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Caryn Terril '00  
*Illinois Wesleyan University*

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Psychosocial Effects of a Parent-Child Communication Activity on Siblings of Children  
with Autism  
Caryn Terril  
Illinois Wesleyan University  
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### Abstract

The goal of the project was to decrease the worries of siblings of children with autism through a parent-child communication activity. Other goals of the project were to increase the accuracy of the parent's perception of the child's worries and to increase the quality of parent-child autism specific communication. The perceived effectiveness of the intervention as well as general family communication were also explored.

Participants were recruited through school districts and support groups serving families of children with autism. 15 parents and 16 siblings of children with autism, between the ages of 6 1/2 and 13, participated in this study. Half the child-parent pairs were randomly assigned to the intervention group, which completed a workbook activity designed to enable the siblings to talk about their autism-related worries with their parents. The other child-parent pairs were assigned to a placebo-control group, which played games together. The hypotheses received marginal support for decreasing worries and for increasing the accuracy of parent's perceptions of child's worries.

## Psychosocial Effects of a Parent-Child Communication Activity on Siblings of Children with Autism

Autism is a developmental disorder characterized by impairment in social interactions, communication, and behavior. Autism affects approximately one in every 1,000 people (Bryson, Clarke, & Smith, 1988), and it is estimated that there are over half a million people in the United States with autism or another pervasive developmental disorder (Dorman & Lefever, 1999). Autism not only affects those diagnosed by the disorder, but it also affects their teachers, parents, extended family members, and typically developing siblings. The few studies that have investigated sibling relationships in which one child has a developmental disability have resulted in conflicting evidence (Cuskelly & Dadds, 1992; McHale, Sloan, & Simeonsson, 1986), and very few of these studies have focused specifically on siblings of children with autism. Nonetheless, certain risk factors have been identified for siblings of children with autism, and interventions have been designed to help siblings who are at risk for adjustment problems (Bagenholm & Gillberg, 1991; McHale & Gamble, 1989). The proposed research project will explore the effects of a parent-child communication activity on siblings of children with autism.

To provide the rationale for the proposed research, the following sections review studies on the problems faced by typical siblings living with a developmentally disabled child and on the interventions designed to alleviate some of these problems. First, the sibling and family experience of living with a developmentally disabled child will be reviewed. Second, different types of interventions intended to help siblings, specifically behavior modification and support groups, will be discussed along with the limitations of this research. Finally, the current study and hypotheses will be described.



## Sibling and Family Experiences of Living with a Disabled Child

### Psychosocial and Behavioral Adjustment of the Typical Sibling

It has been suggested that having a developmentally disabled child in a family places more stress upon the family. For example, the family must decide how to deal with and take care of the developmentally disabled child. Consequently, siblings may assume more responsibilities, which may result in more stress. Siblings of developmentally disabled children spend more time in household chores and care giving duties than siblings of typical children (McHale & Gamble, 1989). These siblings also may feel burdened by the extra responsibility of caring for their developmentally disabled brother or sister (McHale, Sloan, & Simeonsson, 1986). Perhaps as a result of this added responsibility and burden, siblings of developmentally disabled children reported more loneliness for themselves and anxiety about the future for their disabled brother or sister than did siblings of typically developing children (Bagenholm & Gillberg, 1991).

Siblings of developmentally disabled children may have more worries than siblings of typical children. For example, McHale and Gamble (1989) found that siblings of developmentally disabled children had higher levels of anxiety than siblings of typical children. More specifically, Kuncé & Groh (1999) found that siblings of children with autism endorse more worries on a scale designed to measure specific autism-related worries than do siblings of typically developing children. They tended to worry more about public reactions to their brother or sister, danger from their brother or sister, and their brother or sister's well-being. Furthermore, the association between parent and child report of child worries was low, suggesting that parents were not very accurate reporters of their child's worries.

Parents may have special concerns about the typical sibling. For example, mothers of disabled children reported more often than mothers of typical children that the typical male sibling was depressed or aggressive (Lobato, Barbour, Hall, & Miller, 1987). This study also found that sisters of disabled children were more likely to be considered

aggressive by their mothers than were sisters of typical children. Mothers of children with Down syndrome were more likely to believe that their typical children had emotional or behavioral problems (Gath & Gumley, 1987). It appears that in some cases the parents' concerns have been accurate. That is, Gath and Gumley (1987) found that siblings of children with Down syndrome were more likely to have deviant behaviors if their developmentally disabled brother or sister was also deviant.

Even though siblings of developmentally disabled children tend to have more responsibilities, more worries, and occasionally more behavior problems than siblings of typical children, it does not necessarily mean that the majority of siblings of developmentally disabled children will have adjustment problems, such as developing negative self-concepts, a lower level of achievement, and misbehaving in school and at home. For example, Breslau, Weitzman, and Messenger (1981) found that siblings of disabled children did not differ from siblings of typical children on overall psychological adjustment. Mates (1990) also found that siblings of autistic children did not differ significantly from siblings of typical children on adjustment measures. Besides being very similar to siblings of typical children in psychological adjustment, siblings of disabled children have been found to engage in social and play behaviors similar to siblings of typical children (Caro & Derevensky, 1997).

Further, some studies have found that siblings of disabled children can benefit from having a disabled brother or sister. Grossman (1972) found that siblings of developmentally disabled children were described by their parents as being more compassionate, understanding, and tolerant than siblings of typical children. Siblings of autistic children have also been found to have a more positive self-concept than siblings of typical children (Mates, 1990).

