	0
Helping the sibling resolve peer-related problems	4.00	1	5	1	0	0
Promoting a sense of family togetherness	4.00	2	3	2	0	0
Doing things to take care of my relationship with my spouse	3.71	2	2	2	1	0

Table 19

Items for Mother's Report Card - Deluxe Intervention

Items	Pre-Post Discrepancy	Pre	Post
Doing things to take care your own needs	+1.62	2.88	4.50
Doing things to take care of my relationship with my spouse	+1.25	2.50	3.75
Helping the sibling learn to get along with the other child	+ .88	3.50	4.38
Taking care not to place too much responsibility on the sib	+ .88 Dling	3.75	4.63
Doing activities with just the sibling	+ .88	4.00	4.88
Promoting a sense of family togetherness	+ .87	3.63	4.50
Helping the sibling resolve peer-related problems	+ .75	3.75	4.50
Being available to the sibling	+ .75	4.25	5.00
Promoting interactions between the sibling and the child with autism/PDD	+ .75	3.63	4.38
Recognizing when something is troubling the sibling	+ .62	4.38	5.00
Enhancing the sibling's self-esteem	+ .50	4.13	4.63
Helping the sibling cope with stress	+ .38	4.00	4.38
Talking to the sibling about the nature of autism/PDD	+ .37	4.13	4.50
Enhancing the sibling's individuality	13	4.13	4.00
Giving the sibling individualized attention	31	3.88	3.57

Table 20

Items for Mother's Report Card - Standard Intervention

Items	Pre-Post Discrepancy	Pre	Post
Enhancing the sibling's individuality	+1.00	3.00	4.00
Taking care not to place too much responsibility on the sib	+ .72 ling	2.57	3.29
Enhancing the sibling's self-esteem	+ .86	2.57	3.43
Giving the sibling individualized attention	+ .57	3.00	3.57
Helping the sibling cope with stress	+ .43	3.00	3.43
Promoting interactions between the sibling and the child with autism/PDD	+ .29	3.57	3.86
Promoting a sense of family togetherness	+ .28	3.29	3.57
Helping the sibling learn to get along with the other child	+ .14	3.57	3.71
Recognizing when something is is troubling the sibling	+ .14	3.86	4.00
Talking to the sibling about the nature of autism/PDD	+ .14	3.86	4.00
Helping the sibling resolve peer-related problems	.00	3.71	3.71
Being available to the sibling	.00	3.43	3.43
Doing activities with just the sibing	.00	3.15	3.15
Doing things to take care of my relationship with my spouse	.00	2.29	2.29
Doing things to take care of your own needs	42	2.71	2.29

APPENDIX B

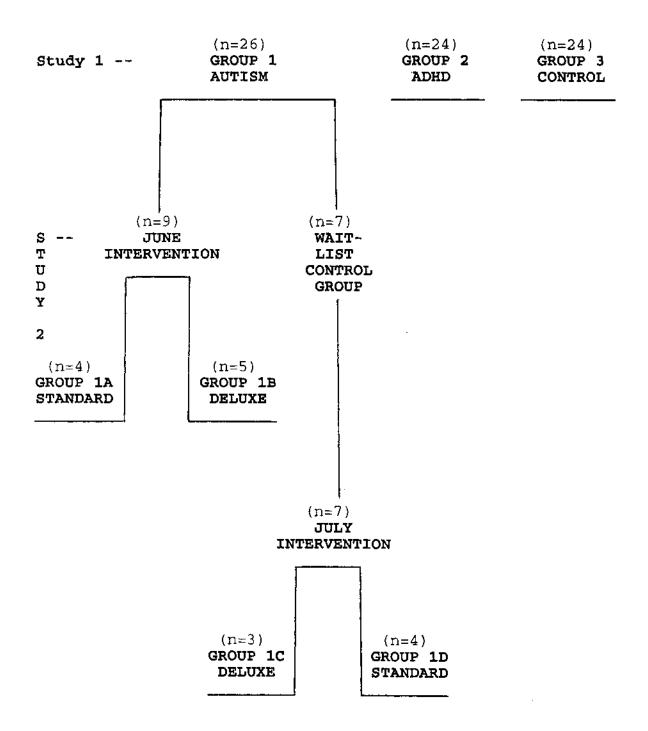


Figure 1. Group Structure for Studies 1 and 2

# APPENDIX C RECRUITMENT MATERIALS

#### Introductory Letter to Parents

April 15, 1994

Mrs. Mary Jones 1515 Main Street Anvtown, Texas 76200

Dear Mrs. Jones:

I would like to thank you for expressing an interest in our research project involving brothers and sisters of children with autism. In an attempt to respond to the complex needs of these youngsters, the University of North Texas will sponsor four sibling groups scheduled to begin this summer. The University of North Texas, located in Denton, is a brief drive from the Dallas and Fort Worth areas. The groups will take place twice a week from 2:00 p.m. to 4:00 p.m. and will run for approximately four weeks. The group will include siblings between the ages of 8 and 12; however, it may be the case that the age range will be expanded. This group will be led by doctoral students in clinical and counseling psychology under my supervision.

The group will address the many stressors and challenges relevant to siblings. The purpose of the group is to assemble siblings together in a benign forum and help them to better understand, address, and discuss their unique concerns as brothers and sisters of children with autism. Aside from teaching coping skills and strategies, the group will afford these youngsters the opportunity to meet and interact with other children with the similar experience of having a brother or sister with autism. Siblings will actively participate in a series of workshops, discussions, and recreational activities (munchies will be served at every meeting!). They will benefit from not only the information attained, but from the group experience as well.

We request that you please take the time to discuss the group openly with your child and answer questions that might emerge. We have included a letter written for siblings to help them understand what the group is all about. Many times parents are so eager to have their children take part in a group that they inadvertently pressure the child to participate. This is would be very unfortunate and may only make the sibling more resentful.

In order to evaluate our group, we will ask that you and your child complete a number of surveys and questionnaires. All of the collected information will be treated as confidential, kept in secure files, and destroyed once it loses its scientific value. Your questionnaires will be not have your name or your child's name on it, rather they will only be identified by a code number. We will be collecting a variety of information both before and after the group intervention and then once again a few weeks later. We expect to submit the data that emerge from this project to professional organizations and journals so that others might benefit from our efforts. We will describe group data rather than individual data.

One of the major objectives of this project is to compare group formats. Therefore, the intervention will involve your participation in one of four structured support groups. Two groups will meet in June and the other two groups will meet in July. The sibling component will be identical in structure and format for the four groups. However, two of the groups (one in June and one in July) will involve the

participation of the mothers. The other two groups will not involve the mothers. Your family's participation will involve random assignment to one to the groups so families will not have a choice as to which of the four groups your family will be assigned. It is our professional opinion that any of the groups can be beneficial to families of children with autism.

