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The Effects of a Parent-Child Communication Intervention on the  
Worries of Siblings of Children with Autism

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Proposal for Senior Thesis Research Project

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## Abstract

This study was designed to assess the effects of parent-child activities on the siblings and parents of children with autism. Existing research suggests that the experience of having an autistic child in the family is highly variable and may have negative outcomes for the typical sibling. The difficulty in predicting sibling outcome may be caused by the lack of a theoretical framework organizing the factors hypothetically affecting sibling coping abilities, therefore a stress and coping model of siblings of children with autism is provided. Currently there has been only limited information reporting successful intervention efforts for this population. The current study attempted to correct many of the limitations of previous sibling intervention studies by including a larger sample size, objective measures, a control group, and parental involvement in the intervention. Participants were twenty-five siblings of children with autism and their parents. This study used a between groups design to evaluate the worries of sibling of children with autism after a brief one-time intervention. The experimental group of parent-child pairs completed a workbook focused on autism-specific worries, while the control group played games together. The results indicate that the workbook activity increased parental accuracy in reporting their typical child's autism worries. Exploratory analyses also lend some support for the proposed model of sibling reaction to an autistic brother or sister.

## The Effects of a Parent-Child Communication Intervention on the Worries of Siblings of Children with Autism

Autism is a severe neurodevelopmental disability characterized by impairments in social interaction and communication and restricted, repetitive and stereotyped patterns of behaviors and interests (American Psychiatric Association, 1994). Autism is initially diagnosed in early childhood and affects almost all domains of functioning (Burack, Charman, Yirmiya & Zelazo, 2001). There are several specific diagnoses within the autism classification including autistic disorder, Asperger's Disorder, and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS). Autism is estimated to affect approximately one in 1,000 people, about one-third of whom are children (Bryson, Clarke, & Smith, 1988; Powers, 2000).

Autism affects not only the individual with the disorder, but also those in social contact with the autistic child. Families with a handicapped child are hypothesized to be at a greater risk for potential problems because they are challenged by a chronic and puzzling disorder (Trevino, 1979). Parents, extended family members and typically developing siblings of children with autism are especially affected because the disabilities inherent to the disorder add multiple stressors to these family members' lives. For instance, there is an extensive literature documenting stresses that parenting a child with autism can have. Parents of children with autism may feel "stretched beyond their limits" several times each month (Sharpley, Bitsika & Efremidis, 1997) and their daily routines are complicated by stressors such as their child's language and cognitive deficits (Bebko, Konstantareas and Springer, 1987) and impaired parent-child relationships (Konstantareas & Homatidis, 1989). Recognition of the special stress an autistic child



places on the family is important in understanding the reactions of typically developing siblings. Few studies, however, investigate autistic children and their typically developing siblings, as most studies have been parent-focused.

Although there is some literature specific to siblings of children with autism, there is a dearth of well-designed empirical research on this subject, therefore the general literature on siblings of children with chronic disease also provides important context for the proposed study. An estimated 60% of the over 40 studies of siblings of children with chronic illness reviewed by Williams (1997) report an increase in sibling risk. In addition, several clinical observations suggest that having a chronically disabled sibling can have negative outcomes for the typical child. For example, Seligman (1983) reported that the typical siblings are the members of the family most at risk for problems caused by a disabled family member. Some of the possible consequences of having a brother or sister with a chronic disability include guilt, low self-esteem, depression, anxiety, and anger as expressed in the typical child through internalizing and/or externalizing symptoms (Wolf, Fishman, Ellison, & Freeman, 1998; Bagenholm & Gillberg, 1992; Gamble & McHale, 1989; Gold, 1993). Other researchers have found that siblings of children with autism or a chronic disability, compared to siblings of typically developing children, often feel more confused and more discouraged talking within their family about the sibling (Bagenholm & Gillberg, 1991; Deal & MacLean, 1995) and that they had less nurturing sibling relationships (Kaminskey and Dewey, 2001). Rodrigue, Geffhen, & Morgan (1993) found that siblings of autistic or chronically disabled children were found to have more internalizing and externalizing behaviors than siblings of normal children.

On the other hand, the experience of having an autistic child in the family is highly variable. That is, not all typical siblings describe their handicapped sibling in the same way and there is a wider range of reactions for the siblings of handicapped children than for siblings in control groups (McHale, Sloan, & Simeonsson, 1986). Some studies have found that the siblings of children with autism were not at a significant increased risk for difficulties. Kaminsky & Dewey (2001, 2002) found that measures of adjustment difficulties and loneliness of these siblings did not differ from control groups and that these sibling relationships had positive aspects such as less quarreling and less competition. Likewise, no significant differences were found on measures of perceived self-competence or parent's report of social competence (Rodrigue, Geffhen, & Morgan, 1993). One study even concluded that the positive self-concept, academic achievement, and behavior of siblings of children with autism did not suggest a need for special intervention within this population (Mates, 1990). On a related note, several positive effects also have been found among typical siblings of children with a chronic disease such as maturity and enhanced compassion (Williams, 1997; Wilson, Blacher, Baker, 1989).

In sum, negative and positive results have been associated with having a brother or sister with chronic disabilities. What aspects of these studies help explain the variability and inconsistencies in the results? First, these studies consider different variables within sibling adjustment as dependent variables, ranging from psychiatric classifications to self-competence to family communication. Second, the use of different operational definitions of autism and the frequent practice of including siblings of children with different disorders also confound the results. Third, samples tend to be

homogeneous, composed of predominantly white, middle-class, educated parents. These participants are usually self-selected to take part in such a study and therefore may not be representative of the full population of families with a child with autism. Fourth, there are no controls for the mild genetic autism link called the broader autism phenotype commonly found to affect these siblings' social skills, communication skills, and behaviors to some degree. These four factors combined represent the need for a more comprehensive way to study the influence of an autistic child on the typically developing sibling.

The brief reflection of sibling literature that has been presented reveals two needs: the need for better assessment and intervention of these siblings, and the need for a model that predicts which siblings are most at-risk. To date, there is no empirically sound method for predicting which children will be most affected by an autistic sibling and to what magnitude. The difficulty in predicting sibling outcome may be caused by the lack of a theoretical framework organizing the factors hypothetically affecting the coping abilities of typical children of autistic siblings. A stress and coping model of siblings of children with autism is proposed to organize the factors involved in the variability in sibling outcome.

