# A TARGETED INTERVENTION FOR SIBLINGS OF CHILDREN WITH AUTISM SPECTRUM DISORDERS: THE EFFECTS OF A SIBLING SUPPORT GROUP

By

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#### ABSTRACT OF THE DISSERTATION

A Targeted Intervention for Siblings of Children with Autism Spectrum Disorders: The

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The sibling relationship provides a unique context for the development of interpersonal skills and lays the groundwork for extensive social situations with other children. Siblings of children with autism spectrum disorders (ASDs) experience multiple stressors and increased caregiver demands that children with neurotypical siblings do not face. While some siblings do not experience significant adjustment problems, it appears that other children may have greater vulnerability to the development of significant adjustment problems and internalizing disorders. Very few studies have investigated the effect of a support group for children who have a sibling with ASD. The present study evaluated the effects of Project SibSTAR (Straight Talk about Autism Realities), an eight week support group that incorporated didactics, discussion, and role plays while using rigorous research design and psychometrically-sound measures. Twenty siblings of children with ASD were randomized to either the active or delayed intervention group. While the groups received the same intervention, the time-lagged design allowed for the assessment of a multiple baseline design across both groups and skills. In addition, participants reported on measures of psychological and social functioning at baseline,

post group, and 6 week follow-up assessments. During these assessment sessions, data were also collected on play-based interactions within the sibling dyad. Outcomes were assessed across a variety of domains, including intervention acceptability, concepts taught during group, play-based behavioral principles, and self-report of internalizing symptoms, self-competence, and perceived social support. Results indicated that participants increased their knowledge of autism, coping and problem solving skills, and their knowledge of behavioral skills. Further, trend level decreases in internalizing symptoms were found from baseline to post group assessment, and significant differences were found on measures of perceived social support and social self-competence. While participants indicated high satisfaction with the intervention package, no significant differences were noted on play-based interactions with their sibling. The implications and future directions of this line of research are discussed.

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#### Introduction

The sibling relationship is the most longstanding relationship that one has over the course of a lifetime (Conway & Meyer, 2008). Siblings of children with autism are no exception: During childhood, they will spend considerably more time with their brother or sister than any other individual (Orsmond & Seltzer, 2007a). Although every sibling relationship has its moments of strength and of struggle, the criterial symptoms inherent in autism do not lend themselves to easily fostering a sibling relationship. Autism is characterized by impairments in socialization and communication, and restricted and repetitive interests and behaviors (DSM-IV-TR, 2000). Taken together, a child with autism likely exhibits little to no eye contact, poor social reciprocity, a delay or complete lack of spoken language, and an insistence on performing nonfunctional routines and rituals repetitively. In short, children with autism make for difficult playmates.

In comparison to other children who have a sibling with a chronic disability, brothers and sisters of children with autism have to cope with a unique set of obstacles. Only recently, researchers have sought to investigate how this relationship impacts neurotypical siblings and how sibling support groups may play a role in mediating these challenges. In childhood and adolescence, siblings describe both positive and negative aspects of their relationship with their sibling with autism, and there is growing evidence that these children may be at heightened risk for developing social and behavioral problems (Orsmond & Seltzer, 2007a).

## The Sibling Relationship

There is evidence that the early social interaction style first developed between siblings is subsequently used with peers throughout a child's life (Abramovitch, Pepler, & Corter, 1982). Prior to investigating the differences in the relationship with a sibling with an autism spectrum disorder (ASD), it is important to first understand the relationship between two typically developing siblings.

As with most studies focused on sibling interaction, Abramovitch, Corter, and Lando's (1979) classic study relied on a naturalistic observation of typical sibling dyads during play in the home. Although they were free to leave the play area, the researchers found that the children spent 90% of their time in the same room and interacted a great deal. The children made approximately 59 initiations and responses per hour, averaging nearly one per minute. Interestingly, the gender of the pair and the interval between ages did not affect the level of interaction. However, gender did play a role in the nature of these interactions as boys were significantly more likely to engage in physical aggression and older girls were more likely to engage in nurturing "mothering" behavior. The younger child in the dyad also showed a surprising amount of initiative, initiating 35% of prosocial acts (vs. 10% of all antagonistic acts). An important developmental skill, the younger child's play accounted for 80% of the imitations in the dyad.

Later studies expanded on the literature by applying the same observational methods in comparing sibling dyads in which one child had Down's syndrome to dyads in which one child had autism (Knott, Lewis,& Williams, 1995). Results showed that dyads including a child with Down's syndrome spent significantly more time in the same room than did the pair including a child with autism. Parental data indicated that throughout the course of the day, Down's syndrome pairs spent 58% of their free time together, compared to 28% of time for the ASD pair. In addition, the autism dyads made fewer initiations to one another overall in comparison to Down's syndrome pairs. When

their siblings did attempt to engage them in play, their efforts were characterized by a limited repertoire of social bids which likely reflected their sibling's limited interests, as research has found that children with autism tend to play with a limited range of toys and objects in routine ways and have deficits in pretend play (Baron-Cohen, 1987; Bruckner & Yoder, 2007; Lewis & Boucher, 1988). Children with Down's syndrome made approximately 16 prosocial interactions in an hour, whereas children with autism averaged 6. Further, children in the autism dyads were less responsive to one another and imitated each other less. Taken together, the children with autism spent less time interacting with their sibling, there was less interaction when the siblings were together, and the interactions were of a poorer quality than those in the Down's syndrome dyad.

One might expect that when siblings' attempts to play with their brother or sister with autism are not met with success, the pursuit of play may decrease as the neurotypical child is rarely reinforced with a positive interaction. The mean age of the children in the Knott et al. (1995) study mentioned above was six years, and for many children these relationships may further deteriorate over time as they are continually dismissed. This is especially unfortunate as these deficits in social interaction are central to autism, and the sibling relationship has the potential to provide a consistent medium for the development of play skills.

A second study by these authors attempted to answer the question of whether the quality of sibling relationships declines over time (Knott, Lewis, & Williams, 2007). Using a longitudinal design, dyads with ASD were again compared to dyads with a Down's syndrome sibling to track relationship development over the course of 12 months. Results show that the amount and rate of initiations of both prosocial and

antagonistic interaction increased slightly in the autism dyads over the course of the year, but further analysis suggested that these interactions were "stage-managed" by the neurotypical sibling and reflected little joint interaction. The increase in initiations made by the child with autism were minimal. By the end of the year, children with autism averaged three more initiations per hour, while the Down's syndrome group nearly doubled their amount of initiations, increasing opportunity for reciprocal play with their sibling.

Despite the lack of initiations, siblings of children with autism still persisted in attempting to engage their brother or sister. Siblings of children with autism and Down's syndrome averaged 18.9 and 32.1 initiations per hour at time one and 60.3 and 62 at time two, respectively. Imitation, an important skill in reciprocal play behavior, also increased across both dyads. However, in the Down's syndrome dyads the disabled child maintained the interaction by imitating the siblings, and this pattern was reversed for the autism dyads. Neurotypical siblings began to imitate their brothers and sisters with autism as a means of maintaining play. Surprisingly, not only had siblings of children with autism not abandoned the hope of playing with their brother and sister, but their efforts to initiate had more than doubled, while their imitative play tripled. Even though the sample sizes in this study are small and have limited generalizability to other dyads, the results are encouraging in that siblings demonstrated a high degree of persistence.

Evidence suggests that persistence is an important predictor of the quality of relationship between siblings (Rivers & Stoneman, 2008). In addition to data on play behavior, psychologists have administered self-report questionnaires to siblings in an attempt to gain insight into their perspectives on the relationship. Relationship quality

was found to be highest when both the neurotypical child and the child with autism were rated as high on persistence by parent report, though having at least one child rated as persistent appeared to benefit the relationship. This study lends support to Knott and colleagues' (2007) work that siblings of children with autism may find it beneficial to be persistent when interacting with their brother or sister. Persistent children may be more tenacious in attempting to engage their siblings with ASD in social interactions, repeating their play bids until they achieve the desired response.

Interestingly, neurotypical siblings reported most relationship satisfaction when levels of persistence were dissimilar in the dyad, regardless of which sibling was rated as being highest in persistence. This finding may also hold true in typically developing dyads, as it seems likely that sibling pairs would get along best when one is persistent and the other more amenable. Parents, however, reported that high persistence in the neurotypical, rather than the child with autism, predicted greater relationship satisfaction between the two. Rivers and Stoneman (2008) hypothesized that this is because a highly persistent neurotypical child will repeatedly attempt to engage their brother and sister in play, allowing for increased opportunities for interaction between the pair.

When children with autism interact with their family members, they often choose their sibling as their preferred playmate (El-Ghoroury & Romanczyk, 1999). Despite parents' greater number of play elicitations toward their child with autism in a play-based observation, the sibling with ASD still gravitated towards their brother or sister. This may be explained by the neurotypical child as being not as interested or potentially as skilled as parents in compensating for the sibling's deficits. Surprisingly, the child with autism made the greatest number of initiations toward the sibling as opposed to either parent, a

trend that mirrors typically developing children's preference for play partners who are close in age.

Given the difficulties inherent in having a brother or sister with autism, studies have examined how the neurotypical child experiences and reflects on their relationship with their sibling. Kaminsky and Dewey (2001) surveyed 45 sibling pairs between the ages of 8-18, divided evenly into Down's syndrome, autism, and control groups. All neurotypical siblings completed the Sibling Relationship Questionnaire Revised (SRQR; Buhrmester & Furman, 1990) to assess their perception of their sibling. Siblings in the Down's syndrome and autism groups both reported less conflict with their brother or sister, greater admiration of their sibling, and less competition relative to controls. In comparison to the Down's syndrome dyads, siblings in the autism dyads reported less prosocial behavior towards their brother or sister, though this was more consistent with measures of prosocial behavior in the control group. In keeping with the criterial symptoms of the disorder, siblings of a child with autism also reported significantly less intimacy and nurturance by their sibling with autism than both the Down's syndrome and control dyads reported. Irrespective of group, boys reported less prosocial behavior and affection, less nurturance by their sibling, and greater competition with their sibling as compared to girls.

Perhaps the most surprising finding from Kaminsky and Dewey's work is the relationship between the participating sibling's report and the severity of the reference child's disorder. The nature of autism as a spectrum disorder accounts for a wide variability in symptom expression and independent functioning levels. As such, one might hypothesize that the more severe a child's disability, the more likely it is that the

sibling will report a poorer relationship as a result of impaired functional communication, behavioral deficits, and increased stress on the family. Historically, both parents and professionals identify the child's language impairment as being the most severe stressor for the family (e.g., Bebko, Konstantareas, & Springer, 1987). However, the results of the survey study showed no effect of severity across groups. All children with Down's syndrome in the study were verbal, compared to 90% of the children with autism. Though this study excluded children with Asperger Disorder and Pervasive Developmental Disorder Not Otherwise Specified, it appears as though the participants still likely fell in the mild to moderate range, given that an estimated 50% of all children with autism are nonverbal (Leyfer et al., 2006). An effect for severity may have been noted if there was greater variability in the sample.

During childhood and adolescence, ASD siblings primarily describe positive aspects of their sibling relationship, such as greater admiration, less conflict and competition, as well as a partner to do activities with (Orsmond & Seltzer, 2007a). However, siblings also reported concerns of embarrassment as a result of the disorder, particularly as they neared adolescence. They also expressed concern about destruction of their things by their sibling, aggression towards them by their siblings, social isolation, and the fate of their brother or sister's future. In comparison to siblings of children with intellectual disabilities or siblings of children without any disability, ASD siblings expressed more concern about their sibling's future, played less with their sibling, felt lonelier, and had fewer friends (Bagenholm & Gillberg, 1991).

Nearly absent from the literature is an examination of how neurotypical siblings' perceptions of their brother or sister change during adulthood. One exception to this is a

study by Orsmond and Seltzer (2007b), which offers some insight into the evolution of this relationship. Compared to adults who have siblings with Down's syndrome, siblings of adults with ASD felt more pessimistic about their brother or sister's future, had less contact with their sibling, reported lower positive affect in the relationship, and were more likely to claim that their relationship with their parents had been affected. Dyads were more likely to report a positive relationship when the neurotypical sibling had lower education levels, lived closer, used problem-focused coping strategies, and when the sibling with ASD was higher functioning.

# **Psychosocial Adjustment**

To date, the research investigating psychosocial adjustment and outcomes for siblings of children with ASD is mixed. As Cuskelly puts it, "To anyone reading the literature reporting research studies of the psychological adjustment of the siblings of individuals with a disability, the overwhelming impression is one of contradiction and confusion" (1999, p.111). As a result, studies that cite evidence for fostering psychosocial adjustment are reviewed, followed by those that cite negative outcomes and risk factors for this population.

#### Factors which promote positive psychosocial adjustment.

A study by Giallo and Gavidia-Payne on 49 siblings of children with various disabilities, found sibling's perceived intensity of daily uplifts significantly predicted prosocial behavior (2006). It may be that the researchers were tapping into a general optimism construct, such that those siblings who are likely to find little positive moments in every day are also more likely to have positive social interactions with others. While

uplifts are believed to buffer individuals from stress, it may be that for these children the daily uplifts are able to counteract the effects of elevated daily stress.

This study also put forth evidence for the positive effects of the family (Giallo & Gavidia-Payne, 2006). Adhering to a family routine predicted fewer adjustment difficulties in siblings, compared to siblings with irregular family routines. It is likely that family routines lend some semblance of stability and structure in a family that otherwise might have been negatively impacted by the child's disorder. Unsurprisingly, siblings from families who use effective communication and problem-solving were reported to have the best adjustment outcomes. Effective communication likely serves to buffer stress in these families. Parents who are effective communicators and problem solvers may model and reinforce these same behaviors in their children, making them more likely to be effective at handling stressors themselves.

Some studies have suggested that girls may be more resilient to adjustment difficulties than boys. Verté, Roeyers, and Buysse (2003) found that sisters of children with high functioning autism saw themselves as more socially competent relative to controls with typically developing siblings and, between the ages of 12-16 especially, reported a more positive self-concept. Across both groups, siblings with a more negative self concept were less socially adept, while siblings with a more positive self-concept scored higher in the social domain. Even though the authors found that boys between the ages of 6-11 are more at risk for internalizing and externalizing disorders, they conclude that siblings of children with high functioning autism are not more susceptible to adjustment problems than siblings of children without a disorder. However, one point worth noting here is the severity of the ASD. All children in this sample with high

functioning autism had normal IQ's and partook in a semi-residential treatment program in which they were not at home Monday through Friday.

However, a more severe Autistic Disorder only sample yielded similar results (Macks & Reeve, 2007). In a sample of 51 siblings compared to 35 controls, results indicated that siblings with a brother or sister with autism had a more positive view of their overall personal characteristics, and the authors suggest that the presence of a child with autism actually enhanced the psychosocial and emotional development of non-disabled siblings. There may be a couple reasons why these children score better on these measures: (1) it may be that they compare themselves to their disabled sibling, and as such see themselves in a more positive light, or (2) as a result of their situation, these children are more mature and better able to reflect on their capabilities. While children in the control group scored in the normal range on these measures, children with siblings with autism still scored higher, reflecting a significant difference.

Ferrari (1984) also showed that siblings of pervasively disabled children had the highest ratings of social competence and the lowest mean for externalizing behavior problems compared to siblings of children with diabetes and healthy control siblings. Across all groups, girls were found to fair better on ratings of self-concept, school and social competence ratings, as well as a teacher's ratings of self-esteem. Interestingly, among both the diabetes and developmental disabilities groups, earlier diagnosis of the disorder and the amount of time elapsed since the diagnosis were associated with lower levels of behavior problems and higher self esteem, while less time since diagnosis was marked by increased frequency of problem behavior and decreased self esteem ratings.

In comparing the adjustment and performance at home and in the school of siblings of children with autism, Mates (1990) found no evidence that siblings' performance in either domain required intervention. It was hypothesized that there might be gender differences and different adjustment trajectories of children from differing family sizes. However, Mates found no difference on measures of siblings' adjustment across gender, or between siblings from two-child or multi-child families. Another study comparing family size and gender found no significant effect for either variable on adjustment and found that overall children with siblings with autism did not differ significantly from children with a sibling with Down's syndrome or intellectual disabilities of an unknown genetic etiology (Pilowsky, Yirmiya, Doppelt, Gross-Tsur, & Shalev, 2004).

# Factors which hinder psychosocial adjustment.

Meta-analytic reviews paint a less optimistic picture, uncovering a statistically significant and negative overall effect for children who have a sibling with a general chronic illness (Sharpe & Rossiter, 2002). Although not directly investigating ASD, parents who have one child with a chronic illness reported greater psychological distress (i.e., depression, anxiety) and decreased cognitive development scores and peer activities for their neurotypical child relative to controls. Consistent with much of the existing literature, internalizing behaviors such as anxiety and depression were more prevalent in this sample than externalizing behaviors such as ADHD. Sharpe and Rossiter (2002) hypothesize that that this is due to increasing caregiver demands, and that children who have a sibling with a disability and are frustrated by the situation are less apt to act out in aggressive or hyperactive ways given the sensitive nature of their siblings' health.

Alternatively, it is likely a complex combination of many factors that cannot be accounted for in such a straightforward fashion. Children with a disabled sibling face increased demands, and this is often accompanied by an unintended diminishing of parental attention, the child's frustration, and embarrassment. In a situation where parents are likely already severely stressed, it may be easier for the child to internalize, rather than externalize, these feelings.

In addition, Sharpe and Rossiter (2002) found poorer outcomes for neurotypical children who had siblings who required daily medical treatment in comparison to children who had siblings without disabilities. This is in accordance with the notion that the more severe the illness, the more likely it is to negatively impact siblings. In the case of autism, more severe cases are often manifested behaviorally, characterized by increased aggression and self-injurious behavior. Only one study has investigated the relationship between behavior problems of children with developmental disabilities and siblings' behavioral adjustment (Hastings, 2007). After controlling for demographic factors, the level of behavior problems of the child with disabilities was a significant positive predictor of the neurotypical sibling's behavior problems two years later. As such, there was evidence that a higher level of problem behavior in the disabled sibling acted as a risk factor for sibling behavioral issues over time, and this relationship was not bidirectional in nature.