Please note than in order to be considered for this project, you will need to agree to participate in this study regardless of the group (only the sibling participates versus the sibling and the mother participates) or month (June versus July) to which my family is assigned. Although you are free to withdraw your participation at any time, to ensure the success of this project it is important that you consider participation very carefully. If you are you are unable to commit to biweekly visits to Denton over a four week span or have travel plans that will affect your attendance, this project may not be appropriate for your family at this time. If this is the case, we would be more than happy to contact you in the future when we plan a similar group.

There will be no charge for participation for this service, as financial support for this project has been granted by the Faculty Research Office of the University of North Texas. However, a small one time fee of \$10.00 will be collected to help defray some of the costs associated with snacks and supplies for the youngsters (if this would present a hardship to your famility please discuss with myself or the group leader). We will be happy to provide babysitting services if needed during the group meetings. Also in order to celebrate the conclusion of the group, a "graduation"

party" will be held for the siblings.

I have overseen a similar project in the past and the siblings found it to be a very rewarding and enjoyable experience. If you are interested in this experience for your son or daughter, please return the attached forms in the self addressed stamped envelope. We will provide you with further details as they become available. If you have any further questions, I can be reached at (817) 565-4715.

Sincerely,

David Celiberti, Ph.D. Project Director

#### PARENT CONSENT FORM

I am aware that Dr. David Celiberti from the University of North Texas is interested in conducting research evaluating group interventions for siblings of children with autism. I have read over the introductory letter and have discussed the group with my child. I am willing to have myself and my child participate in this project. I understand that the sessions will meet biweekly, will last approximately two hours each, and will continue over three weeks.

I understand that four identical sibling groups will be conducted, two involving the participation of the mothers and two not. I am aware that the first two groups will begin in June and the second two groups will begin in July. I understand that our participation will involve random assignment to one of the groups. I am giving my consent to participate with the understanding that Dr. Celiberti does not know at this time to which of the four groups may family will be assigned. I agree to participate in this study regardless of the group to which my family is assigned.

I am also aware that as part of his work with the siblings, Dr. Celiberti will be collecting a variety of information both before and after the group intervention and then once again a few weeks later. I am willing to have him ask questions of both myself and my participating child. I am aware that some of the questions that will be asked concern thoughts and opinions about myself and my children and that the same is true for the information collected from my child. I also understand that although some children may have some mild discomfort when filling out the surveys, most children fill out similar instruments without any difficulties or discomfort.

I understand that the material collected will be treated as confidential and all records will be destroyed when they lose their scientific value. Any information collected will be identified by code number and will not be associated with my name or my child's. I am aware that any research presentations that result from this project will describe group data rather than individual data and will disguise both of our identities so that it will be impossible to know who participated in the study.

I am aware that my child's participation in the group may benefit him or her. He or she will have the opportunity to share his or her feelings and thoughts with other young siblings in a supportive group environment. He or she will also learn new skills and participate in some fun activities (games, arts and crafts, etc.).

My decision to participate has been considered very carefully and I am willing to make the necessary commitment at this time. However, I know that I may withdraw my own and my children's participation from this project at any time without penalty. My questions about the project have been answered to my satisfaction. I understand that should I have any questions in the future, I may contact Dr. Celiberti at the University of North Texas at (817) 565-4715.

Parent	<del></del>	Date
Witness		

#### Sibling Introductory Letter

April 15, 1994

Dear Katie:

Hi!

We want you to know about what we will be doing this summer at the University of North Texas. We are putting together a group for brothers or sisters of kids with autism. Your parents may have already told you that this is a research project, which is just a couple of big words that mean a study. We are like scientists and we are trying to come up with ways to help brothers and sisters like yourself.

In the group we will talk about what it is like to live in a family like yours. You can talk as much as you want, it's up to you. Sometimes kids feel funny talking to new people. We want you to know that this is OK and that these feelings usually go away. We will also play some games, do some art stuff, and maybe even listen to some stories written by other kids like you.

The group will meet for 2 hours, twice a week for a month. There will be snacks and a break in the middle. We think that you will have fun in the groups as well as learn some new things. The one bad thing about taking part in the group is that it might mean that you will miss some activities with your friends at home. So you should think this over very carefully before you decide to take part in the group.

You will also need to fill out some papers about yourself, your brother or sister, and your family. This will be done before the group starts for the first time and then later after the group has met for a month. About a month after the last group meeting, we will get together for a big party and you will fill out papers for the last time.

If you have any questions, you can ask your mother or the project director, Dr. Celiberti. Once the groups start, you can ask the group leaders to explain anything that you don't understand. If you decide you want to take part in the group, let your mom know. Please read and sign the following form and have your mom sign the bottom part when you are finished. We hope we get to meet you!

Thank you,

David Celiberti Project Director

#### Consent to Participate in Sibling Project

I am aware that Dr. David Celiberti from the University of North Texas is interested in conducting research evaluating a group intervention for siblings of children with autism. I have read over the introductory letter and have discussed the group with my child. I am willing to have myself and my child participate in this project. I understand that the sessions will meet biweekly, will last approximately two hours each, and will continue over four weeks.

I understand that four identical sibling groups will be conducted, two involving the participation of the mothers and two not. I am aware that the first two groups will begin in June and the second two groups will begin in July. I understand that our participation will involve random assignment to one to the groups. I am giving my consent to participate with the understanding that Dr. Celiberti does not know at this time to which of the four groups may family will be assigned. I agree to participate in this study regardless of the group to which my family is assigned.

I am also aware that as part of his work with the siblings, Dr. Celiberti will be collecting a variety of information both before and after the group intervention and then once again a few weeks later. I am willing to have him ask questions of both myself and my participating child. I am aware that some of the questions that will be asked concern thoughts and opinions about myself and my children and that the same is true for the information collected from my child. I also understand that although some children may have some mild discomfort when filling out the surveys, most children fill out similar instruments without any difficulties or discomfort.

I understand that the material collected will be treated as confidential and all records will be destroyed when they lose their scientific value. Any information collected will be identified by code number and will not be associated with my name or my child's. I am aware that any research presentations that result from this project will describe group data rather than individual data and will disguise both of our identities so that it will be impossible to know who participated in the study.

I am aware that my child's participation in the group may benefit him or her. He or she will have the opportunity to share his or her feelings and thoughts with other young siblings in a supportive group environment. He or she will learn new skills and participate in some fun activities (games, arts and crafts, etc.).

My decision to participate was considered very carefully and I am willing to make the necessary commitment at this time. However, I know that I may withdraw my own and my children's participation from this project at any time without penalty. My questions about the project have been answered to my satisfaction. I understand that should I have any questions in the future, I may contact Dr. Celiberti at the University of North Texas at (817) 565-4715.

Parent	Date			
Witness				

# Recruitment Flyer (for Group 2)

# Attention all Student Clinicians SUBJECTS NEEDED

We need your help in contacting potential subjects.