In summary, siblings of developmentally disabled children assumed more responsibilities, have more worries, and may exhibit more behavioral problems than siblings of typically developing children. However, they may also benefit from their

developmentally disabled brother or sister. The siblings of developmentally disabled children do not differ on overall psychological adjustment and tend to be more understanding, compassionate and tolerant than siblings of typically developing children. Nonetheless, their psychosocial and behavioral experiences differ in many ways from siblings of typically developing siblings.

### Family Interactional Patterns

Having a child with a developmental disability may also affect how the entire family members interact with one another. Some parents have noticed that a developmentally disabled child can positively affect the sibling relationship. For example, mothers of developmentally disabled children described the sibling relationships more positively than mothers of typical children (McHale, Sloan, & Simeonsson, 1986).

However, the quality of the relationship and interactions between the developmentally disabled child and the typical sibling may differ from typical siblings' relationships and interactions. With the added care giving duties, there may be less time for the siblings to engage in ordinary sibling activities with their disabled brother or sister. Their brother or sister's disability may also limit the amount of time and the degree to which the siblings interact or play with them. For example, children with autism interacted less with their siblings than did children with Down syndrome (Knott, Lewis, & Williams, 1995). Many of these interactions between siblings and their developmentally disabled brother or sister were initiated by the typical sibling.

Besides having a different type of relationship with their developmentally disabled brother or sister, typical siblings may not interact as much with their parents or receive as much parental support as siblings of typical children. For example, Satterwhite (1978) found that the well-being of the physically handicapped child determined family life and that the needs of the typical siblings were placed behind the needs of the handicapped child. When mothers did interact with the typical child, they tended to deliver twice as many commands and directions to the typical child than mothers without developmentally

disabled children (Lobato, Miller, Barbour, Hall, & Pezzullo, 1991). Siblings of mentally retarded children also reported feeling dissatisfied by the inadequate attention from their parents (Bagenholm & Gillberg, 1991). McHale and Gamble (1989) also found that siblings with a developmentally disabled brother or sister perceived that their mothers treated them more negatively compared to the perception of siblings without a developmentally disabled brother or sister.

Besides receiving less parental support, the typical sibling may be unintentionally used by the parents to make up for deficits of the disabled child. For example, parents tended to have more expectations for their typical children than their developmentally disabled children (Gath & Gumley, 1987). The siblings also reported that they feel this pressure from their parents to excel and to make up for their disabled brother or sister, and they believed that their parents' expectations are higher than what is appropriate for their age and capabilities (Sullivan, 1979; Klein, 1972; Hayden, 1974).

Further, parents may not be communicating enough with the typical siblings about their developmentally disabled brother or sister. Kaplan and Fox (1968) found that parents were sometimes reluctant to talk with their typical children about their disabled brother or sister and that retardation was not openly talked about in some families. More recently, Bagenholm and Gillberg (1991) found that 55 percent of the siblings of autistic children in their sample lacked the words needed to explain what was wrong with their brother or sister and 35 percent felt that they could only talk with someone outside the family about their developmentally disabled brother or sister. However, communication between parents and siblings about their developmentally disabled brother or sister can be helpful. If the parents are open and communicate about the child's disability with the typical siblings, the typical siblings may be better adjusted than if the parents never discussed their child's disability (Grossman, 1972; Gogan & Slavin, 1981; Lavine, 1977).

### Variability in Sibling Adjustment

Although siblings of developmentally disabled children may not necessarily exhibit overall differences in psychological adjustment in comparison with siblings of typical children, there appears to be greater variability in the adjustment in siblings of developmentally disabled children. For example, McHale, Sloan, and Simeonsson (1986) found that siblings of children with autism and siblings of children with mental retardation did not differ, on average, from siblings of typical children in terms of their attitudes toward their sibling and their perception of their sibling's role in the family. However, after a closer analysis, they found that the siblings of children with autism and mental retardation had a wider range of answers. These siblings tended to be at one extreme or the other when describing their relationship with their developmentally disabled brother or sister; whereas, the siblings of typical children tended to gravitate around the mean.

Given that there are siblings of disabled children who report anxiety, loneliness, depression, increased responsibilities, increased parental expectations, decreased parental support, and interactional differences with their sibling, various types of interventions may help alleviate these problems. As a result, various sibling training programs, workshops, and support groups have been established to help siblings of developmentally disabled children talk about and overcome some of the problems they face while living with a developmentally disabled brother or sister.

#### Interventions for Siblings of Children with Autism

##### Behavior Modification

One type of intervention for improving sibling relationships has been to teach the sibling how to modify their brother or sister's behavior. College-aged siblings have been successful in acquiring skills to teach their developmentally disabled brother or sister basic domestic and self-care skills (Lobato & Tlaker, 1985). It has also been shown that siblings as young as eight years old can be trained to modify their brother or sister's

behavior. Celiberti and Harris (1993) were able to teach three separate 8 to 10 year old siblings of autistic children various behavior skills to use while playing with their autistic brother or sister. They found that the individual siblings became more comfortable playing and interacting with their autistic brother or sister. Similarly, Schreibman, O'Neill, and Koegel (1983) taught behavior modification skills to three separate 8 to 13 year old siblings of autistic children and found that after mastering these skills, the individual siblings were able to produce improvements in their brother or sister's behavior that allowed the siblings to interact more. These siblings also reported an increase in positive statements about their relationship with their autistic brother or sister after completing the training sessions.