The finding that increased severity hinders adjustment was corroborated in an early study that investigated juvenile rheumatic disease patients and their healthy siblings. Daniels, Moos, Billings, & Miller (1987) found that the degree of patient health dysfunction was associated with greater reported problems in the sibling. In addition,

increased parental dysfunction, family stress, and less family cohesion and expressiveness also predicted later problems for the healthy sibling. Still other studies have found that the mother's marital adjustment score was an equally significant predictor of the child's self-concept score, suggesting that maternal happiness and stress may play at least some role in the child's concept of him or herself (Ferrari, 1984). The important role of family interaction cannot be understated within this context. In fact, familial factors may be stronger predictors of sibling adjustment difficulties than siblings' own experiences of stress and coping. Relative to a normative sample, neurotypical children with siblings with diverse disabilities were found to have a higher degree of adjustment problems affected by many familial factors, such as socio-economic status, parent stress, family time and routines, and family problem solving and communication (Giallo & Gavidia-Payne, 2006).

Although Macks and Reeve (2007) found that the presence of a child with autism enhanced adjustment overall, when multiple demographic factors were assessed with a risk scale composite, they significantly predicted emotional and psychosocial adjustment difficulty for siblings of children with autism, but not for a control group. Taken together, this suggests that when multiple demographic risk factors are combined, the sibling has increased difficulty emotionally and psychologically coping with the child with autism. It is important to note that the only demographic variables assessed in this study were household income, total number of children in the family, and gender, age, and birth order of the participating child. It is surprising that the authors found a significant interaction with so few variables, and they never explicitly state which combination of demographic factors is most likely to increase psychosocial maladjustment.

Overall, siblings had significantly increased ratings for overall adjustment difficulties, emotional symptoms, peer problems, and lower ratings on prosocial behavior relative to an age-matched control sample, again suggesting higher rates of internalizing behavior (Macks & Reeve, 2007). Interestingly, the daily stress that siblings reported experiencing and their means of coping did not significantly predict adjustment difficulties, whereas parent stress was found to be a strong predictor of sibling adjustment. While socioeconomic status was identified as a predictor for poorer sibling adjustment, these difficulties were mediated by parental stress and family resilience factors, again highlighting the important role that family likely play in buffering siblings.

Ross and Cuskelly (2006) also found siblings to be at increased risk for internalizing disorders in their study of 25 children with a brother or sister with ASD. Ten of these children scored in the clinical or borderline range of the internalizing scale on the Child Behavior Checklist (Achenbach, 1991). Interestingly, when they were compared to the nonclinical siblings on measures of coping, there were no significant differences in the coping strategies used and their mean efficacy scores. Siblings were most likely to use emotion regulation and wishful thinking coping to deal with problems related to their siblings, and were least likely to employ blaming others and self-criticism. Given that the sample had a mean age of ten, it is somewhat surprising that these children did not seek to blame their brothers and sisters with autism.

It is necessary to note that these studies are not without an important caveat. Very few studies in the literature attempt to tease apart the functioning levels of children with autism. As mentioned previously, the nature of autism as a spectrum disorder allows for a heterogeneity of cognitive functioning under the same nomenclature. While research has

shown that sibling's stress is positively correlated with the intensity of medical treatment in chronically ill children (Sharpe & Rossiter, 2002) little is known about the role of symptom severity as a potential moderator for psychosocial outcomes in neurotypical siblings. One would expect that children with a sibling with high functioning autism or Asperger syndrome would experience different stressors than children with low functioning siblings, but this has yet to be substantiated in the literature. Going forward, researchers must make a greater attempt at distinguishing important behavioral characteristics of the children in the sample prior to investigating the impact on siblings.

## The Efficacy of the Sibling Support Group

Explaining autism to a neurotypical sibling is a difficult task for parents. More often than not, they will be asked questions they don't know how to answer, such as, "How did he get it?", "Will she get better?", and "How do we make it go away?" Providing simple explanations from a very young age and encouraging the expression of fears and confusion will result in best possible outcomes for siblings (Howlin,1988), yet research has shown that there is a sizable gap between what parents believe their children understand about the disorder, and what they actually grasp. Glasberg (2000) interviewed siblings of children with autism and their parents to evaluate their understanding of the disorder. While parents accurately estimated their child's understanding of the definition and etiology of autism, the child's understanding of the implications of the disorder were repeatedly overestimated.

Support groups may play a critical role in helping to close this gap. The concept behind sibling support groups is not exclusive to autism, yet its application to this group of children is relatively unusual: Only one study has been published on support groups

specifically for children with siblings with autism (Smith & Perry, 2005). For reasons reviewed previously, these children may be at heightened risk for developing problems, especially internalizing disorders, and are likely to benefit from learning about the disorder and having a forum to share their experience. Sibling groups assist in aiding with the psychoeducation of autism at a level that siblings can understand. Indeed, the primary purpose of most sibling support groups is to provide information (Summers, Bridge, & Summers, 1991). A second purpose is to help siblings share successful ways of coping with problems in a forum where other children relate to their experiences. Autism can be a very socially isolating disorder for the neurotypical sibling, and support groups offer a gathering of children who understand one another's daily struggles. Although support groups should not be considered a substitute for individual therapy, they do let children express feelings in a safe environment that is free of criticism. In Summers and colleagues' (1991) review of sibling support groups for children with brothers and sisters with general disabilities, parents noted that their children had gained additional knowledge, learned new coping strategies, were increasingly understanding and cooperative with their sibling, and were less pessimistic than before the group. In one group, nearly all children had an increase in unprompted positive verbalizations regarding their family.

McLinden, Miller and Deprey (1991) piloted a six session group for siblings of children with special needs, differentiated as cognitively impaired, physically handicapped, or multiply handicapped. A total of 11 children ages 7-12 participated, with six assigned to the sibling group and five assigned to a waitlist condition. The group met for an hour once a week, and were administered the CBCL (Achenbach, 1991), the Piers-

Harris Children's Self Concept Scale (Piers & Harris, 1969) and two scales developed by McLinden prior to the first group and following the final group. It was found that participation in the group had a significant effect on the child's perception of social support, however no differences were noted on measures assessing behavior problems, self-concept, or knowledge about and attitudes towards children with handicaps. In contrast, mothers anecdotally commented that children were playing with their siblings more, and all but one of the children in the group also showed a decrease in negative behavior.

Although the age range in this study might appear small (7-12), the authors commented that it may have hindered the group more than expected, as older children focused on their friend's reaction to their sibling, and the younger children in the group did not express any embarrassment about their sibling. They also commented that it was immediately clear that participants' understanding of their brothers and sisters with handicaps was largely related to their chronological age. Glasberg (2000) found that children's understanding of their sibling's autism became more sophisticated with age, but largely corresponded to the child's Piagetian stage. Therefore, it seems likely that a child who is seven would have varying concerns from a twelve year old, and sibling groups will likely run most effectively if these age differences are taken into account. Furthermore, researchers have shown that when information is provided at a developmentally appropriate level, it serves to buffer the negative effects of a potentially stressful discussion about the disorder (Harris & Glasberg, 2003).

An important element of the sibling group is that the child finds it enjoyable. For many children who participate, this is often the single activity over which they have ownership, and strides are taken to make sure it is as pleasurable as possible. Dyson (1998) reports on a sibling group for children with siblings with a variety of disabilities and offers insight into what activities the children enjoyed. In many ways this group was run more like a summer camp, and included activities such as hiking, swimming, and roller skating over the course of six two hour sessions on a Saturday morning. In post intervention interviews, the children reported that they learned how to improve their relationship with their sibling and enjoyed learning about their sibling's disability the most. When asked what they wanted more of, instead of answering "swimming" or "sports" they replied that they wanted more psychoeducation about their siblings, behavioral techniques, and in particular wanted to hear from an adult who had a sibling with a disability.

Further results from support group studies focused on siblings of learning disabled children (Naylor & Prescott, 2004) and children with challenging behavior (Evans, Jones, & Mansell, 2001) offer encouraging outcomes. Though admittedly poorly operationalized, siblings reported increased self-esteem, social interaction with their sibling, coping strategies within the family, and understanding of disability issues (Naylor & Prescott, 2004). Interestingly, the authors believed that the key part which participants enjoyed the most was being able to talk to an adult during one on one interviews about their experience growing up with a sibling with a disability. Similarly, Evans and colleagues (2001) reported increases in self esteem, involvement with the disabled sibling, and knowledge about the disorder.

While the feedback from siblings and parents is encouraging, little is known about the maintenance of these positive changes over time. Only one study to date has investigated the effects of sibling support groups with a follow-up session. In one of the more rigorous sibling group designs, Lobato and Kao (2002) conducted an integrated group intervention with both parents and siblings of children with chronic illnesses and disabilities. The decision was made to run a simultaneous parent group based on the perceived impact of parental support and understanding in the literature. Fifty-four children between the ages of 8-13 and their parents attended six 90 minute sessions, and roughly one quarter were siblings of a child with autism. Parent and child groups were typically run separately, only uniting on specified activities for a portion of four sessions.

Results comparing pre and post measures showed that sibling knowledge of the disorder increased (especially for children with a brother or sister or autism), scores on the negative adjustment scaled decreased per child report, parental report of global behavior problems decreased, and both internalizing and externalizing behaviors were significantly decreased. However, at three month follow-up only the externalizing behavior continued to decrease, while internalizing behavior stabilized. These results are especially interesting for two possible reasons: (1) It may be that siblings were effectively able to utilize and maintain new behavioral techniques and coping skills, or (2) It may be that facets of the internalizing score reflect subclinical depression and anxiety which, although decreased from pre to post treatment, persisted in the absence of the group. The Lobato and Kao (2002) study makes a significant contribution to the literature with the addition of a follow-up and measurement of multiple domains of functioning. As the authors point out, the synergistic effects of both the parent and child were never directly examined, though this would make an interesting next step.

A 2005 study by Smith and Perry represents the only publication of a sibling support group specifically for brothers and sisters of children with autism. Though sibling support groups targeting autism have become more popular in the past decade, this represents the only published study known to the present author. The data from the study were collected from groups run over several years. The sample consisted of 26 siblings, between the age of 6 and 16 who met weekly for eight consecutive weeks. The authors list five aims for the group: (1) increase knowledge and understanding of ASDs, (2) provide an accepting atmosphere in which siblings can discuss their feelings, (3) share coping methods, (4) enhance self-concept, and (5) encourage siblings to have fun in a supportive environment. This was accomplished through a medium of exercises, games, activities, and discussions. Sibling self-concept, knowledge of autism, adjustment and coping, and internalizing and externalizing behavior were measured both before the first group and after the final group.

It was found that the sibling's self-concept (as measured by the Piers-Harris Self Concept Scale) and knowledge of the disorder both significantly improved. Overall, both parent and participant satisfaction with the group was very high. No changes were noted on a measure of coping and adjustment. Importantly, this scale was created by the first author for the purposes of the study and had very poor reliability. Coping could potentially play an integral role in determining outcomes for children with siblings of autism, and very little is known about how children cope with having a sibling with a lifelong disability. More stringent, psychometrically validated measures are needed. A follow-up to assess maintenance and change over time would have strengthened the

design and provided important information. In addition, it is difficult to make any conclusive statements in the absence of a control group.

Overall, Smith and Perry (2005) make an important contribution to the literature by designing a program specifically for children who have a sibling with autism. Although sibling support programs for children with autism are not uncommon, little is known about the effects of such groups due to insufficient program evaluation. Given the prevalence of ASDs and potential risk factors associated with being a sibling of a child with autism, the need to create research based support groups for these children is obvious. To date, there is one manualized treatment for siblings which is trademarked under the name of SibShops®. This program was developed for children with a brother or sister with a general disability, and it currently has over 200 sites operating in the United States as well as Belgium, Canada, Guatemala, Iceland, England, Ireland, Japan, New Zealand, and the Philippines. This program was created by two individuals without formal training in psychology or education, and there is no research to validate its use, yet its popularity speaks to the need to address this population of children.

Though groups like SibShops® likely do more good than harm, empirically validated groups would undoubtedly offer the greatest amount of benefit. Interestingly, it is estimated that over 40% of the children who attend a SibShops® program are there because they have a brother or sister with autism, and yet there is no component in this program to uniquely address these children. Future studies on support groups need to be more systematic in their application of the techniques used in the group and in the measurement of specific idiographic variables. Control groups lend credibility to a study, and the addition of a follow-up or longitudinal design serves to further validate findings.

Ideally, group sessions will be manualized to allow for the replication and corroboration of successful findings.

Living with a sibling with autism adds significant stressors to a child's life. Based on the diagnostic criteria, relationships with an individual with ASD may be awkward or appear nonexistent. Though the research is largely inconclusive, it is likely that these individuals are more vulnerable to internalizing disorders such as anxiety and depression, and yet little has been offered in the way of assessment, prevention, or treatment. The existing research on sibling groups looks very promising, and the systematic application of these groups to siblings of children with autism is long overdue.

#### Method

# **Participants**

To qualify for entry into the study, participants were required to be between 8-12 years old and have a brother or sister with a diagnosis of Autistic Disorder, Asperger's Disorder, or Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS; see *participant characteristics* below for further description of the sample). In addition, each participating sibling required one enrolled parent to respond to baseline and follow-up questionnaires. Exclusionary criteria for the neurotypical sibling included a diagnosis of an autism spectrum disorder, developmental, or behavioral disorders and/or previous experiences in a support group for children with disabled siblings.

## Recruitment.

Recruitment was conducted through several sources. Parents of children on a wait-list to receive center-based services were contacted through the Outreach Division of the Douglass Developmental Disabilities Center (DDDC), a program of Rutgers

University for the treatment of individuals with ASD ages three years to adulthood. One hundred and three parents received a letter inviting participation in a study of sibling support groups for their neurotypical child. Three families responded to the letter; two were deemed ineligible based on prior experience in a sibling support group, and one was not old enough to qualify for the study. Siblings of children with an ASD were also recruited through flyers sent to families with a child currently enrolled at the DDDC. Three families indicated interest in participation through this source; two families contacted study personnel after recruitment was closed, and one was enrolled. Additionally, three families contacted the principal investigator prior to the group beginning, and requested to be wait-listed until the study began. These participants were also enrolled.

Flyers were also sent to support groups for parents who have children with autism in Middlesex, Monmouth, Mercer, Somerset, and Union counties. This resulted in 19 interested participants, 14 of whom were enrolled. Two families were unable to participate due to other commitments, two families incorrectly interpreted the purpose of the study as services for the child with ASD, and one family contacted study personnel after recruitment was closed. Flyers were also sent to psychologists and psychiatrists in the area who were identified as having many patients with autism. One participant was recruited through a psychiatrist's office and enrolled in the study.

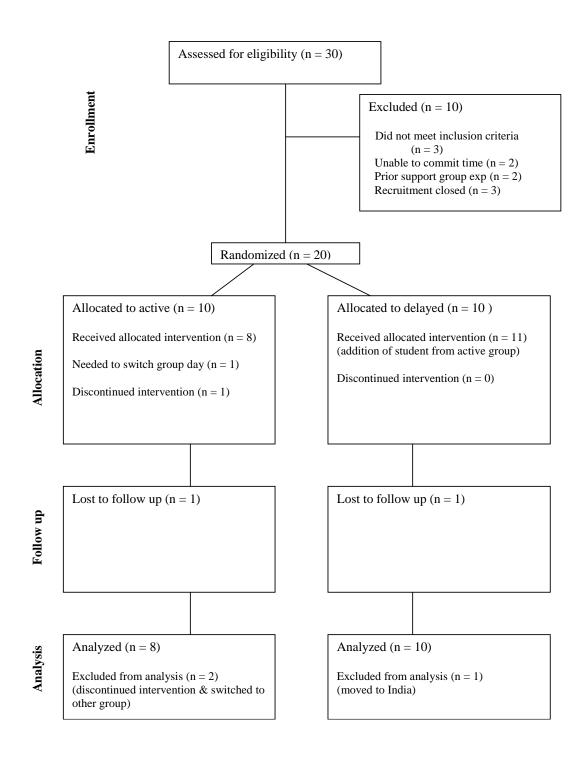
Finally, a notice of recruitment was also placed on the website of Autism New Jersey, a non-profit organization providing resources and information to families. One individual responded to the ad and was enrolled in the study. This study and its

procedures were approved by the Rutgers University Institutional Review Board prior to advertising and direct recruitment.

#### Attrition and attendance.

Prior to beginning the group, 20 families completed parental consent and sibling assent forms, attended the baseline assessment session, and completed all baseline paperwork. These families were then randomized into either the active or delayed treatment groups. Following basement assessment and prior to the start of the group, one parent who had previously been randomized to the active group contacted study personnel to request a change to the delayed group based on family commitments which would have prevented her child from participating. In order to ensure her child's ability to complete the study, the request was granted. Another child attended the baseline assessment and the first two group sessions before his mother contacted study personnel to withdraw him from the study due to a recent parental decision to divorce and a resulting inability to coordinate childcare. This participant's data was excluded from all analyses. One child's family moved to India following the final group session, and she was unable to complete post and follow-up assessments. This participant's data was excluded from all within group analyses. Finally, another child attended the baseline assessment, group sessions, and post assessment, but was unable to be reached for the follow-up assessment. Figure 1 provides an overview of participant flow.

Figure 1. Consort Diagram of Participant Recruitment and Retention



Nineteen siblings attended sufficient sessions (e.g. four or more) to receive adequate exposure to the intervention and were considered completers. Session turn-out among participants was excellent, with the active group attending a mean of 7.5 meetings out of 8 (range = 6-8), and the delayed group attending a mean of 7.18 meetings (range = 4-8). The most commonly cited reasons for missing sessions were for pre-planned summer vacations and difficulty coordinating childcare for the sibling with ASD. In the case of participant 8, her four missed sessions were a result of parents not being able to leave work in time to drop her off at sessions.