Families with at least two children are needed to participate in a research project studying sibling relationships and how children feel about themselves and their families.

The participating child must be between 8 and 12 years of age and no more than 4 years older or 5 years younger than their sibling receiving services at the Psychology Clinic. The participating child must also be in good health. The other child must be a client here at the clinic and the diagnosis must be other than Autism, Pervasive Developmental Disorder NOS, or Mental Retardation.

Mothers and one of the siblings will be required to fill out questionnaires and answer some questions.

Psychology extra credit points are available to the mother if she is a student at UNT

and

a drawing will be held for all participants for a chance to win

# \$\$ FIFTY DOLLARS \$\$

If you have a client meeting the above criteria, please contact Roki Abakoui, Joelle Oizumi or Laura Vogel at 565-4329 for further information.

Thank You for your help.

#### PSYCHOLOGY CLINIC SIBLING TRAINING PROJECT

Who we are. The University of North Texas Psychology Clinic provides a variety of mental health care services to individuals and their families. It is also a feaching, training, and research center supported by the Psychology Department and the University. Services associated with this project are provided by doctoral students in the Clinical and Counseling Psychology program under the supervision of Dr. David Celiberti.

Confidentiality. Participants are assured that their contacts with the Clinic will remain confidential. Clients should understand, however, that in some situations, we are mandated by state or federal law to release information (e.g., cases of child abuse/neglect or when there is clear indication that you are in danger of physically harming yourself or another person).

#### CONSENT

I understand that the Group Leaders, who are under the supervision of Dr. Celiberti, will need to videotape parts of the sessions for training purposes and audiotape one small part of the child assessment for the accurate transcription of verbal data. The audiotapes will be only be used if the student feels that she has missed something that the child may have said. I have read and understood the policies as described above. I consent to the use of audiotapes and videotapes for training and research purposes. I also understand that I may withdraw this consent at any time.

Participant	date
Group Leader	date

#### FAMILIES NEEDED

Families with at least <u>two</u> children, one of whom is diagnosed with Attention Deficit Hyperactivity Disorder (ADHD) are needed to participate in a research project being conducted at the University of North Texas (or we are willing to come to your home). Researchers are studying sibling relationships and how children and mothers feel about themselves and their families.

The sibling of the child with ADHD must be between the of 4 and 10 and no more than 6 years older or younger than his or her brother or sister.

Mothers and the sibling of the child with ADHD will be required to fill out questionnaires and answer some questions.

All interested families may take part in this study. As an incentive, a drawing will be held for all participating siblings for a chance to win

## \$\$FIFTY DOLLARS\$\$

In addition, families will have the opportunity to engage in research and to contribute to the understanding of parent and sibling relationships!!!

For further information please contact Roki Abakoui, Joelle Oizumi, or Laura Vogel at (817) 565-4715 or (817) 565-4329

# Recruitment Flyer (for Group 3)

### SUBJECTS NEEDED

Families with at least two children are needed to participate in a research project studying sibling relationships and how children feel about themselves and their families.

At least one of the children must be between 8 and 12 years of age and no more than 4 years older or 5 years younger than their sibling. Both must be in good health and have no known learning problems.

Mothers and one of the siblings will be required to fill out questionnaires and answer some questions.

You do not need to be a psychology student to participate.

All interested families may take part in this study.

Psychology extra credit points are available to any parent who is taking an undergraduate psychology course

and

a drawing will be held for all participants for a chance to win

# \$\$ FIFTY DOLLARS \$\$

For further information please contact Roki Abakoui, Joelle Oizumi, or Laura Vogel at

**☎ ☎** (817) 565-4329 **☎ ☎** 

#### CONSENT TO PARTICIPATE IN RESEARCH PROJECT

I am aware that Laura Vogel, Joelle Oizumi, and Roki Abakoui from the University of North Texas are interested in conducting research evaluating the parents' role in sibling relationships and how children feel about themselves, their siblings and their families. I have read the introductory letter and have discussed participating with my child. I am willing to participate with my child.

I am also aware that as part of the research, Laura Vogel, Joelle Oizumi, and Roki Abakoui will be collecting a variety of information about myself and my child. I am willing to have them ask questions of both myself and my participating child. I am aware that some of the questions that will be asked concern thoughts and opinions about myself and my children and that the same thing is true of the information collected from my child. I further understand that although some children may have some discomfort when filling out the surveys, most children fill out similar instruments without any difficulties or discomfort.

I understand that the material collected (e.g., questionnaires and audiotapes) will be treated as confidential and all records will be destroyed when they lose their scientific value. I also understand that the results of the achievement test given my child will not be provided to me and will remain confidential as will the other questionnaires that my child fills out. Any information collected will be identified by code number and will not be associated with my name or my child's name.

I am aware that any research presentations that result from this project will describe group data rather than individual data and will disguise both of our identities so that it will be impossible to know who participated in the study. My decision to participate is voluntary. However, I know that I may withdraw my own and my child's participation from this project at any time without penalty. My questions have been answered to my satisfaction. I understand that should I have any questions in the future, I may contact Roki Abakoui, Laura Vogel, Joelle Oizumi, or David Celiberti at the University of North Texas at (817)565-4715.

Parent	Date	Witness	Date

#### SIBLING ASSENT FORM

I have thought about this study and have decided to take part in the research project. I am volunteering to fill out the papers, tell a few stories and take a test. I understand that the forms will ask me about my feelings and that sometimes I may feel uncomfortable about this. I also understand that all the things I say and all my answers on the forms will be confidential. That means that I won't put my name on the papers and no one will know how I answered, not even my parents.

I know that my mother has given permission for me to take part in this study. I know that I can stop at any time if I want and no one will be angry with me. I understand that if I have any questions about the study or any of the papers I fill out, I can ask my parents or the person giving me the test and questions.