#### A Stress and Coping Model of Siblings of Children with Autism

A stress and coping model of siblings of children with autism falls within a class of models that help predict how people respond to stressors in their lives. The classic example was proposed by Lazarus and Folkman (1984) in response to public interest in emotions and psychosomatic medicine, stress and coping in adult life and aging, as well

as stress management. Lazarus and Folkman defined psychological stress as a specific relationship between the person and the environment that is appraised by the person. For example, the environment may be evaluated as taxing or exceeding his or her resources and endangering his or her well-being. Theoretically, this type of stress is a dynamic state and therefore there is a constant interplay between the organism and its environment with many variables playing a specific role. These models are used to explain reactions to things as diverse as smoking to cancer. For example, Tunali and Power (1995) created a model to help explain their theories of stress and coping in families with handicapped children. Brodzinsky (1990) adapted the Lazarus and Folkman (1984) stress and coping model to explain children's adoption adjustment. Adoption adjustment is similar to the experience of having an autistic brother or sister because both present unique and permanent psychological stressors for these children.

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 Insert Figure 1 here  
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Figure 1 depicts a stress and coping model of typical child reactions to having an autistic sibling. This model must be considered a speculative prototype because of the lack of research on siblings of children with autism. The model is built on the concept that children's adjustment (see the far right box in Figure 1) to a variety of background factors inherent to having a brother or sister with autism is mediated by cognitive appraisal processes and coping efforts (found in the middle boxes of the model 1). The *Background Factors* include biological factors, person factors, sibling factors, family factors and public/cultural factors (found on the far left of the model in Figure 1).

*Cognitive Appraisal* involves the perception of threats, or primary appraisal, and the appraisal of one's own ability to cope with threats, or secondary appraisal. *Coping strategies* are constantly changing and include active problem-focused coping strategies as well as emotion-focused avoidance strategies. Thus, a child's reaction to the stresses of having a sibling with autism is thought to be influenced by certain background factors, the cognitive appraisal of events as threatening or manageable, and the child's attempts to cope with those events. In the following sections, I will describe each component of the model in increased detail.

### Background Factors Affecting Cognitive Appraisal

#### *Biological Factors*

As described earlier, one factor that is believed to influence a child's adjustment to the stressors of an autistic sibling is his or her genetic makeup. The genetic liability for autism may cause milder but qualitatively similar behavioral characteristics in non-autistic relatives (Piven, 1999; Piven, Palmer, Jacobi & Childress, 1997). This is referred to as the broader autism phenotype. Specifically, siblings of children with autism who fit the broader autism phenotype model may have mild social deficits such as a rigid or aloof personality, communication abnormalities such as language or nonverbal deficits, and stereotyped-repetitive behaviors. Schopler, Yirmiya, Shulman & Marcus (2001) for example, found that more siblings of children with autism are affected with some form of autism when compared with siblings with normal development, lending support for a genetic basis for autism. The effects of a broader autism phenotype may buffer a child from stress or place them at higher risk. For example, broader autism phenotype may protect children by making them unaware of teasing or the eccentricity of their autistic

sibling. Conversely, it may also place the child at a higher risk if such a child is unable to gain social acceptance among peers because of social deficits or if this child is unable to perform up to expectations at school because of communication deficits.

In addition to the effects of a broader autism phenotype, an increased occurrence of other psychiatric problems stemming at least partially from hereditary factors have been observed in families of autistic children. For example, several studies report a lifetime history of major depression in one-fifth to one-third of autism first-degree relatives, with an especially significant increase in recurrence and early onset of major depression (Lainhart, 1999; Piven & Palmer, 1999; Bolton, Pickles, Murphey & Rutter, 1998). Importantly, this increase in depression rate is not explained in entirety by the environmental effects of having a first-degree relative with autism (Bolton, Pickles, Murphey & Rutter, 1998), suggesting a link to hereditary factors from biological variables. Other links have been made with first-degree relatives of children with autism and increased rates of bipolar disorder (DeLong & Dwyer, 1988), anxiety disorder (Abramson, Wright, Cuccaro & Lawrence 1992), social phobia (Piven & Palmer, 1999), and alcohol abuse (Abramson et. al., 1992). These biological factors occur commonly in some families of autistic individuals and ideally should be controlled when assessing siblings having a difficult time coping with an autistic brother or sister.

### *Person Factors*

Drawing on Brodzinsky's model (1990), it is hypothesized that a second variable believed to influence the child's adjustment to the stressors of an autistic sibling are his or her person factors, which include developmental or cognitive level, knowledge of autism, and sense of self.

When siblings lack the developmental ability to understand autism this influences their cognitive appraisal and subsequent coping efforts. Developmental understanding appears to be linked with the types of worries children may have about their autistic sibling, and may be an important factor influencing the way siblings view their brother or sister, their family, and themselves (Lobato, 1985). Folstein & Rutter (1988) found that siblings of children with autism have a greater risk for problems of general intelligence, reading and language. Glassberg (2000) conducted a relevant study by placing siblings in their respective Piagetian developmental stage by age: *preoperational* (2-7 years old), *concrete* (7-10 years old) and *formal* (10 years old and up). Contrary to the hypothesis that children would understand autism in a manner consistent with the appropriate Piagetian stages, all three levels of children responded at a pre-operational level of reasoning when questioned about the definition and etiology of autism, suggesting that this may be a more abstract concept and therefore harder to grasp.

The age of the typical child also affects that child's cognitive level. Younger siblings, such as those at developmentally lower cognitive levels, often feel confused and unable to talk within their family about the disabled sibling and many of these siblings even lack words to describe what is wrong with their brother or sister (Bagenholm & Gillberg, 1991; Deal & MacLean, 1995). Caro and Derevensky (1997) found that older typical children are much more successful at noticing behavioral cues in a handicapped sibling whereas younger typical siblings tended to become easily frustrated with their handicapped brother or sister when they failed to perform the actions the typical child desired. This study also found that younger children had more negative and neutral comments about their autistic sibling whereas older children had more neutral or positive

comments about the autistic sibling. Finally, this study found that older children were able to retain interest in their autistic sibling for a much longer time period than younger typical siblings.

Likewise, the amount of autism specific knowledge a typically developing sibling of a child with autism has gained is an important person variable. Typical siblings are often left out of the training the family receives to interact with the handicapped child (Lobato, 1985) therefore the needs of the typical sibling and involvement in the autism training are often not adequately met and may lead to psychological difficulties. Dellow, Cernerud and Hallberg (2000) found a clear connection between a child's knowledge about a sibling's disability and the quality of the relationship between these siblings among girls with a brother with deficits in attention, motor control and perception (DAMP) and Asperger syndrome.