Table 1

Total Participant Attendance and Average Sessions Attended by Group-Completers

Treatment Group	Participant	Number of sessions attended	Average number of sessions attended
Active	2	8	
	4	8	
	5	7	
	6	8	
	13	7	
	16	6	
	17	8	
	20	8	$\mu = 7.5$
Delayed	1	7	
Delayed	3	7	
	7	6	
	8	4	
	9	8	
	10	8	
	11	8	
	12	8	
	15	8	
	18	8	
	19	7	$\mu$ =7.18

# Participant characteristics.

The final sample included 20 siblings of children with a Pervasive Developmental Disorder (9 girls and 11 boys) between the ages of 8 years, 3 months and 11 years, 11 months (*M*=9.97). The majority of children in the group were the oldest in the family; Fifteen of the children were older than their sibling with autism, 4 were younger, and 1 was a twin. Seventeen of the children had a sibling with a diagnosis of Autistic Disorder, 2 had a diagnosis of Asperger's Disorder, and 1 had a diagnosis of PDD-NOS. A wide variety of ethnicities were represented in the sample; 35% reported as white, 25% were Indian/Asian-Pacific Islander, 20% identified as "other", 15% were Hispanic, and 5% were African-American.

Eighteen participants (90%) came from two parent families in which the biological parents were cohabiting and married, one child came from a two parent family in which the biological parents were unmarried and cohabiting, and one child's parents had recently separated and were living apart. The average number of individuals living in each household for this sample was 4.25. Annual household income was higher than the New Jersey state average of \$69,891 from the 2010 U.S. Census Bureau; 64% of participants came from homes in which parents earned \$100,000 or more per year, 21% earned \$80,000-100,000 per year, 7% earned between \$60,000-80,000, and 7% earned under \$40,000. Levels of parental education were also higher than state norms, with the majority of parents holding at least a bachelor's degree; 10% held a Ph.D. or M.D., 34% earned a graduate degree, and 34% earned a bachelor's degree. 16% of parents had an associate's degree or had taken some college courses, and 6% of parents held a high school diploma.

# **Design**

All assessments were conducted at the DDDC, led by two trained members of the Project SibSTAR research team and supervised by the present author. Each participant and designated parent filled out a questionnaire packet at baseline, two weeks prior to the beginning of the active group (Time 1), at a post screening two weeks after the termination of each respective group (Time 2), and at a follow-up screening 6 weeks after the end of the group to assess for maintenance of skills (Time 3; see Appendix A for Project SibSTAR timeline). Video-recorded behavioral data samples on the play interaction between the two siblings and a brief sibling satisfaction interview were was also conducted during assessments.

Following baseline assessment to determine eligibility, participants were randomized to one of two groups: active and delayed. Ten children were randomized to each group. In the delayed condition, the groups began two weeks after the active group initiated treatment. The purpose of the delayed group was twofold: 1) it allowed for quasi-experimental control in a multiple baseline design across groups and, 2) it provided a replication of the active group's experience in Project SibSTAR. In addition, within each group, individual data were collected in the form of a multiple baseline design across three separate skills.

The three concepts which were targeted in Project SibSTAR included the 1) Knowledge about Autism Scale (KAAS, Ross & Cuskelly, 2006), 2) Project SibSTAR Questionnaire- Coping and Problem Solving (CPS), and 3) Project SibSTAR Questionnaire- Behavioral Skills Training (BST). Data from these measures were the basis for the three skills used in the multiple baseline design. As such, concepts from

these skills were taught and tested sequentially. In keeping with baseline logic, at the start of group 1 participants filled out all three questionnaires in order to give baseline data and show that participants had not spontaneously acquired any new information since completing the baseline questionnaire packets at the preliminary assessment session. These same questionnaires were again given at the end of week 2, after psychoeducation about autism had been taught in the first and second weeks of group. In week 4, the CPS and BST were administered; the information for successful completion of the CPS had been given in weeks 3 and 4, while BST remained in baseline. After behavioral skills training was taught in weeks 5 and 6, the BST was administered in week 6 to assess for change. On these three measures, maintenance was assessed via the post group and 6 week follow-up questionnaire packets.

## **Project SibSTAR.**

Project Sibling's Straight Talk about Autism Realities (SibSTAR) is an eight session group run once a week for two hours. Each session is a combination of games, conversation, and projects designed to educate siblings about autism and facilitate discussion about the sibling experience (See Appendix B). Project SibSTAR is a manualized intervention adapted from sibling support groups which have been offered at the DDDC for the past 30 years. Session content was largely based on empirical studies of support groups for children with disabilities (Celiberti & Harris, 1993; Glasberg, 2000; Lobato, 1990; Martins, 2006; Meyer & Vadasy, 2008). The group included weekly didactic and experiential session content, and consisted of four modules designed to address the specific needs of siblings of a child with autism: 1) Psychoeducation about

Autism Spectrum Disorders, 2) Developing Problem-Solving Skills, 3) Behavioral Skills Training, and 4) Increasing Self-Esteem & Empowering Siblings.

Both groups were led by the present author, a fourth year graduate student in clinical psychology with extensive experience working with children with autism as well as treating neurotypical children in therapeutic contexts. Each group was co-facilitated by two other advanced clinical psychology graduate students with several years of experience working with children with autism as well as neurotypical child populations. Each week, group leaders were supervised by the Executive Director at the DDDC, a licensed psychologist who had extensive experience with sibling support groups and over 40 years of working with individuals with ASD and their families. Supervision consisted of weekly 1-hour meetings for each group.

All groups were held at the DDDC in New Brunswick, NJ and were videorecorded to ensure intervention fidelity. Attendance at groups and successful completion
of assessments were tracked and rewarded with individual sticker charts for each child.
Following the baseline, post, and follow-up assessments, participants and their siblings
were allowed to pick a prize from a treasure chest in recognition of their time and
participation. If the sibling presented a full sticker chart to the examiner (i.e., they had
attended all sessions and assessments) at the end of the project, they were allowed to
choose an extra prize from the treasure chest. At the follow-up session, both the parent
and child rated their overall satisfaction with Project SibSTAR and the children received
a certificate of completion.

#### Measures

In order to encourage the completion of questionnaires, questionnaire packets and corresponding instructions were sent to both the child and the parent in advance of these meetings, and collected by a research team member at the time of the assessment. In situations when it was impossible for the family to complete the questionnaires prior to their appointment, they were allotted time to finish them at the assessment. All questionnaires and materials related to the parent and child were de-identified and marked with the child's assigned ID number. A master list of the children's names and linked identification numbers were kept in a password protected file on the present author's computer.

## Multiple baseline measures.

Knowledge About Autism Scale (KAAS). The KAAS (Ross & Cuskelly, 2006) assessed children's knowledge about their sibling's disorder. Siblings rated 20 statements related to autism as either true or false. Items are based on definitions and criteria outlined in the DSM-IV, and cover aspects such as course, prevalence, etiology, and cognitive ability. Higher scores on the KAAS indicate a greater understanding of the disorder. Cronbach's alpha coefficient was .68, indicating fair reliability.

Project SibSTAR Questionnaire-Coping and Problem Solving; (CPS) and the Project SibSTAR Questionnaire-Behavioral Skills Training (BST). These scales were created by the present author to directly test the skills being taught in the treatment groups. These questionnaires measured what children knew about utilizing effective problem solving and behavioral skills prior to entering the group, what they learned, and how long they retained this information. Each scale consisted of 10 items in a true/false

answer format. Examples of questions include "Part of problem solving is doing it by myself and not asking for help" (CPS) and "When I try and play with my sibling and they do something wrong, it's OK if I prompt them to help them out" (BST). Due to the short nature of these scales, it is common to find low Cronbach values in scales with 10 or fewer items (Pallant, 2010). Cronbach's alpha coefficients were .44 for the CPS and .49 for the BST, indicating poor internal consistency, likely as a result of the brevity of these questionnaires.

### Group design measures.

The Center for Epidemiologic Studies Depression Scale for Children (CES-DC; Weissman, Orvaschel, & Padian, 1980). This scale was used to assess potential depressive symptoms. As previously mentioned, children with a sibling who has a chronic disability may be more likely to suffer from internalizing disorders (Bellin & Kovacs, 2006; Taylor, Fuggle, & Charman, 2001). The measure consisted of 20 items based on the adult measure established by Radloff (1977). To gauge mood and behavior, the participant was asked to indicate how often he or she has experienced each particular symptom over the past week. The measure consisted of 4 subscales examining (1) negative affect, (2) anhedonia, (3) somatic symptoms, and (4) interpersonal symptoms. Potential responses ranged from 0 ("not at all") to 3 ("a lot"). Scores range from 0 to 60, with higher scores indicating greater levels of depressive symptoms. Past research has obtained high internal validity across adolescent samples, with alpha coefficients from .85 and above (Mahon & Yarcheski, 2001; Radloff, 1991; Roberts, Lewinsohn, & Seeley, 1991). Studies with children have shown that the reliability and validity of the CES-DC is particularly sensitive for girls and for children and adolescents aged 12-18 years

(Fendrich, Weismann, Warner, 1990) with moderate test-retest reliability (Faulstich, Carey, Ruggiero, Enyart, & Gresham, 1986). While the adult literature recommends using a score of 16 or higher as indicative of a depressive episode, applying the same score to children and adolescents leads to an inflated number of false positives (Garrison, Addy, Jackson, McKeown, & Waller, 1991; Roberts, Andrews, Lewinsohn, & Hops, 1990; Young, Mufson, & Davies, 2006a). For the purposes of this study, a score equal to or greater than 20 was used as a cut-off score to indicate significant levels of elevated depression symptoms. The mean baseline scores on the CES-DC were not significant for depression (M = 15.00, SD = 9.68). However, two children with elevated scores at 6 week follow-up were referred for individual treatment. In the present study the CES-DC had excellent reliability at baseline ( $\alpha = .87$ ).

Revised Children's Manifest Anxiety Scale (RCMAS, Reynolds & Richmond, 1985). The RCMAS is a 37-item questionnaire that assesses anxiety in individuals ages 6-19. It is a self-report questionnaire with a forced choice format for statements referencing physiological symptoms, social concerns, and worry. Higher scores on the total index and three subscales indicate increased anxiety. The measures also includes a 'lie' scale, to assess for inconsistent self-report. Test re-test reliability ranges from .54 - .76, and it demonstrates high validity, ranging from .83-.93 (Richmond & Reynolds, 2008). Clinical cut off scores of 19 have been recommended in the literature (Boyd, Kostanski, Gullone, Ollendick, & Shek, 2000). The mean RCMAS score of the sample at baseline did not indicate clinical levels of anxiety (M = 8.67, SD = 5.30). The RCMAS had adequate reliability at baseline ( $\alpha = .74$ ).

Self-Perception Profile for Children and Adolescents (SPPCA; Harter, 1985). Also known as the What I Am Like scale, the SPCCA provides a measure of self-perceived competence. It consists of 36 items, each with two statements. The participant must first select which of the two statements of the item describes him or herself most accurately. The participant must then decide whether the chosen statement is "sort of true for me" or "really true for me." Responses are scored from 1 to 4, with higher scores indicating greater levels of self-perceived competence, thereby signifying a lower level of vulnerability. The measure provides a total score of self-perceived competence, and may also be divided into subscales which examine self-perceived competence across 5 domains: academic, social acceptance, physical attractiveness, behavioral conduct, and athletic competence, as well as a subscale denoting global self-esteem. Past research with the measure has provided good internal consistency among middle childhood samples, as Cronbach's alphas have ranged from .75 to .82 (Harter, 1985). In the present study reliabilities ranged between  $\alpha = .81$  and  $\alpha = .89$ , indicating strong internal reliability.

Social Support Scale for Children (SSS-C, Harter, 1985). The SSS-C is designed to assess several sources of positive regard and support that a child may receive from significant others. Four important relationships are assessed: parent, teacher, peer/classmate, peer/close friend. Each subscale contains six items for a total of 24 items. The question format is constructed to overcome the general tendency for socially desirable responding by utilizing a devised structured alternative format. The internal consistency reliabilities for the subscales range from .72 to .88.

Sibling Inventory of Behavior (Schaefer & Edgerton, 1981; Hetherington, Henderson, & Reiss, 1999). This 32-item measure requires respondents to rate the

frequency of positive and negative behaviors of the neurotypical sibling toward the child with ASD within the past two months using a 5-point Likert scale ranging from whether a behavior occurs "never" to "always". The SIB assesses the following six domains: rivalry, aggression, avoidance, involvement, empathy, and teaching. There are no definitive cut-off points on this scale, and typically researchers have grouped the scales into negative and positive subscales and then further divided them into high and low groups by performing a median level split. The reliability of this scale is good, with the internal consistency for all scales except the teaching scale amounting to a Cronbach's alpha of over .70 (Vollig & Blandon, 2003). The overall reliability of the scale in the present study was  $\alpha = .52$ , with individual subscales ranging between  $\alpha = .40$  and  $\alpha = .81$ .

Satisfaction with the Sibling Relationship Scale (McHale & Gamble, 1989). The second sibling-focused scale measures the sibling's happiness with the sibling relationship, satisfaction with time spent with the sibling, caretaking, and the sibling's perception of how well they get along with their brother or sister with autism. In an earlier study, the alpha coefficient was .82 for a modified version for parents and .74 for siblings (Rivers & Stoneman, 2008). In the present study the reliability was  $\alpha = .75$ .

Gilliam Autism Rating Scale, Second Edition (GARS-2; Gilliam, 1995). To account for the severity of the child with autism, parents filled out the Gilliam Autism Rating Scale, Second Edition at Time 1. This instrument has a mean of 100 and a standard deviation of 15. GARS-2 was originally normed on a representative sample of 1,107 persons with autism and has strong psychometric characteristics. Coefficients of reliability (internal consistency and test-retest) for the subscales and entire test are all large to very large in magnitude. The validity of GARS-2 has also been well-

documented. The overall mean level of severity of ASD in the present sample was a standard score of 93.65, indicative of an average level of severity.

Sibling Play Interaction Task. At each assessment time point, siblings played with their brother or sister with autism in an assessment room at the DDDC. Siblings were given the directive "play as you normally would" and were instructed to play for two, 10 minute periods separated by a short break. Play assessments were video recorded to allow for later coding by undergraduate researchers using rubrics from earlier studies to assess for the presence of play related behavior (El-Ghoroury & Romanczyk, 1999) and behavioral techniques (Celiberti & Harris, 1993), such as play initiations, prompting, and praising (see Appendix C).

### Materials.

In order to account for all ages and varying functioning levels of children with ASD, a wide range of toys were available to children during the sibling play interaction task. Toys used included the Playskool Mr. Potato Head, Dora the Explorer Extra Large Coloring Book, Crayola 24 piece Markers, Hasbro's Don't Break the Ice game, Fisher-Price Little People Animal Sounds Farm, Mega Bloks 100 piece Minibloks Tub, Fisher-Price Little People Tow 'N Pull Tractor, Friction Farm Tractor, 1 set of Dominos, Melissa and Doug Pasture Pals 12 Horses, 1 set of playing cards, 1 set of 'Old Maid' playing cards the Little Tike Fold Up and Go Train, Fisher-Price Medical Kit, Play-Doh Case of Colors, Milton Bradley Connect 4, Melissa and Doug Deluxe Wooden Construction Vehicles Chunky Wood Puzzle- 6 Piece, Melissa and Doug Magnetic Puzzle Game – Tow Truck, Imaginarium 75-Piece Wooden Blocks Set, Blip Hair Ball, PinArt,

and the Fisher-Price 2- in-1 Crocodile Keys Xylophone. The video recording equipment used to video all sessions was a Sony DCRSX40 Flash Memory Handycam Camcorder.

## Interobserver reliability.

Trained undergraduate observers independently viewed and coded the videorecorded sibling play interaction task data samples. The sessions were coded for
frequency counts across the target behaviors. For the neurotypical sibling, these included
initiating play, prompting, and praising. Videos were also analyzed for the residual effect
of improved play behavior in the sibling with ASD, including initiating and responding.
The formula for exact agreement interobserver agreement was obtained by dividing the
number of agreements that the behaviors occurred by the number of agreements and
disagreements, multiplied by 100. In instances in which one observer recorded one
instance of behavior while the other did not, a default interobserver agreement of 50%
was established. At least 50% of all sessions for each pair were checked for inter-rater
reliability.

Prior to coding data, undergraduate observers with prior experience working with ASD met with the present author for training. Observers were responsible for memorizing observational codes, and were tested on their ability to define and correctly apply these codes. Initially, they practiced coding on a taped segment from a previous sibling intervention which gave ample opportunity to code all target behaviors from the present study. When observers maintained a mean of 75% agreement across two consecutive training probes, they were given tapes to code from the present intervention. Observers worked independently, and were unaware of the time point they were coding as well as their reliability scores while the study was ongoing. Throughout coding, the

present author tracked reliability and offered feedback as necessary to minimize observer drift.

## Intervention Acceptability and Satisfaction.

Both parents and children were asked to complete a Project SibSTAR Satisfaction Survey regarding the participation in the group. This survey was included in the post-group questionnaire packet, and asked participants to rate different dimensions of the intervention, such as structure, content, and enjoyment on a 5-point Likert scale (1= strongly disagree, 5= strongly agree; see Appendix D and E.). Participants and parents were also given a checklist to note whether they observed several facets of improved interaction with the child with ASD. Finally, two open-ended questions were included for participants to state suggestions for the group and give feedback on preferred vs. non-preferred activities.

# Social Validity of Sibling Play Interaction Task.

Undergraduates who were blind to the purpose of the study coded the play assessment samples. Five participants were randomly chosen from each group, and minutes 3-8 of the play session were pre-selected for coding across all three assessment points. Ratings were assigned on a modified 5-point Likert scale adapted from Ferraioli (2010) to measure the social validity of play interactions (see Appendix F). Higher ratings on the scale indicated more favorable perceptions. Samples were coded for the neurotypical sibling variables, including *empathy*, *responsiveness*, *support*, *directivity*, *enthusiasm*, *intrusiveness*, *frustration*, and *enjoyment*, and variables for the child with ASD, including *responsiveness*, *enthusiasm*, *frustration*, *enjoyment*, and *withdrawal*. In addition, a general rating was obtained to determine the overall quality of the interaction.

## Intervention fidelity.

All group sessions were video recorded to assess for group leader adherence to the intervention procedures as outlined in the Project SibSTAR manual. Undergraduate observers watched all group sessions, and scored each on whether or not the leaders included key components of the program (i.e., lecture points, behavioral exercises, discussion points, role plays). Criterion for adequate intervention fidelity was correct implementation of the manual across 90% of components per each session. Both the active (M = 94%, range = 85-100%) and delayed (M = 97%, range = 91-100%) groups reached adequate intervention fidelity, as described in Table 2.