My Signature	Date
Researcher	Date
My child and I have discussed research project. I have answ project.	his or her participation in the sered my child's questions about the
Parent's Signature	Date

# APPENDIX D MEASURES FOR STUDY 1 AND 2

## DEMOGRAPHIC INFORMATION SHEET 1

Date:	
Partic	ipating Sibling
	Age: Grade: Gender (circle one): Male/Female What type of school does the child attend (circle one)? Public Private
	Does the child have any learning disabilities or psychological problems?  If yes, please describe:
	Are there special activities that the sib is involved in (e.g., art lessons, dance classes, religious instruction)? Yes No If yes, please describe these briefly:
	What is the sib's racial/ethnic background (circle one)?  1=Caucasian (White)  2=African American (Black)  3=Hispanic American  4=Asian American  5=Native American  6=Other
Child	with Autism
	Age: Grade: Gender (circle one): Male/Female Where does the child attend school?
	Please describe your child's level of functioning as well as the nature of his/her behavior problems:
Other	Family Members
	Other(s) living with family:
	Age and relation to the sib participating in the group:

## DEMOGRAPHIC INFORMATION SHEET 2

GROUP #1 Other Family Information							
What is your age? W	hat is the age of the sib's father	?					
What is your current marital statu	s (circle one )?						
1=Single 2=Married	3=Divorced 4=Separa	ted 5=Widowed					
What is your racial/ethnic backgr	ound (circle one) ?						
1=Caucasian (White) 4=Asian American	2=African American (Blac 5=Native American	k) 3=Hispanic American 6=Other					
What is your highest level of educ	cation (circle one )?	***************************************					
4=Some College or Trade	Some High School 3=High S School 5=Four Year Colle es 7= Graduate Degre	ge Degree					
What is the father of the sib's high	hest level of education (circle o	ne )?					
4=Some College or Trade	Some High School 3=High S School 5=Four Year Colle es 7= Graduate Degree	ge Degree					
What is your yearly family incompartner (circle one - if unsure, ple		income of you and your spouse or					
1= \$0 - \$9,999 4=\$30,000 - \$39,999 7=\$60,000 - \$69,999	2=\$10,000 - \$19,999 5=\$40,000 - \$49,999 8=\$70,000 -or more	3=\$20,000 - \$29,999 6=\$50,000 - \$59,999					

## SUPPLEMENTAL INTAKE QUESTIONNAIRE FOR PARTICIPATING FAMILIES IN THE SIBLING GROUP

## Child's understanding and contact with special needs

A. Have you discussed your child with autism's disability with the participating sibling? Yes No	B
B. Please answer the following questions:	
1. How old was the sib when you first discussed special needs?	
How soon after you were aware of your child's problem did you talk with sib?	h the
3. Please estimate how often you have discussed these issues with the sib?  Every day:	<del>-</del>
1-2 times per week: 1-2 times per month: 1-2 times per year: Other:	
Are there any materials that you have found to be helpful to you in these discussions (e.g., books, pictures, videos)?  Yes No	
If yes, please describe:	_
5. Has the sib ever participated in a support group intervention before?  If yes, please describe:	- - -
6. Have you or your spouse/partner ever participated in a support group interbefore?	- rvention
Yes No	
If yes, please when and what purpose:	<b>-</b>

7.	Are there certain words you use to refer to the child's special needs when speaking with your son or daughter?
	Yes No If yes, please list:
8.	Are there any words you try to avoid using? Yes No If yes, please describe:
	Please list the activities/games that your children enjoy together (even for a ief period of time):
	Please describe one or two events that have brought you concern regarding the
	o's adjustment to his brother's or sister's autism:
	Please describe one or two events that have brought you enjoyment garding the sib's adjustment to his brother's or sister's autism:

#### Parent interests

ncerns about enrolling the sib in the group?
other information that you feel will help make your child more group:
-

## Other information for planning group activities

## Please provide a list of the following

<u> </u>

## DEMOGRAPHIC INFORMATION SHEET GROUP #2

Date:	CODE #
Participating Sibling	
Age: Grade: Gender (circle one): Male Fem	aie
What type of school does the sibling attend (circle one)? Public Priva	ite
Does the sibling have any learning disabilities or behavior problems?  Yes No If yes, please describe:	
Does the sibling have any serious medical problems ? Yes No If yes, please describe:	
Are there special activities that the sibling is involved in (e.g., art lessons religious instruction)? Yes No If yes, please describe	, dance classe:
What is the sibling's racial/ethnic background (circle one)?  1 = Caucasian (White)	nerican
Age: Grade: Gender (circle one): Male Female	<del>183 : </del>
What type of school does the child attend (circle one)? Public Private Where does the child attend school?	
Does the child receive any special education services ? Yes No If yes, please describe:	
Please describe the child's difficulties that led to treatment and/or evaluation	on in our clinic:
Please list any diagnoses if known:	
Ooes the child have any serious medical problems ?  Ves No ff yes, please describe:	

## DEMOGRAPHIC INFORMATION SHEET GROUP #2

Other Family Informat					ing's f		
What is your age?	Wna	ii is ine i	age of t	NG 2504	::ng 5 i	ather?	
What is your current ma	rital status (c	ircle one	)?				
1=Single 2=Merried	3=Divorced	4=Sep	areled	5+Wid	owed		
What is your racial/ethnic	background	d (circle d	one) ?				
1 = Caucasian (White)	2 = Airicen An	nericen (Bl	ack)	3 = His	panic A	merican	
4 = Asian American	5 = Native Am	ricen		6 = Oth			
What is your highest leve	<b>e</b> l		What	is the 1	lather	's highest	level
of education (circle one)	?		of edu	cation	(circle	e one) ?	
1 = Grade School			1 = Gre	de Scho	ol		
2 = Some High School			2 = Son	ne High	School		
3 = High School Diploma or GE	D O		3 = High	h School	Diplor	a or GED	
4 = Some College or Trade Sci	haal				-	rede School	
5 = Four Year College Degree				r Year C	_	-	
6 = Some Graduate Courses			6 × Some Graduate Courses				
7 ≃ Graduate Degree			7 = Gra	duate D	egree		
What is your yearly family	y income wh	ich inclu	des the	comi	benic	income of	you and you
spouse or partner (circle	one - if unsu	ire pleas	ie estim	nate) ?			
1 = \$0 - \$9,999	2 = \$10,000 -	\$19,999		3 = \$20	- 000,0	\$29,999	
4 = \$30,000 - \$39,999	5 = \$40,000	\$49,999		6 = \$50	- 000,	\$59,999	
7 = \$60,000 - \$69,999	8 = \$70,000 -	or more					
	Age	Gende (circle o			Living (aircle (	in Same	Home ?
Other Children in Family		Male	Fema	ale	Yes	No	
•		Male	Fema	lie	Yes	No	
		Male	Fema	<b>le</b>	Yes	No	
		Male	Fema	ale .	Yes	No	
Are there other family m	iembers who	live with	the pa	articipa	iting cl	nild ?	
	Age	Gende	er		Relat	ionship to	child ?
	<b>-</b> -	(circle o	_			andmother")	
Other Family Members		Male	Fema	ale.			
		Male	Fema		***************************************		•
		Male	Fema				•
		MIGHT.	LOHIN	n <u>e</u>			

## DEMOGRAPHIC INFORMATION SHEET 1 GROUP #3

Date:		<del></del>				
Partic	ipating	Sibling				
				cle one): Male/Fe (circle one)? Publ		
	Does the If yes, plo	child have any case describe:	learning disabilit	ies or psychological	problems ?	
	Are there classes, n	special activiti	ies that the sib is : tion)? Yes	involved in (e.g., ar No	t lessons, dance	
	}=Caucas		thnic background 2=African 5=Native A	American (Black)	3=Hispan 6=Other	ic American
Other	What typ Does the	e of school doe child have any	s the child attend learning disabilit	cle one): Male/Fema (circle one)? Publies or psychological	lic Private problems?	
Other	•	Members	mily:			
	Age and	relation to child	d:			