A final concept placed in the person factors category is the child's sense of self. Bagenholm & Gillberg's study of the child's sense of self (1991) found that siblings of children with autism were concerned about the future for their handicapped sibling, they were lonely more often, and many of them had peer problems. Harris (1994) states that an increased fear in the typical sibling may act to damage that child's sense of self. This sibling relationship may become one of sadness or indifference, or typical siblings may begin to doubt their self-worth.

On the other hand, several studies support the idea that there is variability among the person factors category. Researchers do report some well-adjusted siblings who manifest positive self-concepts and healthy academic adjustment despite having a developmentally delayed sibling (Mates, 1990). For example, Gold (1993) found no



significant difference in the social competence of these children, and Breslau, Weitzman, and Messenger (1981) found that neither sibling's sex or age had any influence on their psychologic functioning.

### *Sibling Factors*

One of the most important factors influencing the typical child's adjustment to a sibling with autism theoretically will be the experiences he has with his sibling. With increasingly smaller family size, longer life spans, and a greater probability of divorce and remarriage, the sibling relationship may be more important today than in the past according to Bank and Kahn (1982). Sibling relationships are an important part of the social and emotional growth and development of all children, and have been associated with high levels of support and self-worth (Brody, 1998; Jenkins & Smith, 1990).

Sibling conflict even appears to have some positive consequences. Raffaelli (1992) reports that sibling conflict functions to create a context where the age-appropriate issues of individuation and differentiation can be played out. Lastly, Stormshak, Bellanti, and Bierman (1996) add that sibling relationships may foster the development of social skills in addition to providing emotional support.

Sibling relationships may differ when one sibling has autism, therefore decreasing some of the benefits received in typical sibling relationships. Kaminsky and Dewey (2001) used the Sibling Relationship Questionnaire (SRQ) to assess children's perceptions of their autistic siblings. Their results indicate that siblings of autistic children report less intimacy with their sibling and less nurturance. They also report less prosocial behavior in their siblings. Knott, Lewis, & Williams (1996) examined the effect of sibling interactions on the development of children with autism using home

observations and found that the developmentally disabled siblings engaged in fewer bouts of interaction and imitated less.

The age match and the gender match of the typical and autistic siblings may also affect the typical sibling's adjustment. McHale, Sloan and Simeonsson (1986), found that feelings of rejection toward the handicapped child differentiated typical siblings older than their autistic brother or sister from younger typical siblings with older brothers or sisters with autism. These younger typical siblings have more negative and rejecting feelings toward their handicapped sibling than older siblings. This study also found that children reported a more negative family role and more concerns for the future for their autistic sibling if the autistic sibling was a male compared to a female sibling. Also, Gold (1993) reports that younger typical brothers and older typical sisters have a more difficult experience with an autistic sibling than other combinations of sex and gender. For example, clinical observations have found that the older child may have a more difficult time achieving adolescent independence (Harris, 1994).

### *Family Factors*

Beyond the sibling relationship, family characteristics play an important environmental role in the typical child's adjustment (Dellve et. al., 2000). Some of the important family factors include the following family demographics: socioeconomic status, family size and presence of extended family, resources, quality of parent-child relationships, family communication, and parental marriage satisfaction.

Howlin (1988) discussed how economic and social factors might exert important influences on the extent to which siblings of children with autism are affected. Caring for an autistic child can have considerable financial implications and it is often difficult for

mothers of autistic children to work outside the home because of childcare needs. In addition, financial strains add to other burdens on the family, consequentially increasing the risk of problems. On the other hand, higher economic status families may experience a different type of stress because of their increased expectations and discrepancies between their wants for the child and the autistic child's actual achievement.

Family size is another family factor influencing the adjustment of siblings of children with autism. Trevino (1979) contended that larger family sizes increase the normalcy of the atmosphere within families with a handicapped child. Likewise, McHale, Sloan, & Simeonsson, (1986) found that siblings of children with autism felt less embarrassed about their sibling's disability and reported fewer feelings of burden regarding their sibling when these siblings came from larger families. Families also benefit when they make use of extended family members such as willing grandparents whenever possible (Howlin, 1988).

Family social support is yet another critical determiner of a typical child's reaction to a brother or sister with autism. Kaminsky & Dewey (2002) found that siblings of children with autism report receiving high levels of social support from family, friends, and teachers. They also found that siblings of children with autism whose parents utilized support groups had more access to information about autism and were more able to use this resource to interact with other families of children with autism. On a related note, Trevino (1979) observes that limited resources can be devastating on typical siblings, especially when they are expected to share the load. Wolf, Fisman, Ellison & Freeman (1998) found that social support became a more significant factor

overtime, with lower levels of social support associated with parent and teacher reports of adjustment difficulties in typical siblings of children with disabilities.

Theoretically, the quality of the parent-child relationship and family communication is especially important at predicting those siblings of autistic children most at-risk for problems. Brody, Stoneman, & McCoy (1994) report that in typical samples, higher levels of parental negative affectivity are related to higher levels of negativity and lower levels of positivity in sibling relationships. According to the clinical observations of Harris (1994), good communication is vital to a working relationship and parents and children need to be able to tell each other what they are thinking and feeling, and to agree to solutions that fit the entire family. Harris goes on to say that children who are able to learn from their parents how to communicate well with their loved ones will find these skills useful throughout their lives. Good listening skills are important in creating an atmosphere where typical siblings of autistic children will reveal personal thoughts and feelings to their parents, and likewise, parents who label their own emotions and link them to feelings of concern for the autistic child but not a diminished love for the typical child, are able to ease the typical sibling's concern's about the parent's emotions. In conclusion, Harris points out the variables affecting parent-child relationship quality including communication, listening skills, and emotional labeling. In addition, Harris stresses the equal importance of communication in developing a positive family atmosphere.

The last family factor I will discuss is the affect of marriage satisfaction on the adjustment of children with autistic siblings. Rodrigue et. al (1993) finds that higher marital satisfaction among parents of children with autism is also associated with higher

levels of self-esteem in siblings. A similar study finds that both parents and siblings appear to adjust better to having a developmentally disabled child in the family with satisfying marriages (Rodrigue et. al., 1990).

### *Public/Cultural Factors*

Public and cultural factors are the final type of environmental influence included in the model depicted in Figure 1. These factors include the public response and understanding of the autistic child, peer understanding of the situation, and accessibility to services.