Group behavior modification programs have also attempted to enhance interactions between autistic children and their siblings. Clark, Cunningham, and Cunningham (1989) found that role playing, problem solving, and group contingency measures enabled siblings to learn to attend to their autistic brother or sister, to avoid coercive strategies with their autistic brother or sister, and to use sign language with their autistic brother or sister. This group behavioral program also found that after training, the autistic child's negative behavior decreased as his or her sibling interacted more with them. In addition, parents reported an improvement in sibling interactions and a decrease in sibling conflicts at home. Lobato (1985) was also able to use role-playing, modeling, coaching, and differential feedback in a workshop to enhance preschool siblings' knowledge of their brother or sister's disability.

In summary, the behavior modification studies have been able to teach siblings of children with autism skills and that these behaviors, in turn, appear to improve their play and social interactions with their autistic sibling. However, behavior modification is very time consuming, requires skilled trainers, and does not specifically address parent-child relationships.

### Support Groups

Besides behavioral programs, sibling support groups have been established to help siblings cope with living with a developmentally disabled child. Over 30 years ago, Kaplan and Fox (1968) began a support group for siblings to help them share their experiences of living with a developmentally disabled child. Other support groups, such as Sibshops, allow siblings to obtain information about their sibling's disorder and to obtain peer support (Meyer & Vadasy, 1994). These support groups work under the premise that siblings can benefit from discussing negative interactions they are experiencing with their developmentally disabled sibling. Wilson, Blacher, and Baker (1989) found that a majority of the parents and typical siblings that they studied were interested in some sort of sibling support group.

Siblings report that one of the most important aspects of a support group is how to improve their relationships with their developmentally disabled brother or sister. Dyson (1998) found that learning about their brother or sister's disability and how to interact with them were a favorite part of a support group. In another support group, siblings and parents reported that the support group was a positive experience in which siblings could openly talk about their problems with siblings of other disabled children (Crouthamel, 1988).

Unfortunately, not all support groups have resulted in improvements in sibling relationships. Kaplan and Fox (1968) found that parents were sometimes reluctant to allow their children to participate in support groups. The parents expressed concern about the siblings revealing things the family tries to keep quiet. McLinden, Miller, and Deprey (1991) also found that their workshop only had limited benefits. Although the siblings enjoyed the workshop and the mothers reported some improvements in the sibling relationship, the workshop did not change the siblings' attitudes, self-concept, knowledge, or problem behavior as measured on pre- and post-test analyses.

### Flaws and Gaps in Research

Because the support group research is most relevant to the proposed study, a detailed review of the limitations of this body of literature is needed. Five major limitations characterize the support group research studies: lack of objective measures, lack of control groups, small sample size, heterogeneous group membership, and lack of parental involvement.

First, although many interventions are successful, it is difficult to determine the degree of success because many interventions have not involved objective measures of child outcomes. For example, Crouthamel's (1988) support group was considered a success based on the facilitators subjective opinions and informal discussions with the participating siblings. Kaplan and Fox (1968) also felt that their support group was successful although they did not report how they assessed this success. Dyson (1998) used open-ended questions to determine if her support group was successful. Siblings were asked what they had learned from the experience and what they had liked most about the group. Because there is no information available on the reliability and the validity of her assessment technique, the effects of support groups on sibling learning and adjustment are not clear.

Another problem with the support group research is the lack of comparison or control groups. Only McLinden, Miller, and Deprey (1991) involved a control group in their study, and this was due to the fact that half of their sample could not participate in the actual support group. The other studies (Fox and Kaplan, 1968; Crouthamel, 1988; Dyson, 1998) did not contain a control group.

A third problem with many of the interventions is that the sample sizes were extremely small. McLinden, Miller, and Deprey's (1991) support group consisted of six siblings in the support group and another five siblings in the control group. Fox and Kaplan (1968) also had very few siblings, 5 to 14 per group, in their support groups. Crouthamel (1988) did have twenty siblings participate in her support group. However,



because she initially sent out 1500 letters advertising the support group, this group may not be representative of the larger population of families. Fortunately, Dyson (1998) was more successful in recruiting participants, as forty-five siblings participated in a support group over three years.

Fourth, many of the support groups were not exclusive to autism. Most of the support groups were made up of siblings of children with various disabilities. For example, Dyson's (1998) support group consisted of siblings of children with mental retardation, autism, attention deficit disorders, communication disorders, learning disorders, sensory impairment, developmental delays, physical handicaps, and unspecified disorders. The other support groups ranged from a group for siblings of retarded children (Kaplan & Fox, 1968) to a group for siblings of developmentally disabled children (Crouthamel, 1988) to a group for siblings of mentally retarded, physically disabled, or multiple disabled children.

Finally, in all of the reviewed studies, parents were not truly involved in the interventions. The siblings were able to talk with other siblings about their problems but were not able to talk to their parents about their concerns in the support group context. Occasionally the parents were involved in the first meeting of the support groups (Kaplan & Fox, 1968; Crouthamel, 1988), but this initial meeting was more of an information session about what the support group would entail rather than the actual support group. Also, the parents met separately from the siblings in the initial meeting of one study (Kaplan & Fox, 1968). Some studies also included the parents in the final meeting of the support group, but this final meeting was usually a party rather than an actual meeting (Dyson, 1998; Crouthamel, 1988).

### Current Study

The current study tested the effectiveness of a parent-child communication activity, specifically a workbook about autism-related worries, to alleviate the worries of siblings of children with autism. The participation of parents in this intervention was

considered critical for many reasons. Parents of children with developmental disabilities tend to inaccurately report their typical child's worries (Kunce & Groh, 1999), report more emotional and behavioral problems in their typical children (Gath & Gumley, 1987), give their typical children less attention (Bagenholm & Gillberg, 1991), and have more expectations of their typical children (Gath & Gumley, 1987). Despite this, parents have not been involved in previous sibling-focused intervention studies (Crouthamel, 1988; Kaplan & Fox, 1968; McLinden, Miller, & Deprey, 1991). In contrast, the collaborative completion of the workbook in the proposed study allowed parents and children the opportunity to discuss the child's worries.