Table 2

Intervention Fidelity Ratings for Project SibSTAR By Group

Week	Active (Weekly %)	Delayed (Weekly %)		
1	95	95		
2	93	100		
3	85	100		
4	87	93		
5	100	93		
6	90	100		
7	100	91		
8	100	100		
Average TI	94%	97%		

### **Description of Data Analyses**

The unique design features of this study allowed for both within subjects and single-case interpretation. For the within subjects data, statistical tests were used to analyze differences on pre and posttest measures. As such, a repeated measures multivariate analysis of variance (MANOVA) was conducted on both groups to investigate differences across all measures from baseline, post, and follow-up screenings. In addition, three potential moderators were examined: severity of the sibling's autism diagnosis, social support, and self-competence.

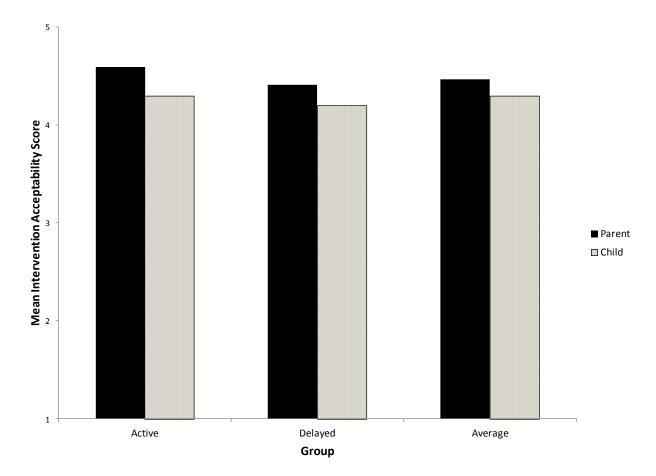
The participants were also measured on 1) knowledge of autism 2) coping and problem solving, and 3) behavioral skills training. These three questionnaires formed the basis for a multiple baseline design across skills for each participant. These scores were then combined across groups to assess for anticipated changes on measures at baseline, interim, post, and 6 week follow-up assessments. Utilizing a multiple baseline design enables conclusions about specific treatment effects for these three variables and provides treatment analysis for the Project SibSTAR manual. The addition of an extended baseline for the delayed treatment group allows for the interpretation of a multiple baseline design across groups. As such, the average scores of participants in the active treatment group are compared against the average scores of the participants in the delayed treatment group on all three measures. This design permits an evaluation of whether children in both groups were able to learn these skills when directly targeted and assess how effectively they maintained these skills. The interpretation of multiple baseline data is conducted through visual inspection of trends and levels in the data.

# **Results**

# **Intervention Acceptability & Satisfaction**

Overall, across groups parents and children rated Project SibSTAR as very satisfactory, as depicted in Figure 2.

Figure 2. Average Intervention Acceptability By Group

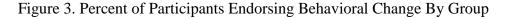


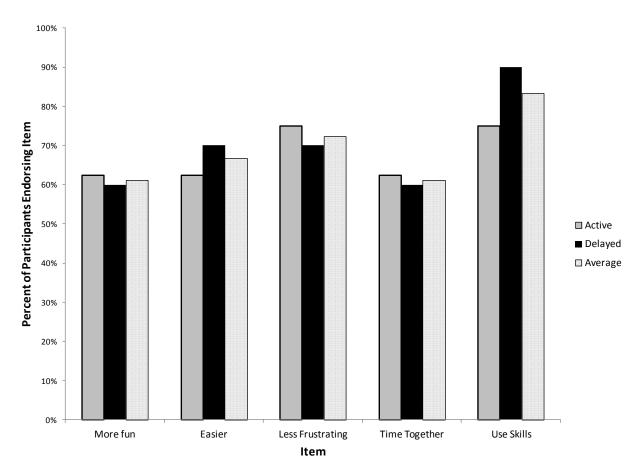
Out of a possible 5 points, the active group had a mean of 4.59 and 4.3 on a measure of group satisfaction for parents and children, respectively. Scores were only slightly lower

in the delayed group, with M = 4.41 for parents and M = 4.2 for children. For children, the item most likely to receive a low score was individual item 7 "I feel like spending time with my brother or sister is better because of the group" (M = 3.89). Items 7 "I was frustrated by the group" (M = 4.72, reverse-coded) and 2 "I felt that the group was a good idea for me" (M = 4.67) received the highest endorsements.

Data were also collected on potential benefits of the group in a checklist format.

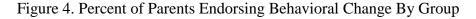
Behavioral differences noted by siblings are presented in Figure 3.

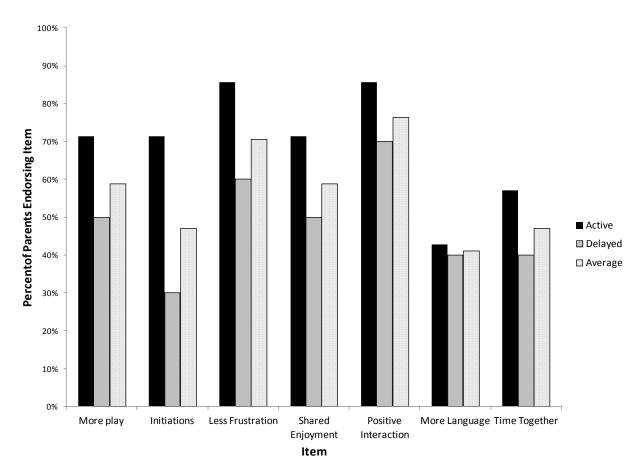




Participants were most likely to endorse item 17 "I feel I can use my new skills" (M = 83.3%) and item 14 "I feel less frustrated with my sibling" (M = 72.2%). Across the active and delayed groups, participants endorsements were largely consistent across category, with the largest difference noted in the utilization of skills item (active group, M = 75%; delayed group, M = 90%).

Parents were given a different checklist of behavioral change observed among the dyad at home, and their results are portrayed in Figure 4.





Across all items, parents in the active group were more likely to endorse observing behavioral change in their children following the group. Parents were most likely to agree that their children had more positive interactions with one another (M = 76.5%), their neurotypical child appeared less frustrated when interacting with their sibling (M = 70.6%, reverse-coded) and both children appeared to be enjoying one another more (M = 58.8%). In addition, parents were least likely to note the neurotypical sibling using more language when attempting to play with their brother or sister (M = 41.2%).

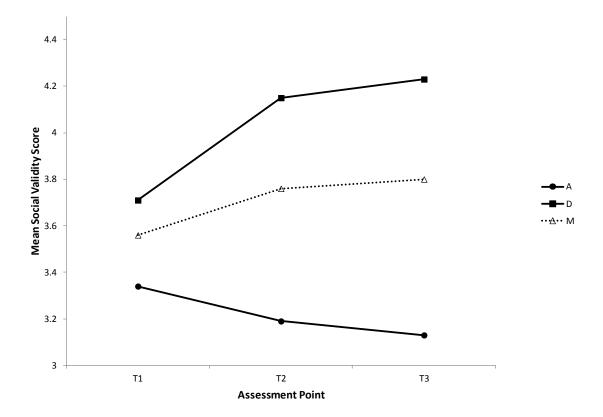
# **Social Validity**

Ratings of social validity by naïve observers resulted in significant differences across the active and delayed groups. The eight items on the neurotypical sibling scale (i.e., empathy, responsiveness, support, directivity, enthusiasm, intrusiveness, frustration, and enjoyment) were averaged to create a mean sibling social validity score, scored on a 1-5 Likert scale. These data reflect play samples taken across all time points: Baseline (T1), Post group (T2), Follow-Up (T3). Figure 5 reflects the average neurotypical sibling social validity score for each group and for the combined overall mean across groups. Visual analysis indicates a significant positive effect for the delayed group across all three time points. However, the active group data reveals the opposite trend in the neurotypical sibling's behavior.

Similarly, the five items which comprised the scale for the sibling with ASD were averaged to create a mean ASD sibling Social Validity Score with a maximum score of 5. For these specific items (i.e., responsiveness, enthusiasm, frustration, enjoyment, and withdrawal) there was a notable positive trend for the delayed group from T1 to T2, which was not observed in the active group (see Figure 6). Consistent with the mean

Social Validity Score for the neurotypical siblings, children with ASD whose siblings were in the active group showed a negative linear trend across all time points.

Figure 5. Mean Social Validity Score for the Neurotypical Sibling By Group



Note. A = active group; D= delayed group; M = mean across groups. Y-axis does not cross at zero.

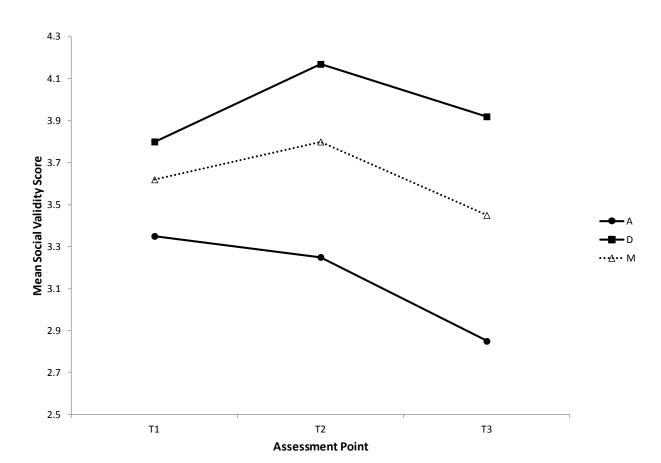


Figure 6. Mean Social Validity Score for the ASD Sibling By Group

*Note.* A = active group; D= delayed group; M = mean across groups. Y-axis does not cross at zero.

For the delayed group, visual inspection revealed significant linear increases on item 14, on which the quality of the sibling interaction as a whole was rated (see Figure 7). Ratings for the active group showed a significant negative trend from baseline to follow-up.

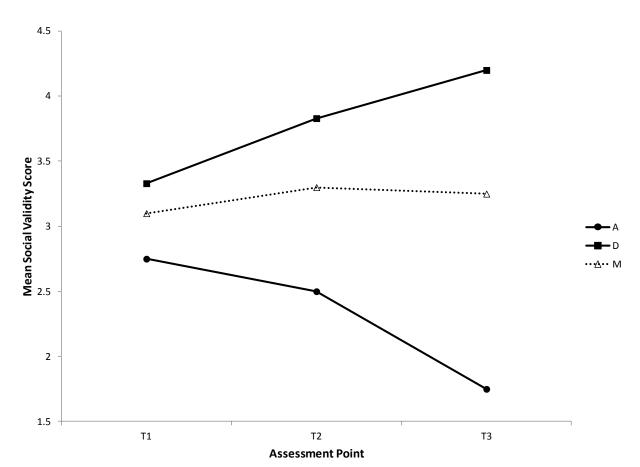


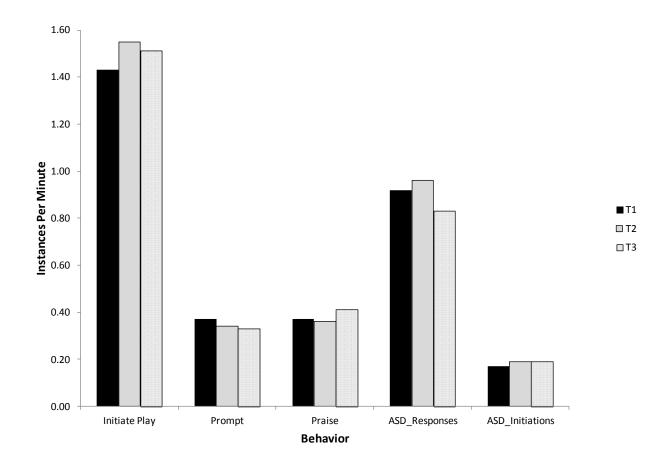
Figure 7. Mean Social Validity Rating for item 14-Overall Quality of the Interaction

*Note*. A = active group; D= delayed group; M = mean across groups. Y-axis does not cross at zero.

# **Sibling Play Interaction Task**

Video-recorded samples analyzed behaviors of the neurotypical sibling targeted in group: initiating play, prompting, and praising their sibling. To capture any residual effect of improved play behavior in the neurotypical sibling, data were collected on responding and initiating in the child with ASD. The findings are presented as average instances per minute for all five coded behaviors across all time points (see Figure 8).

Figure 8. Average Instances Per Minute of Play Behavior in the Sibling Dyad



*Note*. The first three behaviors reflect the neurotypical sibling. The final two, ASD\_Responses and ASD\_Initiations, reflect behavior of the sibling with ASD.

Due to insignificant findings by group, the aggregate data are presented across all participants for greater visual clarity. Visual inspection reveals that the largest increase is in play initiations by the neurotypical sibling from baseline (M = 1.43 initiations per

minute) to post assessment (M = 1.55 initiations per minute). However, the increase in the means is relatively minor. There is minimal observed change across all time points on the neurotypical siblings' attempts to prompt and praise their brother or sister. The children with ASD also have nearly stable rates of initiating and responding across baseline, post, and follow-up assessments.

### Interobserver agreement.

IOA was calculated for 50% of all videos, and totals across behavioral categories as well as overall total are presented in Table 3. Total IOA across all behaviors was 81%, and met criteria for sufficient reliability.

Table 3

Average Interobserver Agreement By Category for Sibling Interaction Task

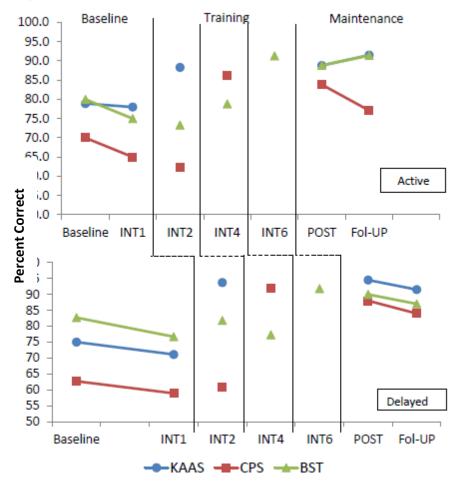
Initiating Play	y Prompting	Praising	ASD_Initiating	ASD_Responding	TOTAL
84.2%	79.5%	83.5%	73.7%	84.3%	81%

### **Multiple Baseline Measures**

The KAAS, CPS, and BST data are presented across groups (Figure 9) and aggregated across skills (Figure 10). Visual analysis of the data yielded consistent and clear effects for all measures following the coverage of a given topic in group. In the active group, baseline data for the KAAS increases from an average of 78.4% correct at baseline and the first group session to 88.3% following training at group session 2. As evidenced by the graph, the active group's score actually improves on the KAAS during maintenance checks, with an average of 88.8% and 91.5% at post and follow-up assessments, respectively. The delayed group's data for the KAAS also shows significant

change, increasing from a mean of 73.1% at baseline, to 93.7% following training probes at interim 2. Performance at the post assessment again continues to improve (M = 94.5%) followed by a slight decrease in performance at the follow-up assessment (M = 91.5%).

Figure 9. Multiple Baseline Design Across Groups-Acquisition and Maintenance of KAAS, CPS, and BST



*Note*: Group sessions coincide with interim data collection points (e.g. Interim 1 = Group 1, Interim 2 = Group 2, etc).

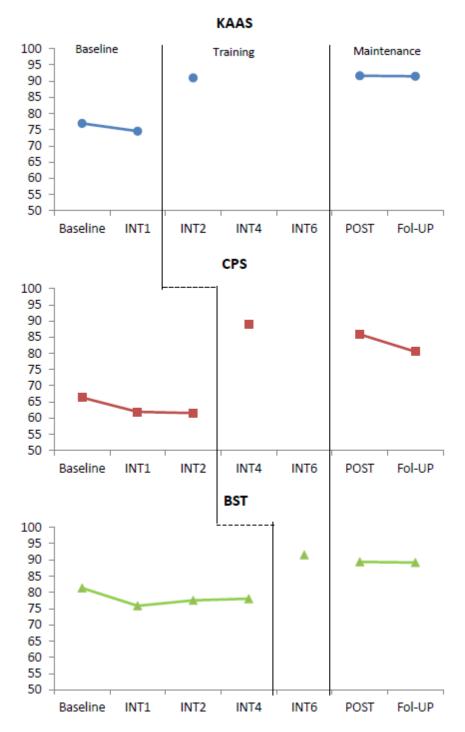
Similar trends are noted across groups for the CPS, which remained in baseline until direct instruction at interim 4. The active group has a decrease during baseline (M = 65.7%) followed by a sharp increase after teaching (M = 86.3%) and a slight decrease at post (M = 83.8%) and follow-up (M = 77.1%). Acquisition across the delayed group

mirrors the active group, with a baseline average of 60.8%, succeeded by an increase immediately following training to 91.8%. Maintenance probes again showed minimal decreases at post (M = 88%) and follow-up assessment (M = 84%), while still remaining significantly higher than baseline levels.

BST remains in baseline the longest, and is targeted in interim 6 with similar results. The baseline average for the BST in the active group is 76.7 % correct, followed by an increase to 91.3% after training, and continued stable responding during maintenance probes (M = 90.1%). Data from the delayed group show a baseline average of 79.6%, 91.8% correct after training, and an average of 88.5% correct across maintenance probes.

Further evidence for the effect of training can be seen by visual analysis of Figure 10, which includes average acquisition data collapsed across group in a multiple baseline across skills design. The KAAS had a sharp increase post training, with an increase of 15.3% from baseline to interim 2. Participants maintained their scores from interim 2 through maintenance probes (M = 91%). Both the CPS and BST showed stable trends during baseline, and pronounced increases immediately after training, for a gain of 25.8% and 13.4%, respectively. On maintenance probes, the CPS decreased slightly after training (M = 89%) at post (M = 85.9%) and follow-up (M = 80.6%) assessment, while the BST remained more stable, with a training average of 91.55%, post average of 89.4%, and follow-up average of 89.2%.

Figure 10. Multiple Baseline Design Across Skills - Mean Acquisition and Maintenance of KAAS, CPS, and BST



*Note:* Group sessions coincide with interim data collection points (e.g. Interim 1= Group 1, Interim 2 = Group 2, etc).