Although more people are aware of autism now than ever before, harmful or incorrect labels still prevail. One reason for the increased public awareness of autism is that it is being discussed more in the media today than in the past. Unfortunately, much of this coverage does not provide an accurate description of the underlying cause of autism nor the variability in the types and severity of symptoms. Common sources of public autism knowledge are movies such as *Rain Man*, *The Boy Who Could Fly* and *Backstreet Dreams* which provide autism stereotypes ranging from the “savant” to the “mute kid”. These films portray some of the common characteristics of autism, but often appeal more to the public’s curiosity than they provide useful autism education. Public misconceptions about autism can potentially affect the outcome of living with a sibling with autism. Similarly, peer reactions also affect a sibling’s adjustment to living with an autistic child and may be a potentially painful experience. Harris (1994) discusses that although many children respond to a child with a mental disability with curiosity or kindness, others may react with ignorance, fear and even cruelty. McHale, Sloan and Simeonsson (1986) suggest that classroom mainstreaming provides more difficulties for

siblings of children with disabilities because the increased contact between handicapped and non-handicapped children provides more opportunities for the sibling to have to cope with reactions from his or her peers toward the handicapped child.

The lack of readily accessible services is another factor influencing a sibling's adjustment to an autistic child. Some communities provide multiple organized services to families of children with autism, but this is more of an exception than a rule. Even the school systems provide only minimal teacher training. Helps, Newsom-Davis, and Callias (1999) investigated teachers' views of autism and their training needs. Teachers and support staff were found to hold various views about autism that were significantly different from those of mental health professionals. In addition, 95% of regular education teachers had received little or no autism-specific training. The lack of readily accessible services has become increasingly important, as the recent movement towards deinstitutionalization has meant that many handicapped children must be integrated in the context of the family. According to McHale, Sloan and Simeonsson (1986) the movement toward integration necessitates that community programs and facilities, respite care, day care, summer camp and school programs, and support groups for parents are provided to help ease the problems families with autistic children may face.

### The Influence of the Cognitive Appraisal

Lazarus and Folkman (1984) describe two types of cognitive appraisal that affect how an individual responds to stressors in the background factors: Primary and secondary appraisal. *Primary appraisal* is the evaluation of the potential impact of an event on an individual. Three types of primary appraisals have been distinguished in

relation to one's well-being and include irrelevant, benign-positive, and stressful evaluations. Irrelevant appraisals mean that a stressor is assumed to have no effect on an individual's well-being whereas benign-positive appraisals will occur if an outcome is perceived positively. Lastly, the model is most interested in stressful appraisals which include feelings of harm/loss, threat, and challenge as these are the types of appraisals associated with coping efforts. *Secondary appraisal* is a complex evaluative process in which the person judges possible steps to meet the demands of the stressful event.

Lazarus and Folkman's research and observation shows that the way a person appraises a situation influences the coping process and how the person reacts emotionally. Thus, cognitive appraisal helps explain why different people react in different ways to similar situations.

Despite extensive searching of the PsychLit database, I was unable to locate research on the attributional thinking patterns of siblings of children with autism. Although there is a lack of systematic research, research on autism worries do provide some insight into the cognitive appraisal of the typical siblings of autism children. Kuncze and Groh (2001) found that siblings of children with autism report significantly more sibling-specific worries and social worries, as well as marginally significantly more total worries and self worries compared to siblings of typically developing children.

### Coping Strategies

Coping efforts are also important mediators of thought, feeling, and action. Coping is defined by Lazarus and Folkman (1984) as constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised

as taxing or exceeding the resources of the person. This definition is process-oriented and can either aid or hinder successful adaptational outcomes. In the early literature, two types of coping strategies were distinguished. *Problem focused strategies*, as defined by Brodzinsky (1990), are actively directed at managing or altering the problem causing the distress and when conditions of stress are appraised as amenable to change. *Emotion focused strategies* are used when there has been an appraisal that nothing can be done to modify harmful, threatening, or challenging environmental conditions (Lazarus and Folkman, 1984). These strategies are used to passively decrease the stress by changing the actual meaning of the stressful event in itself. Although there is currently no empirical research that relates directly to the coping strategies of siblings of children with autism, clinical information is provided in this area.

Limited clinical wisdom specific to the coping strategies of siblings of children with disabilities is found in such literature as Harris (1994). Harris discusses communication as a vital tool in coping with an autistic family member, stressing the communication between a typically developing sibling and the parents. The quality of parent and child communication can act as a way to both actively verbalize and share worries and problem focused strategies to change the stress of living with a sibling with autism, as well as act to help children reframe the situation through emotion focused strategies.

Siegel & Silverstein (1994) draw on their extensive clinical experience and identify and describe four prototypical types of roles representing different personal coping styles among siblings of children with autism. These roles play a part in the sense of mastery and control the siblings have over their situation. A 'parentified' child reacts



to the autistic sibling by taking on a parental caregiving role. This can affect the child's self-esteem when he learns to take on the parentified role in order to receive love or approval. A 'withdrawn' child removes herself from the family activities both physically and emotionally, and is at risk for depression and poor school performance. An "acting-out" child is at risk for numbed emotions, maladaptive behaviors, and problems in adolescence. Finally, the 'superachieving' child is a master of and also externalizes his feelings of conflict and anxiety through extreme behaviors. These roles demonstrate coping strategies of typical children with disabled siblings such as an increase in externalizing behaviors, a normalized way for typical siblings to communicate to their handicapped sibling, and increased caretaking strategies.

### The Adaptational Outcome

The final component of the model (Figure 1) is the adaptational outcome. Research in sibling outcome was summarized in the introduction section of this proposal, emphasizing conflicting results found in the literature on the adaptational outcome of having a sibling with autism. The stress and coping model of typical children's adjustment to an autistic child described above may help researchers make more accurate predictions of such an outcome and to better identify those siblings more at-risk for difficulties, to understand how and why certain factors affect the typical siblings, and to make sense of the many contextual variables.

### *Current Study*

Although some children seem to suffer relatively few negative consequences from the stresses of an autistic sibling (McHale, Sloan, & Simeonsson, 1986), extreme and

adverse reactions to the autistic sibling and difficulty coming to terms with the problems associated with these impairments is exhibited in a small number of these children (Howlin & Yates, 1989). Further, despite many positive consequences of living with an autistic sibling, typical siblings do have many special demands and stresses to deal with, as imposed by the autistic sibling (Harris, 1994).