There were several differences between this study and the previous support group studies. First, this study was a brief intervention, lasting two rather than several sessions. Second, this study involved a treatment and a placebo group, as well as pre- and post-testing using objective measures. Further, an exclusive focus on siblings of children with autism and the active involvement of their parents in the intervention also made this study unique.

On the basis of the previous research, four primary hypotheses were developed. First, it was hypothesized that completion of a parent-child communication activity would decrease worries in siblings of autistic children more than participation in a placebo activity. Second, it was hypothesized that participation in the treatment condition versus the placebo condition would increase the accuracy of parent's perception of their child worries. Third, it was hypothesized that the communication activity would be perceived as more effective by parents than the placebo activity. Finally, it was hypothesized that the communication activity would increase autism specific communication in the family but not necessarily increase general communication in the family.

## Method

### Participants

Recruitment of participants occurred by sending a descriptive flyer to local autism support groups and school programs. The support groups and school programs helped sponsor the project by providing a location for the experimental sessions and by mailing an announcement letter to the families. 300 letters were distributed through various support groups and school programs. Sixteen typically developing siblings and their parents participated (See Table 1 for demographics). The participating children were primarily elementary school age ( $M = 9.12$ ,  $SD = 2.19$ ), female (69%) and Caucasian (94%). Also, no children were above the clinical cutoff point for problem behaviors according to the Child Behavior Checklist. All children had a sibling diagnosed with one of the following autism spectrum disorders: autism ( $n = 3$ ), high functioning autism/Asperger's disorder ( $n = 6$ ), pervasive developmental disorder-not otherwise specified/autistic-like tendencies ( $n = 6$ ). According to the Gilliam Autism Rating Scale, most autistic children were considered to be diagnosed with mild or moderate cases of autism. Most of the autistic siblings were boys (87%). One primary caregiver per child also participated in the study. Of the participating adults, most were women (80%) and were the birthparent of the typical child (93%). All adults also had some college education ( $M = 15.67$ ,  $SD = 1.84$ ).

### Measures

Child Measures. All child measures administered as pre- and post-tests. Children completed the Autism Worries Survey (AWS; Kuncé & Groh, 1999). The questionnaire consisted of 46 items and yielded a total score as well as five subscale scores associated with different areas of concern: self-focused, sibling-focused, family-focused, social, and specific autism worries. For this study only the total number of worries was examined because no hypotheses were made about the specific subscales. Each item consisted of a statement in the format "Some kids worry that..." and was accompanied by four simple

drawings of a child's face ranging from very calm to very worried. The child responded to the statement by placing a sticker next to the face that best describes how he or she felt (See Figure 1 for AWS format and sample items).

Children also completed the Parent-Adolescent Communication scale (PAC; Barnes & Olson, 1982). This 20-item self-report questionnaire used a 5-point Likert type scale to assess the amount of openness in the family, who family members confide in, and the extent of problems in family communication. Despite the measure's name, it has previously been used with elementary school children (Knight, Virdin, & Roosa, 1994). We amended some items to simplify the language and concepts for this study. For example, the original item "My mother/father has a tendency to say things to me which would be better left unsaid," was adapted to read "My mother/father sometimes says things to me that they shouldn't."

Children also completed the Autism Communication Scale (ACS) developed for this study. This scale included 10 items and was presented in a format identical to that of the PAC scale. These items assessed parent-child communication specific to the child's autism-related worries, such as "I am comfortable talking to my parent about my brother/sister with autism." This scale turned out to have inadequate internal consistency (Cronbach's  $\alpha = .07$ ); therefore, the data from this scale was not analyzed.

At the end of each activity, children completed the Child Activity Evaluation Form. This two item self-report questionnaire used a 4 point Likert type scale to assess the children's perceptions of the activities. Specifically it asked the children, "How much did you like being with your parent during this activity?" and "How did you feel about the activity?"

Parent Measures. The parent accompanying the child completed a brief demographics questionnaire about themselves and their children. Parents also completed the Child Behavior Checklist (CBCL; Achenbach & Edelbrock, 1983) on the typical sibling and the Gilliam Autism Rating Scale (GARS; Gilliam, 1995) on the child with

autism. The CBCL is a standardized measure that assesses children's internalizing and externalizing problems and yields a profile of a child's behavior in comparison to other children of their age and gender. The GARS is a standardized parent-report measure of autism symptoms that provides an indicator for the severity of the autistic child's behaviors.

Parents also completed the following measures as pre- and post-tests. They completed versions of the Autism Worries Survey and the Autism Communication Scale that paralleled the child versions of these measures. Items on these measures were reworded so the parents answered in terms of their own perspective. For example, the child's version of the AWS stated, "Some kids worry that they might catch autism from their brother or sister. Which one are you most like?" On the parent version, this question was stated as "How much does your child worry that he/she might catch autism from his/her sibling." Similarly, on the ACS the child statement "I talk a lot to my parent about autism" was reworded as, "My child talks a lot to me about autism."

Parents also completed the communication subscale of the Parent Child Relationship Inventory (PCRI; Gerard, 1994). This 23-item self-report questionnaire used a 5-point Likert type scale to assess general quality of communication between parents and children. The communication subscale consisted of 9 questions, such as "I feel that I can talk to my child on his or her level."