## DEMOGRAPHIC INFORMATION SHEET GROUP #3

Other Family Information		
What is your age?	What is the age of the sib's	father?
What is your current marital status	(circle one )?	
1=Single 2=Married	3=Divorced 4=Sep	arated 5=Widowed
What is your racial/ethnic backgro	and (circle one) ?	
•	African American (Black) =Native American	3=Hispanic American 6=Other
What is your highest level of educ	ation (circle one )?	
1=Grade School 2=S 4=Some College or Trade 5= Some Graduate Course		n School Diploma or GED Year College Degree wate Degree
What is the father of the sib's high	est level of education (circle	e one )?
1=Grade School 2=S 4=Some College or Trade 6= Some Graduate Course		n School Diploma or GED Year College Degree uate Degree
What is your yearly family income partner (circle one - if unsure, plea	which includes the combinate of the which includes the combinate of the co	ed income of you and your spouse of
I= \$0 - \$9,999 4=\$30,000 - \$39,999 7=\$60,000 - \$69,999	2=\$10,000 - \$19,999 5=\$40,000 - \$49,999 8=\$70,000 -or more	3=\$20,000 - \$29,999 6=\$50,000 - \$59,999

## Hopkins Symptom Checklist (HSCL)

Selow is a list of problems people sometimes have. Write the number in the blank space mext the question that best describes how much that problem has distressed or bothered you during the past 7 days including today. Please write only one number for each problem and do not skip any items.

NOT AT ATT	A Little Bit	Moderately	Quite A Bit	Extramely
1	2	3	4	5
1 Nervousness or shakines	s inside			
2 Faintness or dizziness				
3. The idea that someone e	ise can control your	Lhoughts		
4 Feeling others are to t		troubles		
5 Trouble remembering this				
6 Feeling easily armoyed				
7 Pains in heart or chest				
Feeling afreid in open     Thoughts of ending your	apaces or on one some	TC13		
10 Feeling that most people	e cannot be trusted			
11 Poor appetite				
12 Suddenly scared for no	reason			
<ol><li>Temper autburst that yo</li></ol>				
14 feeling lonely even whe		•		
15 Feeling blocked in gett	ing things done			
16 Feeling lonely				
17 Feeling blue 18 Feeling no interest in	thinac			
19 Feeling feerful	CITITIES.			
20 Your feelings being eas	illy hurt			
Zi Feeling that people are		le you		
22 Feeling inferior to oth	ers			
23 Nausea or upset stomach				
24 Feeling that you are wa	tched or talked about	t by others		
25 Trouble falling asleep				
<ol> <li>Heving to check and dought.</li> <li>Difficulty making decis</li> </ol>		)		
28. Feeling afraid to trave		or trains		
29 Trouble getting your br				
30. Hot or cold spells				
31 Having to evoid certain	things, places, or a	ectivities because they	frighten you	
32 Your mind going blank				
33 Numbress or tingling in				
34 The idea that you shoul 35 Feeling hopeless about		ir sins		
36 Trouble concentrating	ME IOMIE			
37 Feeling week in parts of	of water backs			
38 Feeling tense or keyed				
39 Thoughts of death or dy				
40 Heving urges to best, i		i		
41 Having unges to break o				
42 feeling very self-consc				
43 Feeling unessy in crowd	is, such as shopping o	or at a movie		
44. Hever feeling close to	another person			
45 Spells of terror or pan	HC			
46 Getting into frequent a	rgunents			
47 Feeling nervous when yo	u are left alone			
48 Others not giving you p	raper credit for your	achi evenents		
49 Feeling so restless you	couldn't sit still			
50 Feelings of worthlessne	ess			
51 Feeling that people will		ou if you let them		
52 Feelings of guilt				
53 The idea that something	1s wrong with your #	rind		

## Parenting Sense of Competence Scale (PSOC)

Below is a list of things one may encounter as a result of being a parent. Write the number that best fits your feelings in the blank space next to the question. Please write only one number for each problem and do not skip any items.

Strongly Agree Partially Neither Agree Partially Disagree Strongly

	Agree 1	Agree nor Disagree Disagree Disagree 2 3 5 6 7
1		The problems of taking care of a child are easy to solve once you know your actions affect your child, and understanding you have acquired.
2		I meet my own personal expectations for expertise in caring for my child.
3		I would make a fine model for a new mother to follow in order to learn what she would need to know in order to be a good parent.
4	·	Being a parent is manageable, and any problems are easily solved.
5		If anyone can find the answer to what is troubling by child, I am the one.
6		A difficult problem in being a parent is not knowing whether you're doing a good job or a bad one.
7	-	Considering how long I'we been a mother, I feel thoroughly familiar with this role.
8		I honestly believe I have all the skills necessary to be a good mother to my child.
9		Even though being a parent could be rewarding, I am frustrated now.
10		I do not know why it is, but sometimes when I'm supposed to be in control, I feel more like the one being Ramipulated.
11	·—	My mother was better prepared to be a good mother than I am.
12		Sometimes I feel like I'm not getting anything done.
13		I go to bed the same way I wake up in the morning - feeling I have not accomplished a whole $loc$ .
14	•	My talents and interests are in other areas, not in being a parent.
15		If being a mother of a child were only more interesting, I would be motivated to do a better $j$ do as a parent.
16		Being a parent makes me tense and aroxicus.
17		Being a good mother is a reward in itself.

			Code +
	мот	THERS' REPORT CARD	
Below as Please g	re a number of things that moth ive yourself a "grade" from the l	iers do. The word "sibling" refe list below and place your grade	ers to the participating child. in the corresponding box:
GRADES	B - Good C - Satis	factory s improvement	
	Giving the sibling individu	ualized attention.	
	Helping the sibling learn	to get along with the othe	r child.
	Helping the sibling resolv	e peer-related problems.	
	Being available to the sibl	ling.	
	Taking care not to place t	too much responsibility on	the sibling.
	Recognizing when someth	ning is troubling the sibling	g.
	Doing activities with just	the sibling.	
	Enhancing the sibling's in	adividuality.	
	Helping the sibling cope	with stress.	
	Enhancing the sibling's se	elf-est <del>ee</del> m.	
	Doing things to take care	of your own needs.	
	Doing things to take care	e of my relationship with n	ny spouse/partner.
	Promoting a sense of fam	uly togethemess.	
	Talking to the sibling abo	out the nature of autism/P	DD.
	Promoting interactions b	etween the sibling and the	child with autism/PDD.