It is of clinical importance to develop and maintain appropriate coping methods for the children most affected by their autistic sibling and therefore I conducted an intervention study in attempt to increase autism specific parent-child communication and to decrease autism specific worries in siblings of children with autism. A review of the current literature within a stress and coping model of children's adaptational outcome as developed by Lazarus and Folkman (1984) and further adapted by Brodzinsky (1990) has been provided as a theoretical framework for siblings of children with autism. Next, intervention efforts such as behavioral interventions and child support groups will be discussed and fit within the theoretical model. It is important to learn what's effective in terms of coping efforts for the at-risk siblings. Finally, I will consider limitations in previous research and present hypotheses for the current study.

### Intervention Efforts

Despite the lack of a widely accepted theoretical model predicting outcome of typical children with autistic brothers or sisters, there have been multiple intervention efforts including behavior modification programs and sibling support groups. Specifically, these intervention efforts appear to target factors such as autism knowledge,

sibling conflict and relationship, quality of parent-child relationships, family communication, and accessibility to services.

### *Behavior Modification*

Behavior modification is one type of intervention effort that is focused on enhancing the relationship between the typical child and his/her sibling with autism though increasing the amount and quality of sibling play. Several studies have been successful at teaching the sibling play skills to use with an autistic child to influence positive and reciprocal playtime (Celiberti & Harris, 1993; Koegal, O'Neill, and Schreibman, 1983; Lobato & Tlaker, 1985). For example, Lobato (1985) was able to use role-playing, modeling, coaching, and differential feedback in a workshop to enhance preschool siblings' understanding of autistic brothers or sisters. Further, Clark, Cunningham, and Cunningham (1989) helped children avoid coercive interactions and to use sign language to increase communications between the siblings.

Behavior modification studies have had some success at teaching siblings of children with autism skills to better cope with their autistic sibling in play and social interactions. The skills they teach the typical siblings may not only foster a positive sibling relationship and help to decrease the occurrence of sibling conflict, but also increase the child's knowledge and understanding of autism. Sibling relationship and sibling conflict factors can be related theoretically to the proposed stress and coping model through their placement in the *sibling factors* background variable. Likewise, autism-specific knowledge is described in the *person factors* background variable. Behavior modification also provides the typical siblings with instrumental problem-focused skills they can use to help *coping efforts* with the experience of having an autistic

sibling. Therefore, targeting each these variables may have an influence on the typical child's adaptational outcome. On the other hand, behavior modification is very time-consuming, expensive, and requires a very skilled trainer. Importantly, these techniques do not specifically target parent-child communication about autism, which is believed to be an important factor in helping to decrease children's worries.

### *Sibling Support Groups*

A complimentary form of sibling intervention program is the sibling support group. Sibling support groups have been established in public and clinical settings, allowing siblings of children with disabilities to interact in a relaxed and recreational environment. These groups focus on learning how to handle common situations experienced by these siblings, and work under the premise that siblings can benefit from sharing their negative sibling feelings and interactions with other children like themselves. Kaplan and Fox (1968) pioneered support group sessions for siblings of developmentally disabled children in order to help the typical siblings verbalize and share their experiences of living with an autistic brother or sister. A more recent form of support group coined "Sibshops", offers information to typical siblings about their developmentally disabled sibling and allows them to gain peer support (Meyer & Vadasy, 1994). Wilson et. al. (1989) surveyed 24 pairs of siblings of handicapped children and found that 55 % of the typical siblings indicated an interest in participating in such a group with 32 % more expressing tentative interests.

Although most support group studies offer only anecdotal clinical observations with regard to their effectiveness, two studies used objective child assessment scales to empirically evaluate the effects of sibshops on the siblings' development. Lobato (1985)

assessed the effectiveness of autism specific information and personal-emotional support provided to preschool-aged children with disabled siblings. The results indicate that their participants became more accurate in their definitions of disabilities, and more communicative in home settings regarding these disabilities. In addition, all participants' parents felt relief and satisfaction with the increased disability communication within their family. A similar study conducted by McLinden, et. al., (1991) adapted Lobato's siblings support group model for older children. Results indicate significant effects on children's perception of the social support they received and a parent interview indicated some improvements in the participants' behavior toward their siblings.

Support group interventions can be related theoretically to the stress and coping model in that they appear to target many variables such as the typical child's sense of self, peer support, and autism-specific knowledge. Support groups also provide siblings with both problem-focused and emotion-focused *coping* tools, acting as an important mediator in the child's adaptational outcome.

Unfortunately, not all studies conclude that support groups for siblings of children with autism provide improvements in sibling relationships and sibling coping. Kaplan and Fox (1968) found many parents were reluctant to even allow their typical children to attend support groups. McLinden, Miller, and Deprey (1991) found that their workshop had very limited benefits and did not improve siblings' attitudes, self-concept, knowledge, or problem behaviors. In addition, there are very few empirical studies on the effects of sibling support groups, and much of this information is anecdotal (Meyer & Vadasy, 1994). Small and heterogeneous sample sizes, lack of objective measures, lack of a control group, lack of parental inclusion, and the addition of siblings of children with

myriad disorders further complicate any results regarding the effectiveness of sibling support groups for children with autistic brothers and sisters.

### *Limitations*

Several limitations characterize the intervention studies of siblings of children of autism. Those previously mentioned were the lack of constant variables and operational definitions among studies, a heterogeneous sample not representative of the true population of interest, and a paucity of theory or models to help explain and organize factors in the coping and adjustment of siblings of children with autism to the stressors they may face. In addition, researchers often have not used objective measures nor included control groups. Interventions studies rarely involve parents but often include siblings of children with a myriad of disorders rather than only siblings of children with autism. Finally, these studies often use extremely small sample sizes.

### Proposed Study

The present study addressed the *cognitive appraisal* component of the stress and coping model for siblings of children with autism. Specifically, it assessed the effectiveness of a parent-child communication workbook activity on decreasing the worries of siblings of children with autism. It carefully attempted to correct many of the limitations of previous sibling intervention studies by including a larger sample size, objective measures, a control group, and parents in the intervention. This study used a between-groups design and evaluated the worries of siblings of children with autism after a brief one-time intervention with a random assignment experimental procedure. This

work built upon the results from several studies conducted at Illinois Wesleyan University (Kunce and Irwin, 2002; Kunce & Groh, 1998).