# **Group Design Measures**

### Descriptive data.

Preliminary diagnostic tests were run on total scores for all measures used in the present study to confirm that the data adhered to assumptions of normality. First, it was tested whether the skewness and estimated kurtosis score (once the constant of 3 was subtracted out; Curran, West, & Finch, 1996) hovered around 0. Values for all total scores were deemed acceptable. Second, examinations of Q-Q plots did not reveal any significant deviations from normality. Thus, it was decided not to perform any transformations on the raw data.

For the present study, the estimation maximization procedure was used to manage missing data and to overcome the limitations of mean substitution or regression substitution (Schafer, 1997; Schafer & Olsen, 1998). Little's MCAR test (Little & Rubin, 1987), for which the null hypothesis is that the data are missing completely at random, was not significant (p > .05). Given these results, maximum likelihood estimates of missing data were created and used in all subsequent analyses. Means and standard deviations for measures across baseline, post, and follow-up assessments are included in Table 4. In addition, correlations for baseline measures can be found in Table 5. The pattern of significant correlations was in the expected direction.

<sup>&</sup>lt;sup>1</sup> Of note, analyses were also conducted on data in which listwise deletion was utilized for participants who missed any follow-ups. The pattern of findings was similar across hypotheses.

<sup>&</sup>lt;sup>2</sup> Surprisingly, correlations between self-perceived competence, depressive symptoms, and anxiety symptoms were higher than expected at baseline. In response, we examined the correlation between the three constructs over time. When examining these relations across the three time-points the correlation

Table 4

Means and Standard Deviations by Measures across Time Point

	Time Point					
Measure	Baseline	Post	Follow-Up			
Depression	15.00 (9.68)	10.44 (9.11)	12.56 (9.01)			
Anxiety	8.67 (5.30)	5.94 (5.65)	6.12 (6.46)			
Self-Competence_Soc	15.89 (4.91)	18.06 (4.70)	18.59 (3.79)			
Soc Support_Tot	57.28 (6.71)	60.44 (6.92)	61.88 (7.63)			
Soc Support_ Friend	17.39 (4.67)	19.50 (3.70)	20.29 (4.08)			
Soc Support_Classmate	17.56 (4.23)	19.11 (3.45)	19.53 (3.42)			
Soc Support_Parent	22.33 (2.09)	21.83 (2.81)	22.06 (2.62)			
SIB_ Positive Tot	52.28 (12.64)	53.33 (13.20)	54.94 (11.78)			

Note: Depression = Center of Epidemiological Studies-Depression Scale for Children (CES-DC) Total Score; Anxiety = Reynolds Children Manifest Anxiety Scale (RCMAS) Total Score, Self Competence\_Soc = Self-Perception Profile for Children and Adolescents (SPPCA), Social Competence Subscale; Soc Support\_Tot = Social Support Scale (SSS) Total; Soc Support\_Friend = SSS, Close Friend subscale only, Soc Support\_Classmate = SSS, Classmate subscale only, Soc Support\_Parent = SSS, Parent subscale only, SIB = Sibling Inventory of Behavior (SIB), positive factors total

between depression and anxiety symptoms (r = .54), self-perceived competence and depressive symptoms (r = .37) and self-perceived competence and anxiety symptoms (r = .54) were all comparable to what is typically found in research on these constructs (Cole, Peeke, Martin, Truglio, & Seroczynski, 1998; Cole, Peeke, Dolezal, Murrary, & Canzoniero, 1999; Uhrlass, Schofield, Coles, & Gibb, 2009).

Table 5

Pearson Correlations between Time 1 Measures

	1	2	3	4	5	6	7	8
1.Depression								
2.Anxiety	.77**							
3.Self-Competence_Soc	60**	40						
4.Soc Support_Tot	52*	30	.74**					
5.Soc Support_Friend	35	13	.28	.65**				
6.Soc Support_Classmate	42	46	.78**	.75**	.07			
7.Soc Support_Parent	03	.27	.18	.25	30	.23		
8.SIB_ Positive Tot	69**	47*	.74**	.58*	.11	.72**	.15	

Note: Depression = Center of Epidemiological Studies-Depression Scale for Children (CES-DC) Total Score; Anxiety = Reynolds Children Manifest Anxiety Scale (RCMAS) Total Score, Self Competence\_Soc = Self-Perception Profile for Children and Adolescents (SPPCA), Social Competence Subscale; Soc Support\_Tot = Social Support Scale (SSS) Total; Soc Support\_Friend = SSS, Close Friend subscale only, Soc Support\_Classmate = SSS, Classmate subscale only, Soc Support\_Parent = SSS, Parent subscale only, SIB = Sibling Inventory of Behavior (SIB), positive factors total

# Data Analysis.

All data were analyzed with SPSS 19.0. To test the hypothesis that Project SibSTAR had a significant influence on participant's depressive symptoms (CES-DC), anxiety symptoms (RCMAS), self-competence (SPPCA), perceived social support (SSS), and behavior towards their brother or sister with ASD (SIB) a repeated measures

<sup>\*</sup> p < .05. \*\* p < .01.

Multiple Analysis of Variance (MANOVA) was used.<sup>3</sup> Specifically, all of these outcomes were entered as Level 1 data, and it was examined if they varied as a function of time. An important issue when interpreting repeated measures MANOVAs is whether the variance of the outcome measures is consistent across time points (known as sphericity). When sphericity is violated (i.e. variance is not consistent across time points), specific corrections need to be made to ensure the model is still consistent with the assumptions of the general linear model. Specifically, if epsilon (E; an index of sphericity) is above .75, it is recommended that one use the Huynh-Feldt correction, while if epsilon dips below .75, indicating a greater violation of sphericity, it is recommended to use the more conservative Greenhouse-Geisser correction (see Lund & Lund, 2012 for further explanation). In the present study, results concerning prosocial behavior towards a sibling with ASD ( $\chi^2(2) = 7.86$ , p = .02;  $\epsilon = .72$ ) and social selfcompetence ( $\chi^2(2) = 9.30$ , p = .01;  $\varepsilon = .70$ ) showed a rather significant violation of sphericity requiring the Greenhouse-Geisser correction for these outcomes, while social support showed more moderate levels of unequal variance across time points ( $\chi^2(2)$ ) = 6.18, p = .05;  $\varepsilon = .76$ ), indicating the need for the Huynh-Feldt correction. For depression and anxiety, the sphericity test was not significant, so the model was run without the need for correction.

<sup>&</sup>lt;sup>3</sup> Due to concerns about the discriminate validity between self-perceived competence, depressive symptoms, and anxiety symptoms, a confirmatory factor analysis was conducted to examine if these three constructs should be treated as a singular construct using AMOS (version 20). Preliminary findings suggested that a one-factor solution was not appropriate for the present study as the Chi-Square was significant for this test ( $\chi^2(78) = 173.52$ , p < ..001; RMSEA = .24; CFI = .37), and a one-factor solution did not provide a better fit than either a two-factor or three-factor solution (p > .10). Therefore, the present exploratory study treated these measures as separate constructs.

With regard to internalizing symptoms, results indicated that the mean depression (F(2, 34) = 2.75, p = .08) and anxiety scores (F(2, 34) = 3.14, p = .06) did not differ at statistically significant levels between time points. However, because of the small sample size (N = 18) and novelty of the present study, it was of interest to the author to consider these findings important, and interpret them at the trend level (defined as p-values greater than .05, but less than .10). As an investigation of the means reveals, depression and anxiety scores decreased at a trend level from T1 to T2 (representative of a lessening of symptomatology), with slight increases from T2 to T3. Thus, it seems that the trend level findings from the repeated measures MANOVA stem from a decrease in symptoms from baseline (Time 1) to post-test (Time 2). See Figures 11 and 12 for a visual depiction of this trend.

Next, I examined vulnerabilities and other associated constructs for internalizing symptoms to see if the program was successful in decreasing any of these processes. In order to test whether the intervention had a significant impact on prosocial behavior, the three subscales on the SIB (involvement, empathy, and teaching) were summed to create a positive behavior factor. Findings for this outcome suggested that mean-levels of prosocial behavior did not vary as a function of the intervention (F(1.44, 24.49) = .67, p = .48). On measures of social support a statistically significant effect for total social support was found (F(1.63, 27.74) = 3.98, p = .04). In addition, subscales on perceived social support from close friends (F(2.34) = 4.22, p = .023) and classmates (F(1.34, 22.83) = 4.32, p = .039) were both statistically significant, indicating an effect from baseline to follow-up (see Figure 13 and Figure 14). However, measures of perceived social support from parents was not statistically significant, F(2.34) = .451, p = .64. Finally, for self-

competence (SPPCA), the social subscale was the only one which showed a significant effect across time point (F(1.39, 23.60) = 5.34, p = .021 (See Figure 15).

Figure 11. Estimated Marginal Means for the CES-DC

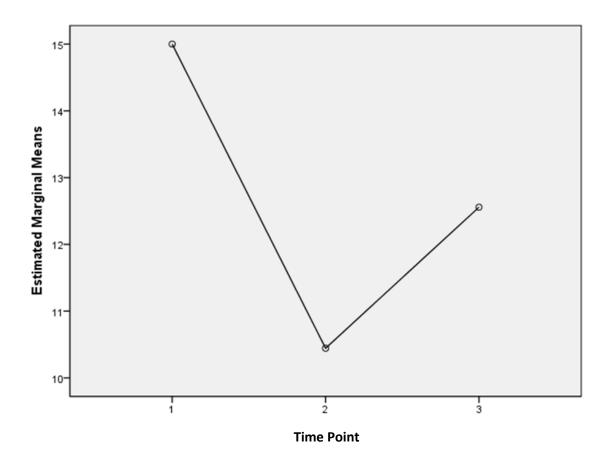


Figure 12. Estimated Marginal Means of the RCMAS

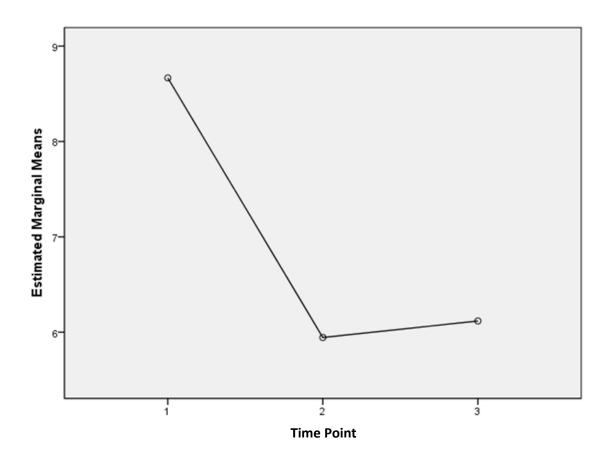


Figure 13. Estimated Marginal Means for the Soc Support\_Friend Subscale

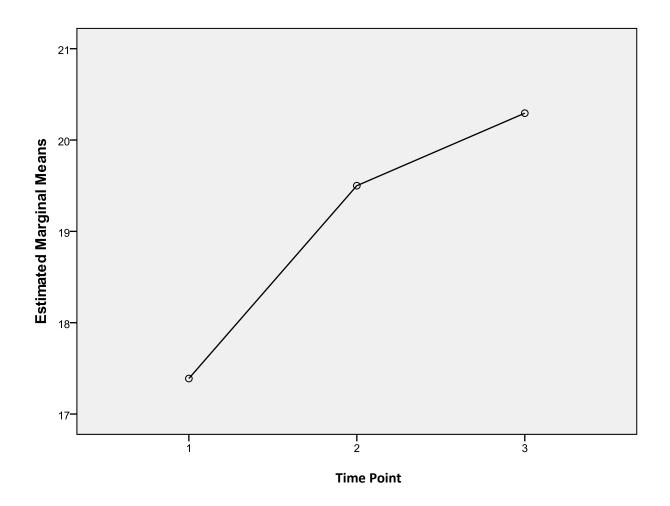


Figure 14. Estimated Marginal Means of Soc Support\_Classmate Subscale

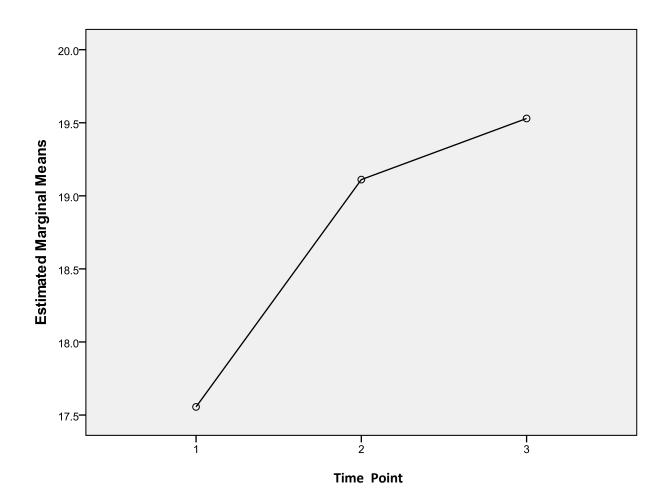
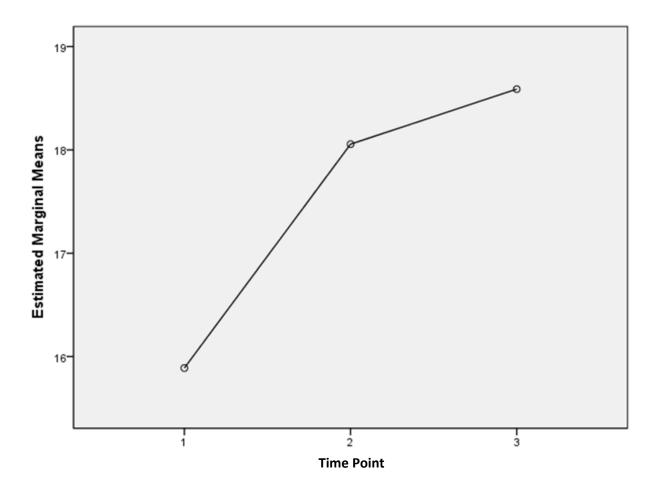


Figure 15. Estimate Marginal Means for the Self-Competence\_Soc Subscale



Finally, I investigated whether specific baseline variables moderated the impact of the group. Specifically, it was tested whether children with higher self-competence (T1\_SPCCA\_TOT), greater social support (T1\_SSS\_TOT), or a sibling with a more severe diagnosis of autism (GARS\_Severity) had a greater decrease in their symptoms of depression and anxiety during the post-test and follow-up. For these analyses, separate

mixed-level MANOVAs were run for each potential moderator, with symptoms of depression and anxiety being run as a within-level (Level 1) variable, and the moderators being run as a between-level (Level 2) variable. With regard to self-competence, the interaction between time point and self-competence was not significant (F(64,2) = .34, p = .94) suggesting that children did not show different patterns of depression and anxiety symptom reductions based on their baseline self-competence scores. A similar null-finding was found for social support (F(48, 18) = 1.61, p = .14) and severity of a sibling's diagnosis (F(4, 62) = .31, p = .87). Thus, none of the hypotheses regarding moderators were significant in the present study, as children seemed to respond similarly to the group across individual differences on these baseline variables.

#### **Discussion**

## **Intervention Acceptability & Satisfaction**

The acceptability of an intervention program depends not only on its measurable outcomes, but the perception of the program by individuals who have experienced it. Treatment acceptability attempts to measure whether participants believed that the intervention was appropriate, fair, reasonable, and efficacious (Kazdin, 1980; Miltenberger,1990). When working with children, it is especially important that they find the intervention not only informative, but enjoyable. The acceptability of the Project SibSTAR program was listed as "very satisfactory" across both groups, with minor differences noted between those in the active and delayed conditions. Although the differences were marginal, children randomized to the active group and their parents endorsed higher overall mean intervention acceptability compared to the delayed group. It is unclear why these slight differences occurred, though one possible explanation could

be the difference in size between the two groups. Due to one withdrawal from the study and one family who required a change in group assignment, the active group had 8 participants, while the delayed group had 11. It could be that the smaller group size allowed for a more individualized intervention in the active group that participants in the delayed group did not experience. Another possible explanation was that children in the active group, compared to the delayed group, may have felt more connected to their coleaders. However, despite these methodological factors, the differences in acceptability of the group are marginal at best and are not significantly different.

In identifying specific behavioral changes in a checklist format, parents in the active group endorsed greater observable change than parents in the delayed group across all seven categories, with a noticeable difference in the reported frequency of initiations following the group. It may be that parents from the active group who were more satisfied with the treatment as a whole made them more likely to endorse behavioral change in their children. By the children's report, the active group rated three out of five potential behavioral differences as having occurred more often than the delayed group (see Figure 3). The delayed group rated themselves higher on the items "I have an easier time playing with my sibling" and "I feel like I can use my new skills." Overall, these differences on the child self-report measures in the two groups are not significantly different.

Both children and parents were also invited to share feedback in an open-ended format about things which they enjoyed about the group, and were asked to offer suggestions on how to improve the content and structure of Project SibSTAR. In response to the question "What was your favorite part of the group?" participating siblings offered

some of the following: "That it helped me and that in every single class we laughed", "I get to talk to people who understand me completely", "Learning new skills about how to play with my brother and the fun crafts", and "The last assessment." Siblings were also asked to share their least favorite part of the group, and these included: "It was too short, I would have liked it if it was a year long", "Doing the paperwork" and "the role plays." In response to this question, 13 out of 19 children responded "Nothing" indicating high satisfaction with the group. When prompted with the question "is there anything else you would like to tell us about being a SibSTAR?" responses included: "That I liked it a lot and want to come back- it helped me a lot. I might have liked it more though if it was more specific because the things were very general. Like the playing with your sibling would be different for a 2 year old and a 9 and 12 year old", "It is really hard to be a sibling and even more hard to be a sibling with a brother who has Asperger's. The group has helped a lot", and "It's awesome and I would like to join again."

Parents were also asked to share feedback about the program, and their responses were overwhelmingly positive. Some suggested changes included further separating the groups by age and including siblings with ASD in several sessions in order facilitate behavioral skills training in vivo. Overall, Project SibSTAR was a very acceptable intervention package to both participants and their parents. For an exhaustive list of child and parent feedback, refer to Appendices G and H, respectively.