After the activities, parents completed an adapted version of the Treatment Evaluation Inventory-Short Form (Kelley, Robert, Gresham, & Elliot, 1989), a frequently used measure assessing perceptions of intervention techniques. This 6 item self-report questionnaire used a 5 point Likert type scale to assess the parent's perceptions of the effectiveness and the acceptability of the activities, and the degree to which they enjoyed the activities. Only the total score was examined for analysis.

## Procedures

General Procedures. The parent-child pairs participated in two 2-hour sessions that were held two weeks apart. The participants were randomly assigned to either the intervention or placebo control group.

On the first day, the parents and children met together to complete the informed consent and assent forms. Then, the parents and children met in separate rooms to complete the pretest measures. Next, the intervention and control groups met in separate rooms to complete the communication activity or play games together. Following approximately 25 minutes of activities, parents and children completed a brief questionnaire evaluating the activities, and the researchers instructed the parents and children to complete at least one homework assignment together during the week between sessions. Also during this time, the investigators made a phone call to all the participants to remind them to complete their designated activity and to answer any questions or concerns that they may have had at this time.

At the beginning of the second session, parents and children met separately to complete the post-test measures. Then the intervention and control groups met separately for the active part of the study. At the end of the second session, parents and the siblings again briefly evaluated the activities.

Experimental Procedures. Parent-child communication was manipulated by having the participants either collaboratively complete a workbook or by having the participants play games together. In the intervention group, the parent and child completed a workbook designed to allow the siblings to talk about their autism-related worries with their parents. The first part of the workbook contained 33 items that were very similar to the items contained in the AWS. The second part of the workbook contained semi-structured activities to help parents and children discuss and develop coping techniques for different concerns, such as coping with special autism worries (see Figure 2). The parents were given a instructional handout with 7 tips for using the

workbook and for interacting with their child during this time. For example, parents were prompted to "Use encouraging responses to help your child better explain his or her worries (e.g., smiles, nods, "mm-hmm's", "Tell me more")." (See Appendix for Parent Instruction Handout: Tips for Completing the Autism Workbook with your Child).

In the placebo-control group, parents and children played together, selecting from games provided by the investigators, such as cards, drawing, and popular board games. Parents were asked to stay focused on the games and not to talk about autism worries unless their child asked about autism. Parents also received an instructional handout with 7 tips on the general instructions for completing this activity and for interacting with their child during this time. This tip sheet, developed to parallel the one given in the intervention condition, prompted parents to use techniques similar to nondirective play therapy, such as letting the child lead and encouraging the child while playing. (See Appendix for Parent Instruction Handout: Tips for Games Activity).

## Results

### Descriptive Analyses

On the demographics questionnaire, some parents in this study reported that they had never attended a support group (36%) while other parents reported attending support groups once a month (29%). Most parents also reported that their child had never attended a sibling workshop or support group (94%). Prior to participating in this study, 45% of parents also reported speaking to their child about twice a month about autism. Another interesting finding was that most of the children in this sample reported, during pre- and post-tests, that they did have someone to talk to about their sibling with autism (88%) and most of the time it was their parent (see Table 2 for support group and prior autism communication information).

### Child Worries

To assess whether or not the workbook decreased the worries of siblings of children with autism, a mixed within-between 2x2 ANOVA was computed on the Autism

Worries Survey-child report total score. The ANOVA yielded a nonsignificant interaction effect,  $F(1, 10) = .73$ , ns, as well as a nonsignificant main effect for activity,  $F(1, 10) = .004$ , ns. There was, however, nonsignificant trend for the main effect of time on the total number of child worries,  $F(1, 10) = 3.64$ ,  $p < .10$ . An examination of the means showed that, on average, children reported fewer worries after the parent-child activities than before (see Table 3 for means and standard deviations).

Similarly, a mixed within-between 2x2 ANOVA was computed on the AWS-parent report of their child's worries. Neither the interaction of activity and time, nor the main effect for activity, nor the main effect for time were significant. Although not significant, the mean scores did reflect a pattern consistent with the hypotheses and child reports. For example, there was a greater decrease in reported worries in the workbook group (see Table 3).

#### Parent-Child Accuracy

To assess parent's ability to report on their child's autism worries, the degree of association between parent and child AWS scores were examined using the Pearson correlational coefficient. The workbook and games groups were collapsed for these analyses because of the limited number of participants for whom we had complete sets of data ( $n = 10$ ). Parent and child scores did not significantly correlate with one another at session one,  $r = .31$ ,  $n = 10$ , ns. At session two, however, parent and child scores significantly correlated with one another,  $r = .65$ ,  $n = 10$ ,  $p < .05$ . This pattern of correlations suggests that the parents were more accurate at assessing their child's worries at the second session than at the first session.

#### Treatment Acceptability

Independent t-tests were computed on the total score of the Treatment Evaluation Inventory-Short Form and the child evaluation form to assess whether the parents and children thought the activities were acceptable, enjoyable, and effective. There was no significant difference for the parents evaluation of the activities,  $t(22) = .05$ , ns. An



examination of the means showed that the parent had positive reactions to both the workbook ( $M = 4.02$  on a 5 point scale) and to the games ( $M = 4.00$ , see Table 4).

The child's evaluation form asked two questions about whether they enjoyed being with their parents during the activity and whether they enjoyed the activities. There was also no significant difference for the child's evaluation of being with their parent during the activity,  $t(21) = 1.18$ , *ns*. There was a nonsignificant trend for the child's evaluation of the activity,  $t(21) = 1.92$ ,  $p < .10$ , suggesting that children enjoyed the games more than the workbook. An examination of these means also showed that the children had positive reactions to both activities and to being with their parent during the activities. On a four point scale with four being the most positive, children's mean was 3.59 for the workbook and 3.83 for the games. Similarly, the mean score for being with their parents was 3.23 for being with their parents for the workbook and 3.75 for the games condition (see Table 4).