Based on the results of past studies, several hypotheses were proposed. First, it was hypothesized that children's autism-related worries would be lower in the workbook condition in comparison to the games condition. Second, it was hypothesized that parents would be able to predict their children's worries more accurately in the workbook condition as compared to the games condition. Third, it was hypothesized that both parents and children would report improved autism-specific communication in the workbook condition as compared to the games condition. Fourth, it was hypothesized that exploratory analyses will support the usefulness of the proposed stress and coping model of siblings of children with autism.

## Method

### *Participants*

Participants were typically developing siblings of children with autism and that child's biological parent. Detailed demographic information for the participating children and parents as well as information about the autistic sibling and family autism support is provided in Table 1.

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Insert Table 1 here  
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Twenty-five typical siblings of children with autism participated in this study. The 8 female children (32%) and 17 male children (76%) ranged from 6 to 13 years of

age ( $M = 9.63$ ,  $SD = 1.89$ ). Most participants were Caucasian (76%), although African American (4%), Asian (4%), Mixed (12%) and other races (4%) were also represented. Participants ranged from almost seven years younger than the autistic sibling to about 6 years older ( $M = -.43$ ,  $SD = 3.78$ ). These siblings attended support groups an average of just over 4 times a year ( $M = 4.44$ ,  $SD = 10.71$ ), although this figure ranged from 0 to 52 sessions per year. Finally, no participants scored above the 98<sup>th</sup> percentile, which is the clinically significant cutoff for internalizing or externalizing disorders based on the Childhood Behavior Checklist completed by the parent. Five participants (20%) fell between the 95<sup>th</sup> and 98<sup>th</sup> percentile on this measure, however, the majority fell below well below this level (80%), and the mean of the sample did not differ significantly from norms,  $t(23) = .018$ ,  $p = .986$ .

Twenty-three biological parents of typical children of autistic siblings also participated in this study (two parents each worked with two typical siblings). Most of the parents were either in their 30's (41%) or over 40 (54%), although one participant was under thirty (5%). Sixteen mothers (70%) and seven fathers (30%) were represented in the sample, and almost all participants were married ( $N = 22$ ). All parents reported at least a high school education, and most had received some college education ( $M = 15.67$  years,  $SD = 2.16$  years). The number of times the family talked about autism per month ranged from 0 to 100 times ( $M = 12.96$ ,  $SD = 7.59$ ), and report of autism support group visits per year ranged from 0 to 24 visits ( $M = 8.48$ ,  $SD = 7.59$ ).

Parents provided additional demographic information on the non-participating sibling with autism. The age of the autistic sibling ranged from 4 to 17 years ( $M = 8.48$ ,  $SD = 7.59$ ). The gender ratio, four girls (18%) to 21 boys (81%), was typical of the



global autism gender ratio. Finally, the autistic child's clinical diagnosis fell within the following autism spectrum categories: autism (41%), high functioning autism or Asperger's disorder (41%) and Pervasive Developmental Disorder-Not Otherwise Specified (28%). The severity of autism was reported by parents as either mild (32%), moderate (64%), or severe (4%).

A final observation is the attrition rate of the participants in the follow-up phase of the study. Of the 25 original parent-child pairs, 95% (n=21) of the families eligible for the first follow-up survey (3 weeks) could be contacted (three families participated too recently for follow-up measures). In addition, 78% (n=14) of the 18 families eligible for the second follow-up survey (1 year) could be contacted (7 families participated too recently for follow-up measures).

### *Child Measures*

*Autism Worries Survey (AWS).* This is a 50-item questionnaire (Kunce & Groh, 1998) used in previous studies at Illinois Wesleyan University. Items are presented in the "Some kids worry that..." format (See Figure 2). For example, "Some kids worry that they will catch their brother's or sister's autism." The child is asked to indicate his or her degree of worry on a 4-point scale that ranges from "really worries" to "doesn't worry." A 10-item short version of the AWS, called the AWS-Short Form (AWS-Short), was given as the pretest measure to the children to check pre-treatment group equivalence and as a follow-up measure to both the parents and the children in the time one phone survey. The internal consistency of the AWS was excellent,  $\alpha = 0.96$ , and the internal consistency of the AWS-Short Form was high,  $\alpha = 0.87$ .

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Insert Figure 2 here

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*Sibling Relationship Questionnaire-Revised (SRQ-R)* (see Buhrmester & Furman, 1990). This measure consists of 16 scales each containing 2-3 items totaling 48 items. These items measure children's perceptions of their siblings. This measure is a well developed and frequently used self-report measure of sibling relationship qualities. It has substantial empirical support as a reliable measure with high validity.

*Autism Communication Scale (ACS)*. This measure was developed for earlier sibling intervention studies at Illinois Wesleyan University (see Kunce and Irwin, 2002; Kunce and Groh, 2000), and consists of 10 items assessing parent-child communication regarding autism. For example, one item asks "I get nervous when talking to my parent about autism". This measure had an internal consistency of  $\alpha = 0.78$ .

*Coping Appraisal Scale*. This measure contains 10 items created for prior sibling studies (see Kunce and Irwin, 2002). It measures children's feelings of self-efficacy by asking how well they think they could handle certain situations. For example, "If my brother or sister misbehaves in public." Children were asked to place a pen mark next to one of three responses for each situation: I could not handle this, I could sort of handle this, and I could handle this very well. The children's responses are on a 3-point scale ranging from 0 to 2, with 2 representing the highest degree of coping. This measure had an internal consistency of  $\alpha = 0.72$ .

*Child Activity Form.* This is a simple measure developed for the use in earlier sibling intervention studies at Illinois Wesleyan University (see Kunce and Terril, 2000). This form is a two-item questionnaire that assesses the child's perceptions of the activity.

#### *Parent Measures*

*Demographics Questionnaire.* This measure is a brief demographics questionnaire about the parents and their children. This form seeks factual participant data as well and data about family communication and the use of support services.

*Autism Worries Survey (Parent).* This is a parallel version of the AWS (Child) measure except the questions are reworded to have the parents describe their children's worries. This measure had an internal consistency of  $\alpha = 0.96$ .

*Sibling Relationship Questionnaire-Revised (Parent)* (Buhrmester & Furman, 1990). This is a parallel version of the child measure except the questionnaire assesses the parent's perception of the sibling relationship. This measure is a well-developed and frequently used self-report measure of sibling relationship qualities. It has substantial empirical support as a reliable measure with high validity.