### **Social Validity**

Although participants and parents in the active group endorsed more satisfaction with the intervention package, the delayed group had a significantly greater score on measures of social validity. This difference may by notable for several reasons. In the

active group, the mean level of symptom severity of the ASD sibling as measured by the GARS-II was 91.25, compared to 97 in the delayed group, indicating a more severe sample in the delayed group. Typically, when a child has autism, their neurotypical sibling is required to "stage manage" their play in order to prolong the interaction (Knott, Lewis, & Williams, 2007). The delayed group's more severe sample may have played a role in the amount and quality of interaction coded by naïve observers. Put another way, children that have a more severely affected brother or sister have to "try harder" in interactions, and this effort was likely coded. In interactions when the siblings were closer in developmental level, there was less opportunity for overt "teaching" and "coaching" moments by the neurotypical sibling.

Also of note, as the tapes were chosen at random, the quality of the interaction that they captured varied. In the active group, two participants had siblings who were engaged in tantrum behavior for the final two assessment points. The reality of working with children with autism is that they exhibit a wide variety of behaviors, and it requires their sibling to be extremely adept at successfully dealing with problem behavior. The samples chosen for social validity captured the reality of these sibling dyads; on some days, their sibling with ASD may have had an "off" day, and the neurotypical sibling's behavior may have little impact on their brother or sister. In the delayed group, there was little maladaptive behavior during the sibling interaction task, despite the greater overall severity in this group. The overall quality of interaction scores indicate a significant positive linear trend for the delayed group, and a significant linear negative trend for the active group. The mean of the two groups indicates a slight positive trend.

### **Sibling Play Interaction Task**

There was an insignificant effect for the frequency of play initiations, prompting, and praising by the neurotypical sibling across time points. It was hypothesized that increases would be noted across these measures as a result of behavioral skills training taught during the group, however no significant differences were noted and rates remained relatively stable. It may be that the contrived nature of the assessment task was not sufficient at reflecting naturalistic behavior patterns. It is possible that the dosage of behavioral skills training administered in the group was not sufficient. For the majority of participants, the role-play practice sessions, even with a "difficult" pretend sibling, probably did not provide enough exposure to their actual experience.

The nature of autism spectrum disorders make sibling play-based interactions very difficult, and the participants likely needed individualized, in vivo instructions to make substantial gains with their siblings. Studies have shown that intensive, in vivo practice within the sibling dyad can result in substantial, generalizable change (Celiberti & Harris, 1993; Hansford, 2011). It is likely that the skills taught during the group, although useful behavioral techniques, required more individualized instruction to ensure success. Therefore, future efforts may try to build in more one-on-one instruction during this section of the group so that the siblings can better utilize the skills when at home.

### **Multiple Baseline Measures**

Across the KAAS, CPS, and BST, group averages following training were significantly different than baseline average percent correct. Consistent with the hypothesis, the active group's significant effects for the KAAS following training in interim 2, for the CPS in interim 4, and for the BST in interim 6, and these results were

replicated in the delayed group (see Figure 9). The average levels of acquisition were very similar across group, and are a testament to the consistency of program delivery. Interestingly, there were some notable differences in the maintenance of skills. While the active group increased on both the KAAS and BST from post to follow-up, the delayed group had a slight loss in skills for all three measures. The reasons for this gain six weeks after the intervention in the active group is unclear. In the active group, the highest average score on both the KAAS and the BST occur at 6 week follow-up, not immediately post training. The data from the delayed group are more consistent with the hypothesized trajectory; on average, participants are receiving their best scores on the measures immediately after training, with a slight loss of skills at post and at 6 week follow-up. Importantly, even with decreases present at 6 week follow-up, all scores remain higher than baseline levels. This is consistent across both groups, and indicates that the participants were able to learn the skills, and then maintain the majority of new learning.

In investigating the effects of the aggregated data on a multiple baseline design across skills, the effects of the intervention on learning are robust. Another convenient feature of the multiple baseline design allows one to visually identify if learning has occurred prior to the direct training of that skill (Kazdin, 2011). This is especially relevant in the context of an intervention, as it serves as a form of treatment integrity and allows group leaders to track whether they are teaching the intended skill and not skipping to later material. Across all three measures, baselines are relatively stable or are on a decreasing trend, indicating that participants have not been exposed to the skills prior to training, and that no spontaneous acquisition of skills occurred.

#### **Group Design Measures**

Statistically significant decreases were not noted in levels of depression and anxiety across all time points; however, an informal investigation of mean differences between time points does reveal an overall trend, with a decrease in internalizing symptoms from baseline to post group assessment and a minor increase in symptoms between post group and follow-up. It is important to note that, despite previous research citing greater vulnerabilities to developing disorders for siblings of children with ASD (e.g., Ross & Cuskelly, 2006) participants in this study had an average mean across groups that was not indicative of clinically significant depression (M = 15.00) or anxiety (M = 8.67) at baseline levels. There are a number of explanations which might explain the low rates of internalizing symptoms. As mentioned previously, some studies have cited protective benefits as a result of having a brother or sister with ASD (e.g., Macks & Reeve, 2007). It may be that the participants in this study were somehow "safe guarded" against the development of a psychological disorder.

Another contributing factor may be the relatively young age of the sample (M = 9.97). Research has shown that the average age for the onset of a depressive episode in youth is likely to occur in early to mid-adolescence (e.g. Birmaher et al, 2004; Sorenson, Rutter, & Aneshensel, 1991). In addition, research on children who have a sibling with ASD links significant stressors to this period of development (Glasberg, 2000). For example, in early to mid-adolescence, these children are forced to consider their siblings' fate as they grow older, as well as their own role in caring for their sibling. The enormity of pending responsibilities become especially apparent at this time, as concerns become less peer focused and more future-oriented. While this may be an at-risk group, it is a

young sample, with the average age of participants well below the average age of onset for a depressive episode. As such, findings may have been insignificant because children were not experiencing a wide range of depressive symptoms at baseline. However, even with subclinical depression and anxiety scores, there was a statistical trend indicating decreases in depressive and anxious symptoms from baseline to post-group.

Participants did not have significant increases on measures of positive behavior and perspectives toward their sibling. Scores on the SIB were high at baseline levels, with siblings scoring an average of 52.28 out of a possible 75 on the positive behavior factor. This indicates that the neurotypical siblings were already reporting positive acts and thoughts towards their sibling with ASD at baseline assessment. There are marginal increases in a linear trend across assessments, they are not significant. While Project SibSTAR targets behavioral skills training and methods of coping with a sibling's problem behavior, it never directly attempts to make the children feel more positive about their siblings.

Project SibSTAR does appear to have impacted children's perceptions of social support and social self-competence. More specifically, children endorsed statistically significant change on levels of perceived social support from close friends and classmates. Part of the group's curriculum is socially focused, and addresses both the feelings associated with having a special need sibling, and the importance of recognizing and communicating these feelings to others in an appropriate manner. For example, participants were able to speak openly about the embarrassment of having a sibling with ASD, as well as how unfair the disorder could seem at times, often resulting in differential treatment from parents. The expression of these emotions in a forum where

other children could understand and normalize their experience was likely beneficial to participants.

In addition, the group also explained how to speak to friends and classmates about the disorder in a manner with which they were comfortable. Many children commented that one of the most difficult tasks inherent in being a sibling was trying to explain their brother's or sister's disorder to friends. Understandably, they were hesitant to have friends over to their home in an effort to avoid addressing their sibling's disability. During group meetings, participants were given opportunities to talk about their experience in disclosing the disability, emphasizing both successes and failures. These scenarios were then turned into role-plays, in which participants were given an opportunity to practice the skills. Siblings were not directly asked to try these skills outside of the group. However, during the course of the group, several children anecdotally offered that they had approached a friend to speak about their sibling.

The significant findings concerning perceived social support may stem from children having more positive interactions in their social circles outside of the group, or it may have been from the social support they received directly from the group. As the literature states, one of the most significant components of a sibling support group may be the recognition that other children in the group can relate to one's own experience (Pasternack-Chinitz, 1991; Summers, Bridge, & Summers, 1991). The group members themselves may be acting as a novel source of social support for one another. Anecdotally, several parents requested contact information for other children in the group, as a means of staying in touch once the intervention was terminated.

Unfortunately, there are no follow-up data on whether children continued to have friendships with one another outside of the group.

Interestingly, there was not a significant finding for perceived parental support. Closer investigation of the means revealed that parental support was rated very highly at baseline (M = 22.33, SD = 2.09, out of a total possible score of 24). The high scores on this subdomain appear to have created a ceiling effect, in which statistically significant improvement was impossible. However, the children in this group felt very well-supported by their parents, which is often a significant concern for parents. As so much time is spent attending to the child with ASD, parents often struggle to make their neurotypical child feel recognized. The children in the present sample were able to acknowledge and report high levels of parental support.

While trend-level data suggest some effect of the group on reducing internalizing symptoms, the measures of social support and self-competence were statistically significant. In light of these findings, the group may be best conceptualized as a *prevention* group. Because the group focuses on a potentially at-risk population, particularly in mid to late adolescence, the conceptualization of the group as both educational and preventive may be an accurate label. There is a substantial amount of evidence for interpersonally-based prevention programs for adolescents with subclinical depression (Horowitz, Garber, Ciesla, Young, & Mufson, 2007; Young, Mufson, & Davies, 2006a), as well as comorbid anxiety (Young, Mufson, & Davies, 2006b). As its name implies, interpersonal psychotherapy (IPT) impacts internalizing disorders by improving communication methods, and highlighting the impact of these improvements on mood. IPT posits that depression occurs within an interpersonal context, and that

improvements in relationships effect mood. Following this logic, it may be that Project SibSTAR's trend level decreases on internalizing symptoms are a result of participants' improved social support and self-perceived social competence.

Findings across the potential moderators of social support, self-competence, and sibling ASD severity resulted in a non-significant relationship to internalizing disorders. These results suggest that social support, self-competence, and severity of the disorders cannot be used to predict differential response to the intervention as measured by depression and anxiety symptom reduction. Interestingly, when severity was used as a moderator, individuals with a higher functioning sibling endorsed higher levels of depression and anxiety at baseline than their counterparts with lower functioning siblings. On the other hand, symptom severity did not predict future scores on measures of depression and anxiety. However, it is important to note that all analyses concerning moderation should be interpreted with caution due to sample size restraints.

#### **Limitations and Future Directions**

There are limitations with the present study that merit discussion. The size of the sample limits statistical power and prohibits definitive statements regarding group differences. Bonferroni corrections were utilized on all significant repeated measure MANOVA findings, and I did not find significant post hoc differences between time-points. However, this is not surprising given the low sample size in the present sample, and the likelihood of detecting low effect sizes in community samples for processes related to internalizing disorders (McClelland & Judd, 1993). Thus, several theorists have advocated against the use of Bonferroni tests, especially in experimental studies such as the current project as it may be more likely to cause type II error as opposed to

preventing against a type I error (see Nakagawa, 2004 for further explanation). In the present study, the a priori hypotheses were conducted using Bonferroni adjusted alpha levels of .0167 per test (.05/3), which were unable to detect any significant differences across time points.

While the outcome data for depression and anxiety were at trend level, it is possible that the inclusion of more participants would have resulted in significant effects. Future studies should continue to assess anxiety and depression in this at-risk population. A useful approach to utilize in future research may be utilizing quick assessments that are conducted during group sessions, which would give greater insight into exactly when these changes are occurring, and offer more insight into potential mechanisms of change. For example, the significant social support findings raise some questions as to the source of the reported increase. Administering social support questions during group sessions would allow future studies to identify the shift in social support. For example, if participants report increases in perceived social support shortly after joining the group, this may be due to the effects of joining an aptly named "support" group. However, if participants are reporting higher perceived social support at the end of the group, this may be because communication strategies are targeted in the second half of the group. Further studies are needed to determine exactly when and why this shift is occurring.

There are also limitations surrounding the measurement of the sibling interaction task. In developing an observational coding system, decisions need to be made as to which behaviors to include, and which to exclude. Potentially important behaviors cannot always be measured systematically. For instance, there was no measure of the perceived quality of the interaction. While frequency data were collected, improvements in play

elicitations, prompting, and praising were not assessed. It is likely that for some children, there was no increase in the number of behaviors in a session, but that the quality of these interactions increased. Measurement of play-based behavior in a lab setting is not without its drawbacks. Participant's typical play at home may have looked completely different than in the assessment room, and these naturalistic play probes were not captured. Future studies may consider a home-based play assessment or a naturalistic observation in order to gain greater insight into typical sibling play.

Tracking frequency data and combining it across groups makes intuitive sense, particularly when no significant effects are noted. Unfortunately, this interpretation of the data may be misleading. It is possible that important individual differences in play behavior may have been masked in the group data. As mentioned previously, a single child's temper tantrum can cause aggregated data to appear non-significant because of a very low rating.

Another limitation of the study is in its measurement of social validity. The sibling interaction task may not have been an efficient measure to capture naïve observer's impression of change, and a play-based video sample was not the most sensitive form of measurement to capture potential changes observed over the course of the group. A fine-tuned measure might have included elements of sibling and parent perception of the group, multiple baseline outcome measures, as well as group design outcome measures in order to create a more realistic depiction of the breadth of the group. If possible, future groups should attempt to include the sibling with ASD in as many sessions as possible, particularly when rehearsing behavioral skills. While in theory this concept makes sense, in practice it would be difficult to manage multiple sibling

dyads and to work with each one individually. This would require many individuals with sufficient skills in applied behavior analysis to volunteer their time, and these obstacles prevented the inclusion of siblings in the present study,

A limitation which is inherent in a number of research studies is the reliance on self-report questionnaires. For this study, participants were mailed questionnaires prior to their assessment. While the present author included instructions specifying that questionnaires be filled out as independently as possible, it is unclear whether families actually complied with this request.

Future studies should continue to critically analyze the effects of sibling support groups using well-validated measures. As previously described, a larger sample size is necessary to increase power in order to more effectively detect change. However, in the current literature-base on sibling support groups, published studies rely on poorly operationalized measures, often collected at one time point. Those interested in sibling support group outcomes should make a greater attempt to mirror the psychological treatment research, both in their reporting of the group experience and in their use of validated measures. In addition, while a 6 week follow-up was a significant addition to the present study, future studies should attempt to assess follow-up months, and even years, after the completion of the group. Nothing is known about the longitudinal outcomes for siblings of children with ASD who participate in support groups, and the trajectory for these children is largely uncharted.

Although the age range of 8-12 seemed small, it may be pertinent to further subdivide groups by age. In the present study, the 8 and 9 year olds and the 10 - 12 year olds were developmentally in different places. Consistent with Glasberg's findings

(2000), these children were facing unique stressors and had conceptualized autism in varying ways. In the same vein, as much as it is possible, all attempts should be made to keep the functioning levels of the siblings with an autism spectrum disorder relatively similar. While there are clear, overarching similarities between the low-functioning and high-functioning individuals, the differences in the levels of cognitive ability is pronounced, and effects siblings in varying ways. For example, when attempting to initiate play, a sibling who is struggling to maintain eye contact with a very low functioning sibling has a very different experience from the child who is being verbally insulted by their sister with high functioning autism. The response to the sibling with ASD in each sibling is unique, and what works with one sibling may be difficult to attempt with another. Throughout Project SibSTAR, the group leaders were cognizant of the variability in functioning levels among siblings, and every effort was made to give examples that could be applied to everyone in the group. However, if groups could be further subdivided based on the neurotypical sibling's age and the functioning level of their brother or sister, the participants may benefit from more continuously applicable information.

The addition of a control group would be an obvious strength to future research going forward. Difficulties with recruitment did not allow for the inclusion of a control group in this study, but a well-controlled study would be an obvious addition to the current literature base. It is recommended that participants be matched to the extent possible, particularly across age and functioning level of siblings. Control group sessions should mirror a "camp" condition, in which children are introduced to one another and

complete fun activities, but no educational or skill-based information regarding autism is ever relayed.

In summary, the Project SibSTAR program for children who have a sibling with ASD appears to provide both educational and psychological benefits, particularly in the domain of social support. Little is known about the effects of these groups on the psychosocial functioning of the neurotypical children who attend them. Continued, well-designed research on this topic may further the understanding of how best to support this underserved population. By educating children about their sibling's disorder, inviting discussion about the realities they face, and introducing coping techniques and behavioral skills, we hope to make life a little easier for the children who love their brother or sister with an autism spectrum disorder, and to foster a way for that relationship to continue to grow.

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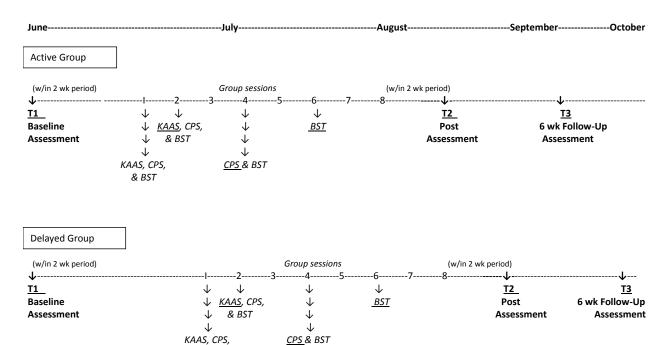
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## Appendix A

## **Project SibSTAR Timeline**

\*Assessment time points for each group@ the DDDC are <u>underlined in bold</u>
\*Underlined questionnaires received training in previous two sessions, while others remained in baseline.



& BST

#### Appendix B

# **Project SibSTAR manual**

## Session 1

Note: Some session content is adapted from activities described by Meyer and Vadasy (1994), Lobato (1990), and Celiberti and Harris (1993).

<u>Goals:</u> Orient siblings to group; early group formation, discussion of autism and disabilities (part 1).

Data Collection: KAAS, CPS, & BST

Agenda:

#### Welcome Activity: Name Tags (10 min)

As they arrive, siblings make nametags out of construction paper, stickers, and string.

### Group 1: Introductions & Name Game (15 min)

Leaders and siblings introduce themselves to one another. Leaders discuss the activities planned for the group. To help learn the names of each member of the group, leaders and siblings play a name game.

#### Activity: Sibling Bingo (15 min)

Each child is given a bingo card and a different colored pen. Each space on the bingo card has an instruction to find someone with a particular characteristic (e.g. Find someone with brown hair and brown eyes; Find someone who has a dog) and ask them to write their name in the bingo square. The child who fills out an entire row on the bingo card and yells "Bingo" first wins and explains who signed for each space on their card.