### Communication

To assess whether or not the workbook improved family communication, mixed within-between 2x2 ANOVAs were computed for each of the following dependent variables: child report of general parent-child communication (PAC), parent report of general parent-child communication (PCRI), and parent report of autism communication (ACS). For both the child's report (PAC) and the parent's report (PCRI) of general communication, the 2x2 ANOVAs revealed no significant interaction or main effects (see Table 5 for means and standard deviations).

Regarding parent-reported autism communication (ACS), the 2x2 ANOVA revealed no significant main effects for time and activity; however, the activity x time interaction revealed a nonsignificant trend,  $F(1, 9) = 4.01$ ,  $p < .10$ . An examination of the means showed that the workbook may have slightly increased the quality of autism communication from time one ( $M = 3.44$ ) to time two ( $M = 3.80$ ); whereas, the games

may have slightly decreased the quality of autism communication from time one ( $\underline{M} = 4.02$ ) to time two ( $\underline{M} = 3.87$ ) (see Table 6).

### Discussion

This study was designed to test the effectiveness of a parent-child communication activity, specifically a workbook about autism-related worries, to alleviate the worries of siblings of children with autism. One of the goals of the intervention was to decrease child worries more than a placebo activity. Results did not support the relative superiority of the workbook to the games; however, results for the child's report did show a nonsignificant trend for a decrease in worries over time for both activities. The lack of significant differences may have been found because the workbook did not adequately discuss children's worries or did not help children overcome these worries. Another possible explanation for the lack of significance could be the small sample size and resulting low power. The lack of a significant interaction could also have been a result of the two activities being very similar. Both groups completed the pretests, and comments from many parents indicated that they discussed autism worries with their child regardless of whether they were in the workbook or games group.

Another goal of the workbook was to increase the accuracy of parent's perception of their child's worries. While parents were more accurate at assessing their child's worries after completing the workbook and the games, this significant correlation may not be reliable because of the limited number of participants. It is also unclear whether the parents in the workbook group were more accurate than the parents in the games group. The small number of participants restricted the analyses that could be performed. The workbook may have facilitated communication about autism and about the child's worries. If parents discussed the workbook with their children, then they may have learned what their children were concerned about. However, the games may have also facilitated communication about autism between parents and children by allowing them

the opportunity to spend time together and because, as described above, parents discussed autism related worries with their child.

Although there were no significant differences for the activity evaluations, both parents and children had positive impressions of both activities. Most parents felt that the intervention was beneficial. Parent comments to open-ended items in a feedback questionnaire included "I think my daughter enjoyed the time for just the two of us." One parent "found that my child has virtually no worries about autism." Another parent thought that just being at a group where "every child here has a brother like Mickey" was beneficial for her child. Another parent felt the intervention was positive in the sense that "my child seems more at ease...knows that we can talk about anything anytime and wants to help her brother."

In contrast, one parent, whose family did not use the word autism, did not feel that the workbook was an acceptable way for her family to discuss autism nor did she like any of the procedures used in the study. Nonetheless, her child enjoyed the activities and liked being able to talk to her mother.

Another goal of the workbook was to increase parent-child communication specifically about autism. The nonsignificant trend regarding autism communication for the interaction between the activities and time reflected the hypothesized pattern: that is, the workbook tended to increase autism communication more than the games did. Another interesting finding was that most of the children in this sample reported that they did have someone to talk to about their sibling with autism and most of the time it was their parent.

Generally, the families in this study already had very positive communication patterns which may explain why the intervention had virtually no effect on general family communication as reported by parents and children. Nevertheless, many parents felt that the workbook and games opened communication for them and their children. Parents made comments such as it "opened up more communication doors for my son and I

concerning autism, it opened up discussion on a daily basis, he seems to want to talk with us about Emily's troubles a little more, and it gave our daughter some things to think about and discuss with us."

Although there were not many significant findings in this study, this study did attempt to correct many flaws in other interventions. First, this study had more objective measures than previous studies. Many previous studies (Crouthamel, 1988; Dyson, 1998) used informal discussions or open-ended questions with their participants to assess the success of their interventions. This study did use the Treatment Evaluation Inventory-Short Form (Kelley et al., 1989) and the Child Activity Evaluation Form to assess the effectiveness of the intervention. The objective measures found similar results as the informal discussions other researchers have used. That is, parents and children had positive impressions of the activities. The Parent-Child Relationship Inventory, the Parent-Adolescent Scale, and the Autism Worries Survey were other objective measures used in this study.

Another advantage of this study was that it included a comparison group, for example the games activity group. Three of the four prior intervention groups did not contain a control group (Fox & Kaplan, 1968; Crouthamel, 1988; Dyson, 1998). This study was also specific to autism; whereas, the previous studies included siblings of children with various disabilities, such as mental retardation, ADD, autism, learning disabilities, developmental disabilities, and physical disabilities (Fox & Kaplan, 1968; Crouthamel, 1988; Dyson, 1998).

Another advantage of this study versus the previous studies was that this study actively involved parents in the intervention. Parents interacted with their children for part of each session and were asked to interact with their child in the same way at home during the intervening week. None of the previous studies were designed for parents to interact with their children as part of the actual interaction, and only one child in this sample had ever participated in a sibling support group or workshop before. This

intervention may have been the first opportunity that many of the children ever had to openly discuss their concerns with their parents. The intervention may have been the stimulus that many of the children and the parents needed to start talking about some of these issues.