*Autism Communication Scale (ACS).* This measure was developed for earlier sibling intervention studies at Illinois Wesleyan University (see Kunce and Irwin, 2002; Kunce and Groh, 2000), and consists of 10 items assessing parent-child communication regarding autism. This measure had an internal consistency of  $\alpha = 0.55$ .

*Parent Activity Evaluation Form: Treatment Evaluation Inventory-Short Form (TEI).* This measure assesses consumer perceptions of intervention techniques and is frequently used.

*Child Behavior Checklist (CBCL)* (Achenback & Edelbrock, 1983). This is a questionnaire designed to assess children's internalizing and externalizing problems. This measure is reliable and frequently used.

*Coping Appraisal Scale (Parent)*. This measure contains 10 items created for this study in order to measure the parent's perception of the child's coping. It is a parallel to the Coping Appraisal Scale, which was used in the child measures. This measure had an internal consistency of  $\alpha = 0.90$ .

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 Insert Table 2 here  
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### *Procedure*

The siblings of children with autism were recruited by notifying autism support groups, school programs, and special recreation programs, as well as sibling support groups in Bloomington/Normal, St. Louis, and the Chicago Suburbs. Recruitment flyers, registration cards detailing the project, and emails were distributed through these organizations, through the mail, or through internet autism list-servs. Participants were encouraged to attend for the opportunity to spend quality time with their typically developing sibling while contributing to the research involving communication and families with an autistic child. In addition, the parent-child pairs received a snack during the activity and the children received a small gift at the end of the session.

Instructions for completing the games activity were sent to the intervention group, and instructions for completing the workbook as well as a workbook itself were sent to the control group approximately one month after participation in the study (following the

first of two follow-up measures). This allowed for the families to try the activity that they were not selected to complete during the study.

Participants were assigned to condition through matched random assignment. There were no group differences found between the workbook and the games condition, including a pre-test for autism worries (See Table 1). The intervention consists of a one-time session for each parent-child pair, lasting approximately two hours (See Table 2). The sessions took place at universities, schools, public libraries and other public facilities. Each session began with the parent-child pairs meeting in the same room to obtain consent and assent.

*Pretest:* Following the assent and consent forms, the parents and children met in separate rooms. The child participants completed pretest measures and the parent participants were given instruction sheets to read for their assigned activity.

*Intervention:* Upon completion of the pretest measures and parental instructions, the parent-child pairs were reunited for the intervention activity. Intervention and control conditions were randomly assigned: the intervention consisted of a workbook activity and the control consisted of a games activity. The participants met in parent-child pairs in private rooms for this portion of the study. Approximately 45 minutes were allotted for these activities.

The intervention group was given workbook assignment to complete (See Figure 3). Prior to this activity, the parent were be given a copy of the workbook and asked to review it and ask any questions he or she might have regarding the activity. They were also given the “Parent Instruction Handout: Tips for Completing the Autism Workbook with your Children.” This handout encouraged the pairs to take breaks during the activity

as needed and to avoid responding in a judgmental manner. The workbook was designed to promote autism specific communication between the child and the parent and specifically focused on that child's sibling-related autism worries. The workbook was divided into two sections. The first section contains 33 items that the child fills out with the parent about specific autism worries such as to an item "I worry that my brother or sister will hurt himself or herself" (See figure 3). The second section contained eight vignettes created to help parents and children discuss and develop coping skills for each of these specific autism worries. The parent-child pairs were asked to complete the first section of the workbook during this intervention period, as well as one of the activities from the second workbook section.

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 Insert Figure 3 here  
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The control group was asked to play games together (e.g., cards, checkers, and chutes and ladders, etc., as provided by the researchers,) during the intervention period. Prior to this activity, the parents were allowed to review the games and ask questions. They also received a "Parent Instruction Handout: Tips for Games Activity," which discussed maintaining their focus on the child and taking breaks as needed throughout this activity. The focus of the games was its similarity to non-directive play therapy techniques.

*Post-Test:* Following the intervention period, the parent-child pairs once again went into separate rooms to complete the dependent measures. Research assistants were available to help the children in completing the measures when necessary.

*Follow-Up:* Parent-child pairs were called about three weeks after the workshop and each participant was asked a short version of the Autism Worries Survey as used in the child pretest measures ( $N = 21$ ; one family could not be reached, three families participated within three weeks from this report). Each participant was also asked about his or her follow-up activity experiences during this phone call. A second follow-up phone survey was conducted approximately one-year following the intervention workshop. Fourteen of 18 participants were contacted, the others could not be reached (in addition, seven families participated this year and are not yet eligible for the second follow-up phone survey). Each participant was asked what they remember about the study, negative and positive consequences, and family communication changes. The inter-rater reliability for the follow-up coding was around 91.1%. All follow-up responses were coded by the author and two assistants, blind to experimental condition.

## Results

### *Group Pretest Comparisons*

Pretest measures were conducted to ensure group equivalency prior to the intervention. T-test analyses revealed no significant differences between the workbook and games group on the following variables: child's age, behavior problems, autism worries, parent education, autistic child's age, or age difference between the typical and autistic sibling. In addition, gender ratios were similar across groups (see Table 1 for analyses of group differences).

### *Child Worries*

Overall, on the Autism Worries Survey (50 total items), typical child participants endorsed an average of 46% of all total worries ( $M = 23.2$ ,  $SD = 12.0$ ) and the parent participants endorsed an average of 48% of all total worries ( $M = 24$ ,  $SD = 11.22$ ). The variability in the number of reported worries is worth noting. Child worries ranged from one to 45 endorsed worries out of a total of 50. Likewise, parent worries ranged from two to 43 on the same scale.

The first experimental hypothesis predicted that the typical child's autism related worries would be lower in the workbook condition in comparison to the games condition. T-test analyses did not support this hypothesis and no differences were found between the child reports for total number of autism worries in the workbook and games conditions  $t(23) = -.248$ ,  $p = .806$ , nor the total intensity in both groups  $t(23) = -.938$ ,  $p = .358$ . (See Table 4 for means and standard deviations for child and parent reports for both number and intensity of child autism worries). Likewise, t-test analyses of parent reports of child worries did not differ for number of child worries  $t(23) = -.035$ ,  $p = .972$ , nor for intensity of child worries  $t(23) = -.606$ ,  $p = .55$ .