#### Group 2: Group Formation (25 min)

Leaders discuss with siblings the purpose of the group and talk in more detail about the activities that the group will be engaged in. Leaders talk about 2 important activities in a group: group name and group rules. Siblings and leaders decide upon a name as a group, using voting or some other strategy if necessary. Group rules should include rule about one person speaking in the group at a time, respect for each other and property of the group, confidentiality/limits of confidentiality, and what should happen when a rule is broken.

## Activity: Collage (20 min)

Leaders and siblings make a collage to hang up at each group meeting. Leader cuts up a large poster board into pieces that fit together like a puzzle. Each group member is given a piece of the puzzle to write their name on and decorate using pictures

from magazines, stickers, glitter glue, and markers. After each person decorates their piece, the siblings fit the puzzle pieces are put back together while the leaders discuss how each piece represent the unique contributions of each person to the group.

#### Group 3: Discussion of Families & Autism (25 min)

Each leader and sibling discuss who makes up their family, including their siblings. While discussing their family, each member draws a family tree on the board with each person in their family. Leaders encourage each sibling who has a brother or sister with autism to give the name, age, and tell a few interesting things about their brother or sister. Then leaders ask siblings to tell what they know about autism, making a list of the characteristics and how children get autism. If the siblings do not bring up each major characteristic of autism, leaders will add to the list.

#### Wrap - Up (10 min)

Review the activities of the group and ask about favorite activities of the group. Leaders provide a preview of the next group. Flier is given to parents, which details the events of the group.

## SibSTAR Session 2

<u>Goals:</u> Group formation, discussion of autism and disabilities (part 2), decrease sibling inhibition of talking during group.

Data Collection: KAAS, CPS, & BST

Agenda:

#### Welcome Activity: Find Name Tags & Making Rain (10 min)

As each sibling comes in, they are asked to find their nametag and join the circle. In the circle, the group is making rain. The leader asks all group members to do what the person on their right is doing. Leader starts making rain by rubbing his fingertips together. The sibling on the right of the leader then begins to rub his fingertips together. Once everyone in the circle has started the action, the leader begins to rub his hands together. Then, the leader initiates snapping fingers, clapping hands, slapping things, and stomping feet. Then, the leader reverses the storm by beginning to slap things, clap hands, snap fingers, rub hand together, and rub fingertips together.

#### Group 1: Review of Previous Week (10 min)

Leaders ask siblings to recall the events of the last sibling group and assist them with recall. Siblings review group rules and discuss anything interesting that happened since the last group meeting. Leaders encourage each sibling to contribute to the discussion.

### Activity: Same/Different (20 min)

Leaders introduce activity by asking siblings to look around and notice that no two people are alike and that each person is special and unique. Leaders divide siblings up into pairs for same/different activity. Each sibling pairs is instructed to make a list of as

many ways that they are the same and ways that they are different as possible in 5 minutes. Then, each sibling pairs presents findings to the group. Activity is repeated to allow each sibling to learn more about another sibling.

### Group 2: Information about Autism - Didactic (20 min)

Leaders ask siblings to review the definition of autism that the group came up with last week. Then, leaders lead a more formal and detailed discussion of characteristics of autism. Leaders discuss main characteristics of autism: social difficulties, communication difficulties, problem behaviors, and difficulties with learning in developmental appropriate language ("trouble learning how to talk"). Leaders ask siblings for examples of each from their own observations of their siblings. Leaders talk about things children with autism are good at and what is known about the genetics of autism, paying attention to the need to debunk myths (e.g. Can I catch autism? Did my parents cause it?).

### Activity: Walking in Another's Shoes (30 minutes)

Siblings are given opportunities to experience what is it like to have certain disabilities (i.e., walk in someone else's shoes).

## ★ Difficulty with Communication: Mime

Each sibling is instructed to communicate a phrase of words to the group without using words. Each sibling picks a phrase out of a hat (e.g., I am 11 years old; Do you like to play basket ball?). Each sibling acts out the phrase while the other siblings try to guess what each phrase is.

## **★** <u>Difficulty with Understanding: Headphones</u>

A volunteer child is sent out into the hall with a facilitator who instructs them to put on headphones. While they are putting on headphones, the group decides upon something that they are going to have the volunteer do. Leaders tell sibling that they are each going to tell the sibling what to do in a soft voice while the child has headphones on.

## ★ Difficulty with Learning: Shaping Game

Volunteer sibling is sent out into the hall to wait with a facilitator. While the volunteer waits in the hall, the leaders and siblings decide upon something that they would like volunteer sibling to do (e.g., pick up a book, stand in a corner of the room and touch a chair). Leaders tell siblings that they are not going to tell the volunteer that they want them to do anything, they are just going to clap when the sibling begins to get closer to the place that they want them to go or begins to do the thing that they want them to do.

Leaders lead siblings in a conversation about the experiences during the walking in another's shoes activity. Leaders encourage each sibling to take turns contributing to the discussion and assist children with making the connection between problem behaviors and frustration due to difficulties associated with having autism.

#### Activity: Same/Different (20 min)

Same/Different activity is repeated except that each sibling is instructed to create a list of the ways they are the same and different from their sibling with autism in five minutes. Then, each sibling presents 3 similarities and 3 differences to the group. Leaders ask

siblings whether it was more or less difficult to find similarities between themselves and their brother/sister or another sibling in the group.

## Wrap - Up (10 min)

Review the activities of the group and ask about favorite activities of the group. Leaders provide a preview of the next group. Each sibling is instructed to bring in a picture of themselves and their sibling to the next group. Flier is given to parents, which details the events of the group and asks them to help their child find a picture of themselves and their sibling for the next week.

## SibSTAR Session 3

<u>Goals:</u> Group formation, problem-solving strategies (part 1), identifying and expressing emotions

**Data Collection:** none

Agenda:

## Welcome Activity: Wall of Fame (10 min)

Each sibling decorates a frame that will hold a picture of themselves and his/her sibling. Each frame will be shared with the group and hung on a poster board with the words "Sibling Group Wall of Fame".

### Group 1: Review of Previous Week & Introduction of Theme (10 min)

Leaders ask siblings to recall the events of the last sibling group and assists them with recall (especially about characteristics of autism). Siblings review group rules and discuss anything interesting that happened since the last group meeting. Leaders encourage each sibling to contribute to the discussion.

Introduce the session's theme: emotions and how to deal with them. Talk about feelings as a normal part of growing up with a brother or sister with autism and discuss that all siblings will have some positive emotions (e.g., pride, love) and some negative emotions (e.g., anger, jealousy). Discuss with siblings that emotions are not right or wrong, good or bad; they are what they are.

## Activity: Strengths and Weaknesses (25 min)

Siblings write down 3 strengths and 3 weaknesses for themselves and their sibling. After completing the list, each sibling will share the framed picture of themselves and their sibling and talk about some of the strengths and weaknesses of their siblings. Leaders help siblings relate weakness of siblings to characteristics of autism and encourage them to talk about emotions that relate to the strengths and weaknesses of their sibling.

## <u>Group 2: Problem Solving Strategy – Didactic (25 min)</u>

Leaders discuss that positive and negative feelings are experiences by all siblings. Although negative feelings are a normal part of having a sibling with autism, they are a cue that there is a problem. Problem solving strategies can help siblings cope with negative emotions in a positive way. Discuss that problem solving strategies do not solve problems for siblings or tell them what to do but does help them solve the problem.

Problem Solving involves identifying that you have a problem and finding a solution to the problem.

Feelings are your cue to Problem Solve: COPE

- **★** Clarify the Problem
- **★** Option List
- ★ Pick the Best Idea
- **★** Evaluate

Work through a couple of examples with siblings, asking for sibling input while modeling problem solving for the siblings.

## Activity: Ball Game/Expressing Emotions (15 min)

Before beginning the ball game, have siblings come up with a list of all possible feeling words that they know (e.g., angry, sad, happy, lonely, guilty, jealous, proud, silly, excited . . .). In the ball game, the siblings toss a ball to each other in a circle. When the ball is tossed to them, the sibling or leader must talk about a positive or negative emotion they have had with their sibling. Leaders encourage siblings to express both positive and negative emotions and use a range of emotion words.

#### Activity: Role-Play Problem-Solving (25 min)

Leaders describe the procedures of a role-play. Each script describes a problem that siblings may encounter (e.g., brother with autism colors on homework or wrecks model airplane; sibling starting at a new school and friends make fun of her sister who has echolalia and hand flapping behaviors). The siblings use COPE to come up with a solution to the problem, and then the role play script is acted out with one leader (who plays the child with autism or the parent) and one student (who plays the sibling).

#### Wrap - Up (10 min)

Review the activities of the group and ask about favorite activities of the group. Leaders provide a preview of the next group and ask siblings to try and use problem solving strategies over the next week. Flier is given to parents, which details the events of the group.

## SibSTAR Session 4

<u>Goals:</u> Group formation, problem-solving strategies (part 2), identifying and expressing emotions

**Data Collection:** CPS & BST

Agenda:

#### Waiting Activity: (15 min)

Siblings begin to create a story about their sibling using index cards and photo books. Use published book "All About My Brother" as an example

### Group 1: Review of Previous Week & (5 min)

Leaders ask siblings to recall the events of the last sibling group and assist them with recall (especially about problem solving strategies). Siblings review group rules and discuss anything interesting that happened since the last group meeting.

#### Discussion of Problem Solving (15 min)

Ask siblings if they had any difficult problems with their siblings during the week. If they used the problem solving techniques, how did they work? Leaders encourage each sibling to contribute to the discussion.

Explain the concept of a buzzword. It is meant as a means of communicating to parents that you urgently need their attention. Have group members brainstorm and choose one buzzword that they can use with their parents. Emphasize that it is good to ask others for help when you are solving problems!

## Group 2: Penny Thoughts (20 min)

Introduce Penny Thoughts to siblings, an advice columnist who answers letters from siblings who have problems that they do not know how to solve. Explain that Penny Thoughts is on vacation, so that we would like their help to answer sibling's questions.

Choose letters from Penny Thoughts' bag: Work through a couple of letters with the group to identify the negative emotion involved and use the problem solving formula (e.g. sibling writes that he is unable to join boy scouts group because mom is unable to drive him to events because she has to drive brother to speech – anger, jealousy). Leaders should act out at least one scenario using COPE.

#### Activity: Role-Play Problem-Solving (25 min)

Have siblings act out solutions to Penny Thoughts' letters. Each script describes a problem that siblings may encounter (e.g., brother with autism colors on homework or wrecks model airplane; sibling starting at a new school and friends make fun of her sister who has echolalia and hand flapping behaviors). The siblings use COPE to come up with a solution to the problem, and then the role play script is acted out. Be sure to include separate acts for the problem and the solution, and have the group identify the COPE acronym as they go. This can be done by assigning the letters in COPE to different children.

#### Group 3: Keep Calm (20 min)

Leaders talk to siblings about the importance of keeping calm after a emotional trigger occurs. Ask siblings to think about how much more difficult problem solving is

when you are not calm. Introduce concept of striking when the iron is *cold*. Have siblings come up with some ways to stay calm after a trigger situation (walk out of room and take a break, counting down from 20, deep breathing, muscle relaxation).

Instruct siblings in simple deep breathing and muscle relaxation. Have siblings practice.

- **★** Deep breathing:
  - -Breathe in for 3 seconds while expanding stomach
  - -Breathe out for 5 seconds
  - -Emphasize the best way to breathe stomach should puff out when we breathe in, and go down when we breathe out.
  - -Explain the "smelling the pizza" analogy to get deep breaths.

#### **★** Muscle Relaxation:

Explain to siblings why we must first tense our muscles, and then relax. Use ROBOT vs RAGDOLL in this illustration.

Tense muscle group for 5 seconds

Release for 10 seconds

Muscle Groups: Hands, Arms, Feet, Legs, Stomach, Shoulders, Face Use recording of Ollendick progressive muscle relaxation tape

Knowledge Check: CPS & BST (leave about 15 minutes)

## Wrap - Up (10 min)

Review the activities of the group and ask about favorite activities of the group. Leaders provide a preview of the next group. Flier is given to parents, which details the events of the group.

## SibSTAR Session 5

Goals: Group development, behavioral skills training

Data Collection: none

Agenda:

## Waiting Activity: (10 min)

Siblings finish creating a story about their sibling using index cards and photo books.

## Group 1: Review of Previous Week & (10 min)

Leaders ask siblings to recall the events of the last sibling group and assists them with recall (especially about problem solving strategies). Siblings review group rules and discuss anything interesting that happened since the last group meeting. Ask siblings if

they had any difficult problems with their siblings during the week. If they used the problem solving techniques, how did they work? Leaders encourage each sibling to contribute to the discussion.

#### Activity: Favorites (15 min)

Have siblings interview one another about their favorite activities and the favorite activities of their sibling. Siblings share their findings with the group. Leaders ask siblings if many of their favorite activities overlap with the favorite activities of their sibling. Have them circle any activities which are shared in order to highlight them. Ask siblings what happens when they try to play with their brother or sister or join the activity that their brother or sister is doing. Encourage siblings to reveal frustration and disappointment associated with trying to play with their sibling.

## Group 2: What is Applied Behavior Analysis? (15 min)

Ask siblings if they know what applied behavior analysis is or if they have ever heard the term before. Help siblings create an age appropriate definition of applied behavior analysis: effective teaching strategy for children with autism. Describe major components for siblings: clear commands, lots of praise, and assistance when needed. Discuss benefits of learning applied behavior analysis for siblings: less frustration and disappointment during play with sibling.

#### Group 3: How to Deliver Play-Related Commands (15 min)

Leaders instruct siblings in components of delivering play-related commands: Obtaining attention; Delivering commands clearly (audible voice, articulate, simple, one at a time); and Using a variety of commands. Leaders discuss with siblings the benefits of using these strategies

Leaders act out a range of clear and unclear play-related commands. Siblings are asked to identify whether the command was clear or unclear.

#### Group 4: How to Use Social Praise as a Consequence (15 min)

Leaders instruct siblings in components of delivering effective social praise: Use social praise for every instance of compliance; Deliver clear and direct praise; Use a wide range of praise statements; and Use behavior-specific praise.

Siblings generate a list of praise statements that can be used during play.

#### Group 5: How to Respond When Child Does Not Comply (15 min)

Leaders instruct siblings in how to respond when child with autism does not comply: Wait 5 seconds; Provide feedback every time child does not respond; Using a variety of prompts; and Praising attempts.

Leaders model a variety of prompting strategies for siblings to rehearse.

#### Activity: Small Group Behavioral Skills Practice (15 min)

In smaller groups, children rehearse behavioral skills. The leaders play the role of the child with autism while the sibling uses behavioral strategies to encourage the child to play. Leaders and other siblings offer feedback after each role play.

## Activity: Human Knot (10 min).

Group forms a circle, puts hands out in center of circle, and grabs any hand they can to form a human knot. Then, the group must work together to untangle themselves without letting go of each other's hands.

## Wrap - Up (10 min)

Review the activities of the group and ask about favorite activities of the group. Leaders provide a preview of the next group. Flier is given to parents, which details the events of the group and how they help to facilitate the development of their child's behavioral skills.

## SibSTAR Session 6

<u>Goals:</u> Group development, behavioral skills training

Data Collection: BST

Agenda:

## Waiting Activity: Making T-Shirts (30 min)

Siblings make t-shirts about themselves and their families. Show them the sample shirt for ideas.

Group 1: Review of Previous Week & Discussion of Behavioral Skills Training (10 min) Leaders ask siblings to recall the events of the last sibling group and assist them with recall (especially about behavioral skills training). Review the 3 categories discussed last week: 1) initiating play 2) praise and 3) prompting. Siblings review group rules and discuss anything interesting that happened since the last group meeting. Ask siblings if they tried any of the strategies during the week. If they used the behavioral skills training techniques, how did they work? Leaders encourage each sibling to contribute to the discussion and reinforce attempts at using strategies.

#### Group 2: How to Respond to Problem Behaviors (10 min)

Leaders talk about strategies to respond to problem behavior. Siblings should learn that they should not intervene during a sibling's tantrums, aggressive, or disruptive behavior. Leaders ask siblings to talk about any situations when they did not know what to do. As a group, decide whether the situation was safe for the sibling to stay in or whether they should leave and find an adult.

Activity: Small Group Behavioral Skills Practice (15 min)

In smaller groups, children rehearse behavioral skills and come up with new activities they could try with their sibling. Each child will begin by brainstorming three new things they can play with their sibling. Leaders should have ideas on hand that might be appropriate (puzzles, blocks, Play Doh, play sets, games, tag, baseball, etc. . .).

In the role play, the leaders play the role of the child with autism while the sibling uses behavioral strategies to encourage the child to play the new games. Leaders and other siblings offer feedback after each role play. The group must use the skills from 1) initiating 2) praising and 3) prompting in all of their skits.

## Group 3: Talking to Friends (15 min)

Leaders ask the group to share experiences that they've had with friends or classmates asking about their brother or sister. Ask how children have responded in the past, and emphasize ways that they can explain autism to their friends.

### Group 4: Talking to Parents (20 min)

Leaders read a scene about a sibling who is having a problem talking to her parents. As a group, siblings and leaders discuss what the sibling can do to figure her way out of the problem. Siblings make a list of thing that they wish their parents knew about being a sibling and discuss ways they can talk to their parents about them.

#### Knowledge Check: BST

## Wrap - Up (10 min)

Review the activities of the group and ask about favorite activities of the group. Leaders provide a preview of the next group and instructing siblings to bring in something special to them to show off to the group (e.g., brownies if they are good at baking; sports trophies; art projects). Flier is given to parents, which details the events of the group and instructing them to help their children bring in something special to share with the group. Send home with "101 ways to praise your sib" and bookmarks with problem solving skills.

## SibSTAR Session 7

<u>Goals:</u> Group development, self-esteem and empowerment, prepare for group termination, discuss maintenance strategies.

<u>Waiting Activity:</u> Gratitude letter. Siblings will write a letter to the families, expressing thanks for the positive things that their families bring to their lives. These are collected and are given to families in the final session.