A significant limitation of this study, similar to previous studies was the small number of participants, which may have limited the chances of finding significant results. It may be difficult to recruit participants for a study, as Crouthamel (1988) demonstrated when she had 20 responses to over 1500 letters advertising a support group. Similar low response rate occurred in this study. Ideally, future studies would ideally include a larger number of participants. Possible ways to accomplish this would be to expand the geographic region participants come from, for example, recruiting subjects outside of central Illinois.

In future studies, a pre-test would not be included. The pre-test, part one of the workbook, and the post-test were a bit repetitive for the children. Some of their answers may have been a result of pre-testing effects rather than accurate reports of their actual worries. As mentioned earlier, comments from many parents indicated that parents in both groups discussed autism worries regardless of whether or not they had the communication workbook. A study without the pre-test measures might reduce or eliminate the chances that the placebo-control group would discuss autism worries. Without pre-test measures, there would be greater differentiation between the intervention and control conditions. Ideally, a Solomon-4-group design would be used with pre-testing treatment, no pre-testing treatment, pre-testing no treatment, and no pre-testing no treatment groups.

To improve this study, better objective measures could be used. There were several limitations of the measures used in this study. The PAC first had to be adapted in order to make it understandable to the children. Even after it was adapted, it still was difficult for several children to comprehend and answer. The PCRI did not differentiate

between the parents as everyone reported good communication in their family. Then the AWS was not designed specifically for the older children in this study and may not have been applicable to their worries.

Another way to improve this study for the future would be to adapt the workbook for older children and teenagers. There were a few 12 and 13 year olds who felt that some things in the workbook were not applicable to them or that they were directed at a younger audience. One parent also "wondered what older children are thinking about the future, relative to what they expect for their autistic sibling."

Future research could also look to include more families that are not college-educated. All the families in this study had some college education and this may explain why few significant results were found. Perhaps, these parents already have very open communication in their family and already spend time with their children discussing their worries. It would be interesting to explore whether this intervention would, perhaps, be more helpful to families where the parents are not college educated. This intervention may allow these parents time and motivation to speak to their child about autism worries.

Since there have been some siblings of disabled children who report anxiety, loneliness, depression, increased responsibilities, increased parental expectations, and decreased parental support, interventions, such as this one, have attempted to help alleviate these problems. Future intervention studies could explore how children's comfort level in talking with their peers about their sibling affects their worries. It would also be interesting to explore whether the severity of autism affects a child's worries. Are all interventions equally effective for mild cases of autism as well as severe cases? This intervention was relatively easy to implement and the initial results were promising; however, the long term effects of this intervention are unknown. Future studies could also look at these long term effects.

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Table 1

Demographics InformationTypical Siblings

Age	$M = 9.12$ , $SD = 2.19$ , range: 6.5-13
Gender	11 girls (69%) 5 boys (31%)
Ethnicity	15 Caucasian (94 %) 1 Biracial (6 %)
CBCL	$M = 48.47$ , $SD = 11.16$ , range: 28-69; 70 is the cutoff for clinical behavior problems

Autistic Siblings

Age	$M = 8.60$ , $SD = 2.78$ , range: 3.5-12.75
Gender	2 girls (13%) 13 boys (87%)
GARS	6 (37.5%) low probability of autism (mild) 9 (56.3%) probably autism (average) 1 (6.2%) high probability of autism (severe)

Parents

Gender	12 females (80%) 3 males (20%)
Education	$M = 15.67$ , $SD = 8.27$ , range: 14-20
Relationship	14 birth parents (93%) 1 grandparent (7%)

Table 2

Frequency that Parents and Siblings Attend Support Groups and Frequency of Prior Autism Communication.

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Parent

Support Groups (per year)	$\underline{M} = 11.71, \underline{SD} = 12.18$ Median = 12 Mode = 0 Range: 0-36
Prior Autism Communication (per month)	$\underline{M} = 5.22, \underline{SD} = 8.62$ Median = 2 Mode = 2 Range: 0-30

Child

Support Groups (per year)	$\underline{M} = .63, \underline{SD} = 2.5$ Median = 0 Mode = 0 Range: 0-10
Someone to Talk to about Autism	
At Pre-test	Yes: 14 (87.5%) No: 2 (12.5%)
At Post-test	Yes: 10 (83.3%) No: 2 (16.7%)

---

Table 3

Means and Standard Deviations for Total Number of Child Worries.

	<u>Total Autism Worries Survey Score</u>			
	<u>Child Report</u>		<u>Parent Report</u>	
	<u>Workbook</u>	<u>Games</u>	<u>Workbook</u>	<u>Games</u>
Session 1	23.14 (9.41)	20.80 (11.52)	26.67 (6.68)	26.33 (8.38)
Session 2	16.86 (14.06)	18.40 (11.61)	19.00 (9.96)	26.00 (11.88)

Note. AWS scores represent mean number of endorsed (yes/no) worries (maximum of 46).

Table 4

Means and Standard Deviations for Activity Evaluation.

	<u>Parent Report</u>	<u>Child Report</u>	
	TEI-SF	Enjoy Activity	Enjoy Being with Parent
Workbook	4.02 (.95)	3.23 (.82)	3.59 (.58)
Games	4.00 (.60)	3.75 (.45)	3.83 (.39)

Note. Higher numbers represent more positive evaluations; parent on scale of 1-5, child on scale of 1-4.