	Code	•
	MOTHERS' REPORT CARD	
the rese	e a number of things that mothers do. The word "sibling" refers to the child particip rch study. Please give yourself a "grade" from the list below and place your grade in ading box:	eting is the
GRA		
	Giving the sibling individualized attention.	
	Helping the sibling learn to get along with the other child.	
	Helping the sibling resolve peer-related problems.	
	Being available to the sibling.	
	Taking care not to place too much responsibility on the sibling.	
	Recognizing when something is troubling the sibling.	
	Doing activities with just the sibling.	
	Enhancing the sibling's individuality.	
	Heiping the sibling cope with stress.	
	Enhancing the sibling's self-esteem.	
	Doing things to take care of your own needs.	
	Doing things to take care of my relationship with my spouse/partner.	
	Promoting a sense of family togetherness.	
	Promoting interactions between the sibling and the other child.	

				~~=	•	_
MOTHERS'	REPORT	CARD				

Below are a number of things that mothers do. The word "sibling" refers to the child participating in the research study. Please give yourself a "grade" from the list below and place your grade in the corresponding box:

Excellent

Good

GRADES:

AB

c Batisfactory D Needs improvement Poor Giving the sibling individualized attention. Helping the sibling learn to get along with the other child. Helping the sibling resolve peer-related problems. Being available to the sibling. Taking care not to place too much responsibility on the sibling. Recognizing when something is troubling the sibling. Doing activities with just the sibling. Enhancing the sibling's individuality. Helping the sibling cope with stress. Enhancing the sibling's self-esteem. Doing things to take care of your own needs. Doing things to take care of my relationship with my spouse/partner. Promoting a sense of family togetherness. Talking to the sibling about the nature of the other child's problems.

Promoting interactions between the sibling and child being seen in the clinic.

RETROSPECTIVE MOTHERS	REPORT	CARD
-----------------------	--------	------

	RETROSPECTIVE MOTHERS' REPORT CARD Code
1D C	know that you have filled this form out before. Today, we would like you to go back and give recif the grade that you feel you should have received <u>prior to</u> enrolling the sibling in this program ther words, what type of grade do you think you deserved <u>before</u> the group started. Please give recif a "grade" from the list below and place your grade in the corresponding box:
GRA	DES: A - Emelient  B - Good  C - Satisfactory  D - Needs improvement  P - Foor
	Giving the sibling individualized attention.
	Helping the sibling learn to get along with the other child.
	Helping the sibling resolve peer-related problems.
	Being available to the sibling.
	Taking care not to place too much responsibility on the sibling.
	Recognizing when something is troubling the sibling.
	Doing activities with just the sibling.
	Enhancing the sibling's individuality.
	Helping the sibling cope with stress.
	Enhancing the sibling's self-esteem.
	Doing things to take care of your own needs.
	Doing things to take care of my relationship with my spouse/partner.
	Promoting a sense of family togetherness.
	Talking to the sibling about the nature of autism/PDD.
	Promoting interactions between the sibling and the child with autism/PDD.

#### MOTHERS' REPORT CARD FOR US

Now we would like you to go back and give us a grade in each area corresponding to how well you think we did in helping you in the different areas. We want to use your opinions to refine our program. Please give us a "grade" from the list below and place your grade in the corresponding box:

Excellent

GRADES:

C - Satisfactory D - Needs improvement F - Poor
Giving the sibling individualized attention.
Helping the sibling learn to get along with the other child.
Helping the sibling resolve peer-related problems.
Being available to the sibling.
Taking care not to place too much responsibility on the sibling.
Recognizing when something is troubling the sibling.
Doing activities with just the sibling.
Enhancing the sibling's individuality.
Helping the sibling cope with stress.
Enhancing the sibling's self-esteem.

	Doing things to take care of your own needs.
spou	Doing things to take care of my relationship with my se/partner.
	Promoting a sense of family togetherness.
	Talking to the sibling about the nature of autism/PDD.
autisi	Promoting interactions between the sibling and the child with

#### Consumer Satisfaction Scale

Below is a list of questions about the sibling support group. Please circle the number that corresponds with how you feel about the intervention in the blank space next to the question. Please write only one number for each problem and do not skip any items. Refer to the scale Above each item.

1. Overall, how helpful do you think the group was to the sibling?

Not At All Helpful		Neutrel		Very Heipful	
1	2	3	4	5	

2. Overall, how enjoyable do you think the group was to the sibling?

Not At All Enjoyable		Neutral		Very Enjoyable		
1	2	3	4	5		

3. What was your overall feeling about the sibling group?

Very Negative		Nautrol		Very Positive	
1	2				

4. What do you think was the sibling's overall feeling about the group?

Very Negative		Neutrol		Very Positive
1	2	3	4	5

5. Do you think the sibling would recommend the group to a peer?

Not Recommend		Neutral		Strongly Recommend	
1	2	3	4	5	

6. As a result of the sibling group, I think the sibling is...

Less Abie To Cope		Neutral		More Able To Cope
1	2	3	4	<u>_</u>

7. As a result of the sibling group, I think the sibling feels...

Less Comforted		Neutral	•	More Comforted
1	2	3	4	5

8. I feel that the sibling is \_\_\_\_\_ of the child with autism.

Less Accepting		Neutral		More Accepting
1	2	3	4	5

## Please answer the following questions:

I think the most helpful part of the group intervention for the sibling was...

I think the least helpful part of the group intervention for the sibling was...

I think the most enjoyable part of the group intervention for the sibling was...

I think the least enjoyable part of the group intervention for the sibling was...

#### Consumer Satisfaction Scale

Below is a list of questions about the sibling project. Please put a check mark next to the item that corresponds with your answer below, or fill in the blank next to the question.

If you were to have participated in the intervention over again, would you have preferred:
Shorter Sessions Sessions the Same LengthLonger Sessions
If you were to have participated in the intervention over again, would you have preferred:
Fewer Sessions Six Sessions More Sessions (please specify)
If you were to have participated in the intervention over again, would you have preferred to meet:
Once a Week Twice a Week Three times a Week Everyday
If you were to have participated in the intervention over again, would you have preferred to meet:
Once a Week Twice a Week Three times a Week Everyday
If you were to have participated in the intervention over again, would you have preferred to meet:
Mornings Afternoons Evenings
How many miles did you travel to get here?
On a typical day, how long did it take you to get here?
Do you work outside the home? Yes No If so, Full Time Part-Time

	things you think may be good for the sibling to know that we did not he group?
Are there	things you think should <u>not</u> have been included in the sibling group?
Please lis	st suggestions and criticisms regarding the group, in general,
	ink other families of children with autism would like to participate in this YES NO
Why or W	'hy Not?

#### Consumer Satisfaction Scale

## Supplemental Form for Parents Participating in the Groups

Below is a list of questions about the intervention. Please write the number that corresponds with how you feel about the intervention in the blank space next to the question. Please write only one number for each problem and do not skip any items. Refer to the scale <u>Above</u> each set of questions.