**Data Collection:** none

Agenda:

Group 1: Review of Previous Week & Discussion of Behavioral Skills Training (10 min)

Leaders ask siblings to recall the events of the last sibling group and assist them with recall (especially about behavioral skills training). Siblings review group rules and discuss anything interesting that happened since the last group meeting. Ask siblings if they tried any of the strategies during the week. If they used the behavioral skills training techniques or problem solving strategies, how did they work? Leaders encourage each sibling to contribute to the discussion and reinforce attempts at using strategies.

#### Activity: Show-Off Siblings (15 min)

Leaders discuss with siblings that even though they are all in the group because they have a brother or sister with autism, they are all unique and special. Each sibling presents something unique and special about self to the group (what they have brought from home). Leaders discuss with siblings that they are important and special even if they were not good at baseball / painting / math etc...

#### Activity: Why We're All Special (15 min)

Group members each write a nice comment about what they liked about every other member of the group. Leaders should also write what they liked about each group member. Each child gets to keep the comments about them compiled in a book to take home. Group members are encouraged to share special things that were said about them.

#### Group 2: Preparation for Termination (15 min)

In preparation for termination of the group, siblings think of strategies to help them cope with new problems that arise. Encourage siblings to think of different methods of bringing up difficult problems with parents and discuss keeping in touch with one another.

#### Activity: Professor for a Day (30 min)

Leaders help siblings prepare an educational presentation for their parents during the next sibling group. Leaders construct a list of all the activities during the groups and siblings choose which activities they would like to present about during the last group. Siblings then decide how they would like to present each aspect of the group.

#### Wrap - Up (10 min)

Review the activities of the group and ask about favorite activities of the group. Siblings present t-shirts to group. Leaders provide a preview of the next group. Flier is given to parents, which details the events of the group and explains that family members are invited to attend the final group meeting.

# SibSTAR Session 8 Final Group & Presentation

<u>Goals:</u> Create a sense of group conclusion; provide an opportunity for siblings and parents to practice collaborative problem solving to facilitate maintenance and generalization

<u>Data Collection:</u> None, but send home packets and schedule post assessment while families are present.

Agenda:

#### Waiting Activity (10 min)

Siblings meet with leaders to prepare for presentation.

#### Family Introductions (10 min)

Siblings, parents, and leaders introduce themselves to the group

#### Sibling Presentation: Professor for a Day (30 min)

Siblings present to parents on the activities of the group and what they learned from the group.

#### Parent Presentation (5 min)

Parents are invited to comment on the sibling presentation and discuss what they learned as a result of the sibling group experience.

#### Sibling-Parent Problem Solving Activity (25 min)

Each family is given a different scenario with a problem to solve and then present about to the group. Families are encouraged to act out how to collaboratively solve a problem.

#### Awards (10 min)

Each sibling is called to the front of the group and presented with a certificate of merit for completion of the sibling group. Each sibling is presented with their picture frame, "why I am special" book, story they created about their sibling, and a blank yearbook. Siblings also give their family members their gratitude letters at this time. Siblings are given the option to read the letters aloud to their family in front of the group.

#### Activity: Sibling Group Yearbooks (20 min)

Leaders discuss with siblings that this week is the last week that the siblings will meet together. Just like at the end of the school year, yearbooks are passed out to the siblings to have their friends sign. Leaders and siblings write notes to one another in the Sibling Group Yearbooks. Leaders encourage siblings to write down the positive things that they learned about each sibling, what they admire about them, and/or what they learned from them.

#### Party! (20 min)

Leaders share that they have enjoyed meeting everyone in the group and getting to know everyone. Leaders state that everyone worked hard and learned a lot from the groups and for that they deserve a party!

#### Appendix C

#### **Observational Codes and Scoring Rules**

### \*If you can't hear it, don't code it!"

#### **Delivering Play Requests**

- Count attending cues such as "look!", or "child's name". However, there must be at least a one second pause between attending cues for subsequent attending cues to count. For example, if a child says "Look. Hey Marty Look over here. Over here!" without a pause, this only counts as 1 tally. If a child says "Look. (pause). Hey Marty (pause). Look over here (pause)". This can count as three separate tallies.
- Tacts, or labeling items, do not count as a play request. Either does self-talk.
- Saying, or teaching information, does not count if it does not require the sibling to respond.
- Asking "What do you want to do?" counts.
- Do not count reprimands for behavior, such as "stop flapping your hands" or "sit nicely"
- If the same request is repeated with no additional prompt within 5 seconds of the first request, do not count the repetition. If it occurs after a five second pause, count it.
- You can code a "negative" play request that requires the child to do something "e.g., Don't put the car on the train tracks!" (requires the child to move car)

#### **Prompts**

- Any attempt to help the sibling. May be physical, verbal, or gestural.
- Does not necessarily need to follow an independent failed attempt.
- Prompting a child to elaborate on a response counts as a prompt
- Modeling a verbal response counts
- Providing the child with the answer counts

#### **Praising**

- Saying "OK" counts
- Count any positive statement toward the sibling following either a physical or verbal response. NOTE: for higher functioning siblings, praise may be more subdued (appropriately so) but still count it.

#### **Responding (Child with Autism)**

- Echoing the neurotypical sibling counts

- A nonverbal response counts! (E.g. when NT sibling says "stack the blocks" sibling begins to stack.
- Even if they respond incorrectly, it counts if they responded.
- A negative response such as "no" counts
- A response must clearly be directed toward their sibling.
- If a sibling imitates the NT sibling's actions, it counts
- Don't count repetitions of the same activity. (E.g. when the NT sibling says "stack blocks" and the child with autism stacks 20 blocks, count the block stacking activity as 1 response.
- Do not code self-talk as responding

#### **Initiations (Child with Autism)**

- Cannot be towards the examiner
- Any interaction with the examiner does not count
- Must be directed toward the sibling, and may be either verbal or physical
- Sibling with autism saying "look" to their sib counts.
- For higher functioning kids, they must be clearly oriented to their sibling.
- Do not code self-talk as initiating

# Appendix D

### **Project SibSTAR Parent Satisfaction Survey**

Please use the scale below to rate the statements regarding your child's participation in the sibling support group.

	1	2	3	4		5
	Strongly Disagree	Disagree	Neither agree nor disagree	Agree		Strongly Agree
1)	My child looked	d forward to the gro	oup sessions			
2)	I felt that the group was appropriate for my child					
3)	My child gained	d new skills from at	ttending the group			
4)	This sibling gro	oup addressed goals	that were important to me			-
5)	My child was fr	rustrated by the gro	up			-
6)	The sibling groueveryday life	up gave my child sk	kills he/she can use in			
7)		•	children's interactions as ng the sibling group			
8)	The sibling grou	up was effective for	r my child			-
9)	The number of	weeks the group rai	n was too long			-
10)	The number of	weeks the group rai	n was too short			-
11)	This sibling gro	oup was relevant for	r my family			-

Have you noticed any of the following changes in your children's behavior following					
your typical child's participation in the sibling support group? Please check all that					
apply.					
More cooperative play	More positive interactions				
More initiations for play	More language in interactions				
Less frustration in interactions	More time spent together				
More shared enjoyment	Other changes (please explain)				
Please briefly describe any other changes you may have noted in your child who					
participated in Project SibSTAR.					
Do you have any other comments about the sibling support group?					

# Appendix E

# **Project SibSTAR Sibling Satisfaction Survey**

Please use the scale below to rate the statements about your participation in the sibling support group.

	1	2	3	4	5
	Strongly Disagree	Disagree	Neither agree nor disagree	Agree	Strongly Agree
1)	I looked forward t	to the group session	ons		
2)	I felt that the grou	p was a good idea	a for me		
3)	I gained new skill	ls from the group			
4)	This sibling group	addressed goals	that were important to me		 -
5)	I was frustrated b	y the group			 _
6)	The sibling group	gave me skills I c	can use in everyday life		 -
7)	I feel like spendin because of the gro		other or sister is better		
8)	It felt good to kno	w other kids who	have a sibling with autism	n	 _
9)	The group was to	oo long			 -
10)	The group was too	o short			 -
11)	I would want to be	e a part of a siblin	g group again		 _

Have you noticed any of the following changes when you play with with your sibling	g
since your participation in the sibling support group? Please check all that apply.	

More fun playing	I feel like I can use my new skills
Easier to play with them	Other changes (please explain)
Less frustrated	
We spend more time together	

What was your favorite part about the group?

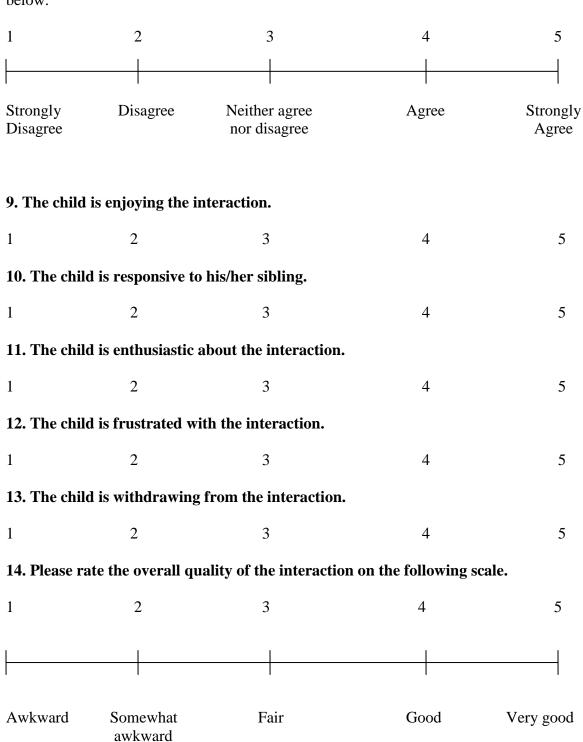
What was least favorite part about the group?

Is there anything else you'd like to tell us about being a SibSTAR?

# Appendix F

Sibling Interaction Social Validity TAPE #			Coder	Date
Please rate the provided below	_	ments about the <i>neuro</i>	otypical sibling usin	ng the scale
1	2	3	4	5
Strongly Disagree	Disagree	Neither agree nor disagree	Agree	Strongly Agree
1. The sib is	frustrated with	the interaction.		
1	2	3	4	5
2. The sib d	emonstrates em	pathy for his/her bro	ther or sister.	
1	2	3	4	5
3. The sib is	responsive to hi	s/her brother or siste	er	
1	2	3	4	5
4. The sib is	supportive of hi	s/her brother or siste	er	
1	2	3	4	5
5. The sib is	enthusiastic abo	out playing with his/h	ner brother or sist	er
1	2	3	4	5
6. The sib is	directing his/he	r brother or sister's	actions.	
1	2	3	4	5
7. The sib is	enjoying the int	eraction.		
1	2	3	4	5
8. The sib is	acting intrusive	ly.		
1	2	3	4	5

Please rate the following statements about the *child w/ASD* using the scale provided below.



#### Appendix G

#### CHILD SATISFACTION SURVEY: QUALITATIVE DATA

#### WHAT WAS YOUR FAVORITE PART ABOUT THE GROUP?

PS01: Amy, Miss Irene, and Miss Mariana teaching me.

PS02: My favorite part was shaping game, name game and bingo.

PS03: The pizza, arts and crafts.

PS04: Pizza.

PS05: I get to talk to people who understand me completely.

PS06: The games and fun.

PS07: I liked everything about the group

PS09: The discussion we had at about 5:30-6:00. That time is when we talked about new skills to play with any sibling and learned important facts about autism.

PS10: Being and hearing about siblings or people with autism, like me.

PS11: I liked when we acted out the letters

PS12: Yearbooks

PS13: Learning new skills about how to play with my brother and the fun crafts

PS15: Aunt Blabby

PS16: The last assessment

PS17: My favorite part of the group was that I got pizza and lemonade, but also that I got to do new cool fun things.

PS18: That it helped me and that in every single class we laughed.

PS19: My favorite part about the group was that it was fun, educational and great friends.

PS20: Learning about COPE, played the name game.

#### WHAT WAS YOUR LEAST FAVORITE PART ABOUT GROUP?

PS01: Leaving.

PS02: Talking about ADHD

PS03: Nothing!

PS04: Nothing

PS05: Nothing.

PS06: Nothing

PS07: None

PS09: It was too short, I would have liked it if it was a year long.

PS10: Nothing

PS11: Doing the paperwork

PS12: Doing nothing

PS13: The role plays

PS15: Play ideas

PS16:?

PS17: I'm not sure about my least favorite part, but if I had to I would say/write I had no least favorite part.

PS18: Nothing

PS19: PINK LEMONDADE!!!!

PS20: Nothing

# IS THERE ANYTHING ELSE YOU'D LIKE TO TELL US ABOUT BEING A SIBSTAR?

PS01: No, not really.

PS02: I like the pizza.

PS03: N/A

PS04: No

PS05: It was lots of fun.

PS06: It's awesome and I would like to join again

PS07: None

PS09: That I liked it a lot and want to come back- it helped me a lot. I might have liked it more though if it was more specific because the things were very general. Like the playing with your sibling would be different for a 2 year old and 9, 12 year old.

PS10: I loved Ms. Amy, Ms. Mariana, and Ms. Irene because they were so very nice!

PS11: I liked meeting the people.

PS12:

PS13: I had a lot of fun

PS15: I love to be me!

**PS16: No** 

PS17: The Sibstar groups are amazingly fun and cool, also if anyone wants to join they should because they would have a FABMOUSE time! I would like to join again!

PS18: It is really hard to be a sibling and even more hard to be a sibling with a brother who has Asperger's. The group has helped a lot.

PS19: Nope! Sorry!

PS20: left blank.

#### Appendix H

#### PARENT SATISFACTION SURVEY: QUALITATIVE DATA

# PLEASE BRIEFLY DESCIRBE ANY OTHER CHANGES YOU MAY HAVE NOTED IN YOUR CHILD WHO PARTICIPATED IN PROJECT SIBSTAR.

Ps01: He encourages his brother and praises him a lot more. He's been much more empathetic towards his brother.

PSO2: My child seems more mature and confident in everything he does. When playing with his brother with Autism, he will use the strategy he learned in group.

PS03: (Nothing)

PS04: he definitely enjoyed the group. He liked going and I could see he was happy with it. He is now explaining things to his brother instead of getting mad when he doesn't understand.

PS05: It helped her feel more "typical", with a group of kids that live same reality she lives. She told me she was never before with so many kids that siblings with autism. And that was NEW for her since most of her friends have typical siblings. — she felt great coming! She learned to cope better with daily situations.

PS06: Learn more things about brother and more ways to cope with them.

PS07: He was eager to share the things he learned of the sibling group. When I get upset he shows me the ways to cope with the feelings.

PS09: A little less frustration and anger when dealing with his sibling. How to handle anger and resentment. An understanding of what autism is. He was always respectful of other people and kids, but this group gave him more complex, holder "approach to understanding autism and other people. He has played and interacted with sibling in the past, that slowed down, but it is starting again.

PS10: X seems more confident in initiating friendships; I think the group gave her a boost in confidence + self-esteem. It helped her to realize she is not alone. This was a great experience

PS11: To soon to tell. Happy he did it.

PS12: They have had some very positive interactions over the summer, but in a flash it could change to fighting. There are many things we wish out son would just ignore about his brother, because his reactions only fuel the fire.

PS13: (nothing)

PS14: (Nothing)

PS15: X has become more eager to get her brother to work and be with her at least watching what she does, she imitates directing her brother to do things appropriately and who holds his hands and talks more about things around to make him comfortable.

PS16: he has more patience for X. Now is because he understands he understands her better not just because I tell him. He makes it a point to make eye contact. He tolerated embarrassment a little bit better.

PS17: Sometimes she used to get steered from the situation but now she is learning how to handle them.

PS18: She is more tolerant of her brother. She is more forgiving of <u>herself</u>. She will remove herself from frustrating interactions and explain that she needs a few moments.

PS19: (nothing)

PS20: X's first opportunity to learn about disability, autism related to his brother. He described to his parents about his new knowledge of autism. He is only 8 years old and needs more time to understand his brothers condition. But this sibling group sessions were a solid platform for his future learning. It is very difficult to answer this question since X is 4 ½ years younger than his autistic brother. X is still very scared of brother due to his brother behavior. So the interaction between them is very minimal.

# DO YOU HAVE ANY OTHER COMMENTS ABOUT THE SIBLING SUPPORT GROUP?

PS01: Great program

PS02: I feel that this was a very well-run group. All the kids played well together. I just wish that there's a way they can keep in touch with each other after the group ended.

PS03: (Nothing)

PS04: It was a really good idea. It's hard for parents to explain Autism. I think he has a much better understanding now.

PS05: In the move of my family; we are very grateful of this opportunity for her. Hoping a group like this, running continuously could be implemented, it could be beneficial for many kids.

PS06: (nothing)

PS07: I would like to thank you all to have the support group for the siblings. It helps a lot for my son to know he's not alone.

PS09: Excellent, well-run, and thank you! Good to meet other going through similar things as this was his first sibling group. More groups please!

PS10: I didn't see much change in the interacting with her sister. I think there should be a couple of sessions with both Autistic and Typical children and instruction on how to interact + engage the disabled child rather than just role play. Engaging both in play together would be wonderful.

PS11: The last night of performance waited to long with sibling. My child with Autism became a little frustrated and had a hard time waiting. It was a lovely program.

PS12: We are very happy to have had this opportunity for our son. It is really important to us for him to know that other kids are facing similar challenges with their siblings even though we have not seen a qualifiable change in behavior.

PS13: (nothing)

PS14: (nothing)

PS15: the group was indeed a good initiative by the DDDC to help siblings interact better with special kids and got tips to deal with problem behaviors, encourage calmness and compliance. We expect that in further groups they get to learn more things to help out special siblings as they grow and face more challenges.

PS16: It was very good for him, he is reserved but he shared a few things with us that he learned about Autism. Most of all he learned that he is not alone, a lot of other kids shared his frustrations and understood him.

PS17: Ms. Amy is the best teacher. She is very great and worked hard with the kids. I am grateful to the whole sibling support group. Thankful for teaching lessons- lemon squeezing and jaw breaker to reduce the stress. These techniques are wonderful for them to handle the stressful situation.

PS18: Our daughter is in a very precarious "pre-teen" phase. We would love to find her some peers closer to her age of 11 or 12.

PS19: The group efforts are really appreciable. Good initiative for the typical child to understand and share feeling with the rest of the group and sibling. Thanks a lot.

PS20: Great job helping kids. It was amazing to see such a passion towards kids.