Table 5

Means and Standard Deviations for the Quality of General Communication

	<u>Average General Communication Score</u>			
	<u>Child Report (PAC)</u>		<u>Parent Report (PCRI)</u>	
	<u>Workbook</u>	<u>Games</u>	<u>Workbook</u>	<u>Games</u>
Session 1	3.40 (.41)	3.88 (.71)	15.67 (3.27)	14.17 (3.60)
Session 2	3.36 (.42)	3.79 (.76)	16.83 (4.31)	14.83 (3.76)

Note. PAC (Parent-Adolescent Communication Scale) scored on a scale of 1-5 with higher numbers being more positive; PCRI (Parent-Child Relationship Inventory) scores could range from 9-36 with lower numbers being more positive.

Table 6

Means and standard deviations for the quality of autism communication-parent report

<u>Average Autism Communication Score</u>		
	<u>Workbook</u>	<u>Games</u>
Session 1	3.44 (.48)	4.02 (.97)
Session 2	3.80 (.32)	3.87 (.80)

Note. Higher numbers represent more positive communication qualities; scale of 1-5.



### Figure Caption

Figure 1. Sample page of the Autism Worries Survey.

Figure 2. Sample pages of autism communication workbook.

This  
child  
really  
worries.



This  
child  
kind of  
worries.



This  
child  
worries  
just a  
little bit.



This  
child  
doesn't  
worry.



*Which one are you most like?*



My brother/sister with autism is \_\_\_\_\_

1. Some kids worry that they might catch autism from their brother or sister.
2. Some kids worry that they will get punished because of something their brother or sister did.
3. Some kids worry that something they did or said or thought made their brother or sister have autism.
4. Some kids worry that their brother or sister will hurt themselves.
5. Some kids worry that their parents don't love them as much as they love their brother or sister. (6)
6. Some kids worry that other kids tease them about their brother or sister. (8)
7. Some kids worry that they will have to take care of their brother or sister when they are older. (10)
8. Some kids worry that they might have autism like their brother or sister. (11)
9. Some kids worry that their brother or sister will break their things. (12)
10. Some kids worry that they get angry at their brother or sister too much. (13)

## Special Autism Worries

1. Some kids worry that they might catch autism from their sister or brother.



This child  
really worries

☐

This child  
kind of worries

☐

This child worries  
just a little bit

☐

This child  
doesn't worry

☐

Which child are you most like?

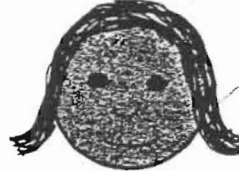
2. Some kids worry that something they did, said, or thought caused their sister or brother's autism.



This child  
really worries

☐

This child  
kind of worries

☐

This child worries  
just a little bit

☐

This child  
doesn't worry

☐

Which child are you most like?

3. Some kids worry that they might also have autism.



This child  
really worries

☐

This child  
kind of worries

☐

This child worries  
just a little bit

☐

This child  
doesn't worry

☐

Which child are you most like?

## Coping with Sibling Relationship

People with autism often find it hard to do things with other people. For example, they often have different interests and play in different ways than other kids. Sometimes it is really fascinating to be with someone that is so special and unique. Other times, it can be very frustrating.

*Keith: I have to be really careful around my sister. Like, I can't say certain things or eat certain food in front of her or she will "go off." Sometimes I set her off. Sometimes she sets me off. And sometimes that makes us get in trouble. I try to remember that she doesn't really understand things the way I do. Sometimes my mom helps by saying I can go play by myself for awhile.*



*Annie: Sometimes I think my brother doesn't like me. He won't let me play with his trains and doesn't understand my games. I do have a game that I can play with my brother! He loves for me to chase and tickle him. Last week he even started the game himself. I liked that!*

By doing this workbook you already are doing something important--talking with other people about your feelings. You can also work on finding new ways to play or do things with your sister or brother.

What are you already good at doing with your sibling? Put your answer

RIGHT HERE 

---

---

Think of a new or different way you want to do things with your sibling. Put your

idea RIGHT HERE 

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## Appendix

## **Parent Instruction Handout:**

### **Tips for Completing the Autism Workbook with your Child**

General Directions: Try to complete Part I with your child tonight. If you have time, complete one or two activities in Part II.

- ☺ Read aloud together to increase interaction.
- ☺ Use encouraging responses to help your child better explain his or her worries. (e.g., smiles, nods, "mm-hmm's", "Tell me more")
- ☺ When completing Part I, try to resist coming up with immediate "solutions" for your child's worries. When adults respond too quickly, children may feel silly or be reluctant to admit to other concerns.
- ☺ Children usually talk more freely when adults listen in a caring and nonjudgmental manner.
- ☺ Try to focus on your child rather than on other people in the room. We encourage you to treat this as "special time" together.
- ☺ Remember, not all worries are problematic! Indeed, many worries actually reflect a child's concern and caring for others. Relax and enjoy learning more about your child's experiences.

**Note:** If you or your child feel uncomfortable with a question, feel free to skip that item.

## Parent Instruction Handout: Tips for Games Activity

General Directions: Spend the activity time interacting and playing games with your child.

- ☺ The goal is to stay engaged with your child, regardless of which games you play.
- ☺ Use encouraging words to help your child feel more involved with you (e.g., smiles, nods, "Good job!").
- ☺ As much as possible, let the child lead the game (e.g., choosing games, who goes first, changing games). When adults let children make choices, children feel important and valued.
- ☺ Children usually have more fun when adults interact with them in a caring and nonjudgmental manner.
- ☺ Try to focus on your child rather than other people in the room. We encourage you to treat this as "special time" together.
- ☺ Remember, the games themselves are not that important. It doesn't matter who wins or loses. Relax and enjoy just spending time with your child.

**Note:** If you and your child get bored with a game, feel free to choose another one whenever you are ready.