Not At All Helpful		Somewhet Helpful		Very Helpful
1	2	3	4	5
1 (	Overall, how I	helpful were the	group discus	ssions ?
2 (	Overall, how i	helpful were the	homework a	ssignments?
3 (	Overall, how I	helpful were the	Sib scenes '	?
4 (	Overall, how	helpful were the	"mini-lecture	s" ?
5 1	How helpful v	vere the session:	s overall ?	
Not At All		Somewhat		Very
Enjoyable	! 	Enjoyable		Enjoyable
1	2	3	4	5
6	Overall, how	enjoyable were t	he group dis	scussions?
7 0	Overall, how e	enjoyable were ti	ne homewor	k materials?
8 C	Overall, how e	enjoyable were ti	ne Sib scene	es?
9	Overall, how	enjoyable were t	he "mini-lect	tures" ?

Please answer the following questions:
The most helpful part of the mothers' group was
The <u>least helpful</u> part of the mothers' group was
The most enjoyable part of the mothers' group was
The <u>least enjoyable</u> part of the mothers' group was
Please list suggestions and criticisms regarding the mothers' group, in general.
Are there things you would have liked to know that were not covered in the group?
Are there things you think should not been included in the mothers' group?
Have you ever participated in a group for mothers before ? Yes No If yes, please describe:
Have you ever participated in a group which focuses on sibling related issues before? Yes No If yes, please describe:
If so, how did this experience compare with either of the previous experiences?

Below is a list of questions about the sibling support group. Please circle the number that corresponds with how you <u>now</u> feel about each question. Please reflect back on the past month (i.e., since the group ended) to answer the following questions.

Please circle only one number for each item and do not skip any items. Refer to the scale below each item.

1. I believe the group was helpful to the sibling.

Strongly Disagree	•	Agree		Strongly Agree
1	2	3	4	5

2. My overall feeling about the sibling group was positive.

Strongly Disagree	Agree		Strongly Agree
1	 	4	5

3. I think the sibling's overall feeling about the group was positive.

Strongly Disagree	Agree			Strongly Agr <del>ee</del>
•		3		5

4. I think the sibiling would recommend the group to a peer.

Strongly Disagree		Agree		Strongly Agree
1	2	3	4	5

5. As a result of the sibling group, I think the sibling is better able to cope.

Strongly Disagree		Agree		Strongly Agree
1	2	3	4	5

6. As a result of the sibling group, I think the sibling feels comforted.

Strongly Disagree		Agree	Strongly Agr <del>ee</del>
1	2	3	 5

7. As a result of the sibling group, I feel that the sibling is more accepting of the child with autism.

Strongly Disagree		Agree		Strongly Agree	
1	2	3	4	5	

8. As a result of the sibling group, I feel that the sibling has a better understanding of autism.

Strongly Disagree		Agree		Strongly Agree
1	2	3	4	5

9. As compared to <u>before</u> the sibling started the group, the number of overall interactions between the sibling and the child with autism has...

Decreased	Stayed	the Same	Increased
	<del> </del>		
1	2 3	4	. 5

10. As compared to <u>before</u> the sibling started the group, the number of <u>positive</u> interactions between the sibling and the child with autism has...

Decreased		Stayed the	Same	Increased
1	2	3	4	5

11. As compared to <u>before</u> the sibling started the group, the number of <u>negative</u> interactions between the sibling and the child with autism has...

Decreased		Stayed the	Same	increased
1	2	3	4	5

12.	How satisfied	are	you	with	your decision	to	have	your	family
	ticipate ?		•		-				

Dissetisfied		Neutral		Satisfied
1	2	3	4	5

The following statement s have to do with skills that were discussed in the groups.

13a. The sibling gains the attention of the child with autism (e.g., eye contact, using his name) when interacting with him.

Never	Occasionally	Sometimes	Often	All the Time
1	2	3	4	5

13b. The above behavior is a result of the my family's participation in the sibling project.

Strongly Disagree	•	Agree		Strongly Agree	
1	9	3	4		

14a. The sibling praises the child with autism when appropriate.

Never Occasionally Sometimes Often All the Time

14b. The above behavior is a result of the my family's participation in the sibling project.

Strongly Disagree		Agree		Strongly Agree
1	2	3	4	5

15a. The sibling tells me when he/she wants special attention.

Never	Occasionally	Sometimes	Often	All the Time
1	2	3	4	5

Follow - up Questionnaire

15b. The above behavior is a result of the my family's participation in the sibling project.

Strongly Disagree		Agree		Strongly Agree
1	2	3	4	5
	g asks me	*	about autism.	All the Time

16a.

16b. The above behavior is a result of the my family's participation in the sibling project.

Strongly Disagree		Agree		Strongly Agree
1	2	3	4	5

17a. The sibling talks to me about his/her feelings.

Never Occasionally Sometimes Often All the Time

1 2 3 4 5

17b. The above behavior is a result of my family's participation in the sibling project.

Strongly Disagree		Agres		
1	2	3	4	<u> </u>

Please respond to the following items:					
1. Have you and the sibling discussed the sibling group over the past month?					
☐ Yes ☐ No					
If yes, please estimate the number of times and briefly describe these discussions.					
<ol> <li>Please describe the types of changes you may have witnessed (include both positive and negative changes) in the past month.</li> <li>A) Between the sibling and the child with autism during play:</li> </ol>					
B) Between the sibling and the child with autism during non-play related activities:					

C) Within the sibling, him/herself:
D) Between the sibling and you:
E) Between the sibling and other people:
3. What was the <u>biggest</u> change the sibling experienced as a result of participating in the project ?

Follow -	up Q	uestio	nnaire
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4. Have the issues that prompted you to participate in the sibling project been addressed?
Yes No
— · · · · · · · · · · · · · · · · · · ·
Please describe.
5. Reflecting back on the past month, I think the most helpful part of the group intervention for the sibling was
group mervennom for the signing was
6. Reflecting back on the past month, I think the <u>least helpful</u> part of the group intervention for the sibling was
A

7. Has the sibli	_				month?
8. Are you curr children?	* *	· <u> </u>		rventions for please desc	
9. In the past monoi the group ?	es 🔲 N	•	i any co	ontact with c	ther members
• / ·	_	_			
By phone	∟ Yes	∐ No	If yes,	how many 1	times ?
By mail	Yes	☐ No	If yes,	how many t	imes ?
in person	Yes	□ No	If yes,	how many t	imes ?
10. In the past month have you had any contact with other mothers of siblings who have participated in the group ?  Yes No					
if yes, please as	nswer the fo	oilowing:			
By phone	☐ Yes	□ No	If yes,	how many t	imes ?
By mail	Yes	□ No	If yes,	how many t	imes ?
in person	☐ Yes	□ No	if yes,	how many t	times ?

#### Supplemental Form for Mothers Who Participated in the Groups

Below is a list of questions about the intervention. Please circle the number that corresponds with how you now feel about the intervention. Please reflect back on the past month (i.e., since the group ended) to answer the following questions. Please circle only one number for each problem and do not skip any items. Refer to the scale below each set of questions.

1. I believe the mothers' group was helpful to me.

Strongly Disagree		Agree		Strongly Agr <del>oe</del>
1	2	3	4	5

2. My overall feeling about the mothers' group was positive.

Strongly Disagree	Agree			Strongly Agree
		1		
	2		•	7

3. I would recommend the mothers' group to a friend.

Strongly Disagree		Agree	Strongly Agree		
	· · · · · · · · · · · · · · · · · · ·	<del></del>			
1	2	3	4	5	

4. As a result of the mothers' group, I think I am better able to deal with sibling related issues.

Strongly				Strongly
Disagree		Agree		Agree
1	2	3	4	5

5. Overall, How often do you use the skills and knowledge addressed in the group ?

Never	Occasionally	Sometimes	Often	Very Frequently
1	2	3	4	5

6. Overall, in the past month, how successful do you feel you have been in applying the information and skills that were addressed in the group?

Unsuccessful	S	omewhat	Successful	Ve	ry Successful
1	2	3		4	5

7. How successful do you feel you will be in continuing to apply the information and skills that were addressed in the group ?

Unsuccessful		Somewhat	Successful	Very	Successful
1	2	3	4		5

8. I use the skills to communicate with the sibling (e.g., answering questions directly, praising the child when he/she asks questions, discussing my own feelings with the sibling) ...

Never	Occasionally	Sometimes	Often	Very Frequently
1	2	3	4	5

9. I use the skills to facilitate interaction between the sibling and his/her brother with autism (e.g., reminding him or her about eye contact, using the child with autism's name, praising both children when they interact appropriately, finding a time when they both want to play) ...

Never	Occasionally	Sometimes	Often	Very I	Frequently
1	2	3	4	<u>.</u>	<u> </u>

## Follow - up Questionnaire

10. I use the behavior skills (e.g., eye contact, behavior specific praise) addressed in the group with the child with autism...

Never	Occasionally	Sometimes	Often	Very Frequently
1	2	3	4	5

11. I engage in strategies discussed in the group to reduce my own stress...

Never	Occasionally	Sometimes	Often	Very	Frequently
			<del></del>	<del></del>	
1	2	3	4		5

Please also respond to the following items:

Reflecting back on the past month, the <u>most helpful</u> part of the mothers' group was...

Reflecting back on the past month, the <u>least\_helpful</u> part of the mothers' group was...

Reflecting back on the past month, is there anything that you think can be done differently to improve our program ?

## APPENDIX E ABRIDGED INTERVENTION CURRICULUM

## ABRIDGED VERSION OF THE INTERVENTION CURRICULUM

Session 1 consisted of three primary objectives which included: 1) Providing the group members with an opportunity to become familiar with each other; 2) Conveying an overview of the goals, objectives, format and rules of the group; and 3) Giving the mothers an overview of the upcoming sessions. To address the above objectives, several activities were incorporated into the session. The session began with a brief introduction by the group leaders and each of the group members. There was an informal discussion of the group quidelines, format, and rules which allowed for questions and comments from the mothers. A discussion about what it is like to have a child with autism in the family from both the perspective of the parents and the siblings was also generated so that mothers would have the opportunity to learn about others' perspectives of their unique situations. Finally, a journal was distributed to each of the mothers for note taking purposes and for writing their thoughts about group sessions or other related material.

Session 2 consisted of the following primary objectives: 1) Providing general information about autism including a brief history, DSM-IV definitions (American Psychiatric Association, 1994), and information about related disorders; and 2) Demonstrating and practicing how to communicate this information to the sibling in a

developmentally sensitive manner. Activities for this session were developed to address these objectives. The first activity was a formal lecture on autism including the history of autism and related disorders. Another activity was developing a group definition of autism for siblings based on each mother's perceptions of how autism could be described in a palatable manner to the sibling which led to a discussion about communicating about autism to the sibling. There was also a role play exercise where mothers were able to practice giving specific information about autism to the sibling with one another.

Session 3 consisted of two primary objectives which included: 1) Considering issues that may result from being the sibling of a child with autism; and 2) Discussing the role parents play in the sibling relationship. To address theses objectives mothers participated in a writing exercise on the emotions of siblings of children with autism to help them "feel" what it would be like to be a sibling of a child with autism. There was also an informal dialoque based on positive, negative, and neutral feelings mothers had about their children's interactions. A skill building activity was provided to teach behavioral strategies for improving sibling interactions. There was a discussion and time given to practice using praise with the siblings in response to contrived situations that may have occurred or will occur in the future between the parents and the siblings. Finally,

mothers developed strategies for helping the siblings deal with stress such as relaxation and problem solving.

Session 4 included the following three primary objectives: 1) Promoting sibling growth and self-esteem by recognizing siblings as individuals; 2) Helping mothers understand the balance between being an individual and being a sibling of a child with autism; and 3) Enhancing the self-esteem and self-identity of the mothers. Initially the mothers constructed an ideal day for themselves to provide them with a plausible means of meeting some of their own needs. Mothers also made a list of things to do with the sibling to enhance his/her self-esteem, that is, things they believed the sibling would enjoy. There was a discussion about specific strategies for improving self-esteem based on information collected by the group leaders. Finally, there was a discussion about questions parents frequently ask regarding the emotional well-being of their children.

Session 5 consisted of the following three primary objectives: 1) Increasing mothers' awareness of the effect of autism on the family, particularly the siblings; 2) Addressing beneficial family interactions and strategies for improving family communication; and 3) Discussing and attempting to gain an understanding of peer interactions of the siblings and how those interactions are affected by having a child with special needs in the family. Activities designed to meet these objectives were conducted during the

session. The first was a writing exercise about differences in parenting the siblings versus the children with autism. There was also a skill-building activity that provided strategies for balanced parenting such as effective listening, quality attention, structured time for the siblings and eliciting help from their partners. Finally, there was a discussion activity about handling siblings and peer relationships which focused on dealing with questions about their child with autism and helping the siblings explain autism to their friends.

Session 6 was the final session of the intervention and served as a review of the essential points of each of the It provided maintenance and previous sessions. generalization strategies for the major areas covered throughout the intervention. The two primary objectives for this session were: 1) Helping mothers learn to maintain the knowledge and skills they gained from the group; and 2) Teaching mothers to maintain and generalize the siblings' skills and knowledge through their own facilitation. objectives were met by doing a role play that focused on communication between siblings, peers and family members. There was also a reiteration of the high points of each session so that mothers could have a review of the more pertinent aspects of dealing with siblings' needs. followed by suggestions for maintaining the skills over time and generalizing the skills to other situations.

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