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 Insert Table 3 here  
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As an additional test of hypothesis one, the 10-item AWS-short form was given to both child and parent participants at the time-one follow-up survey. Similar to the full AWS data, the follow-up information does not support the first hypothesis. The follow-up information was analyzed in a 2 (time) x 2 (activity) analysis of variance. No significant main effects for time,  $F(1, 20) = .071$ ,  $p = .793$ , main effects for activity,  $F$



(1, 20) = 1.34,  $p = .261$ , or an interaction effect for time and activity,  $F(1, 20) = 2.06$ ,  $p = .167$ , were found. Thus, the mean number of worries reported by the workbook group at the time-one follow-up survey ( $M = 4.7$ ,  $SD = .965$ ) did not differ significantly from worries reported by the games groups ( $M = 5.45$ ,  $SD = .920$ ). (See Table 3).

#### *Parent-Child Accuracy*

The second hypothesis predicted that parents would be able to report their children's worries more accurately in the workbook condition as compared to the games condition. There is strong support for this hypothesis based on a strong significant correlation of the child and parent number of reported worries for the workbook condition  $r = 0.888$ ,  $p < 0.000$ , compared to the non-significant correlation for the games condition  $r = -.197$ ,  $p < .540$ . A Fisher's  $r$  to  $z$  transformation was used to test for differences between the correlation for number of worries for workbook and games. The correlation for number of worries was found to be significantly different,  $F = 2.65$   $p < 0.05$ . (See Figure 4).

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Insert Figures 4 and 5 here  
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In addition, data from the time one (3 week) follow-up mini-AWS survey also supports this hypothesis. The child and parent agreement for number of reported worries for the workbook condition at this time were highly significantly correlated,  $r = 0.836$ ,  $p < 0.003$ , compared to a non-significant correlation in the games condition,  $r = .134$ ,  $p < .695$  (See Table 4). Again, a Fisher's  $r$  to  $z$  transformation was used to test for differences between the correlation for number of worries for workbook and games. The

correlation for number of worries was found to be significantly different,  $F = 2.37, p < 0.05$ . (See Figure 5.)

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 Insert Table 4 here  
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### *Autism Communication*

The third hypothesis states that both parents and children would report improved autism-specific communication in the workbook condition as compared to the games condition. T-tests on scores from the child and parent Autism Communication Scales did not support this hypothesis. There was no significant difference between the quality of communication reported by the children in the workbook condition ( $M = 3.00, SD = .572$ ) or the games condition ( $M = 2.93, SD = .806$ ),  $t(23) = .240, p = .812$ . Likewise, there was no significant difference between the communication reported by the parents in the workbook condition ( $M = 4.05, SD = .598$ ), or the games condition ( $M = 3.98, SD = .742$ ),  $t(23) = .233, p = .818$ .

An additional approach to examining autism-specific communication is to look at group differences in the time-one and time-two follow-up data relative to autism communication (see tables 5 and 6). In the first and second follow-up surveys, parents and children were asked questions about the frequency of autism-specific communication. Virtually all parents reported talking about autism-related worries after the study with a non-significant trend for greater parent-child talk in the workbook group in the time-one survey (100% vs. 73%;  $M$  of 5.6 vs. 4.00). Similarly, almost of parents

reported talking about autism related worries in the second follow-up survey, especially in the workbook group compared to the games group (100% vs. 86%). Workbook group parents reported very similar amounts of communication as the games group at the time-two follow-up: “1-5 times total” (43% vs. 66%); “1-3 times a month” (28% vs. 14 %). Child participants were also asked if they talked to their parents about autism worries in both the time-one and time-two follow-ups. It is interesting to note the discrepancies among parent and child reports of communication frequencies in the workbook vs. games groups (40% vs. 73% time-one; 57% vs. 28% time-two).

Time-one and time-two responses suggest that groups may have not only differed in the amounts of autism communication, but also in the types of topics discussed. When asked what topics were discussed, the workbook group’s most frequent responses were “differences from typical child and autistic child development and abilities” (30%) and “other sibling worries” (30%). The games group’s most frequent responses differed qualitatively from the workbook group. The games group’s most frequent responses were “social worries” (36%) and “care-taking worries” (27%). Inspection of time-two follow-up responses suggest, once again, that groups may have differed in the topics. The topics discussed were very consistent with the time-one responses. The workbook group’s most frequent response was “differences from typical child and autistic child development and abilities” (43%) and the games group’s most frequent responses were “caretaking worries” (43%) and “social worries” (57 %).

Finally, groups appeared to differ in the occurrence of citing communication as a benefit of the study. A question added to the first follow-up surveys of the more recently contacted families ( $N = 7$  workbook, 9 games) asked parents if they learned anything new

about their child as a result of the study. 60% of the workbook group responded “yes” compared to only 18% of the games group. Also at time-one, when questioned about positive consequences of the study, the workbook group recalled communication changes more often than the games group as a positive consequence (36.4% vs. 18.2%). In the time-two survey, virtually all workbook and games participants reported positive changes in family autism communication (100% vs. 86%). When asked what types of positive consequences the study had, the time-one workbook group was more likely than the games group to cite communication related consequences including “increased awareness” (40% vs. 18%) and “increased communication” (50% vs. 36%). However, in the time-two follow-up, both workbook and games parents reported low amounts of communication benefits in both groups (14% increased communication, both groups). In addition, at time-two both groups report the same amount of increased communication as a positive result (14% both). The children were asked a similar question about benefits of the study at each follow-up survey. In both the time-one and time-two parent follow-up surveys, children were asked “if there was anything good” from participating in the study. At both time-one, and time two, the workbook group recalled a positive of the study that related to communication more often than the games group recalled a communication benefit (60% vs. 46% time-one; 71% vs. 43% time two).

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 Insert Tables 5 & 6 here  
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*Stress and Coping Model*

Correlational analyses were used in an exploratory analysis of the proposed model, specifically between *background factors* and the *adaptational outcome*, and *cognitive appraisal* and *adaptational outcome* ( See Table 7 for details). The many *background factor* variables that were examined include child's age, child's age difference from autistic child, autism communication, severity of the sibling's autism, sibling relationship quality, and family communication. The *background factors* were operationalized using the parent-reported demographics, the parent and child Autism Communication Scales and parent and child Sibling Relationship Questionnaires. *Cognitive appraisal* was measured using the parent and child number of worries as reported on the Autism Worries Survey in addition to the child Coping Appraisal Scale. Correlational analyses also looked for relationships between *the background factors* described and the child's *adaptational outcome*. The *adaptational outcome* was measured using the internalizing and externalizing scales from the parent reported Child Behavior Checklist.

Most *background variables* did not significantly correlate with the *cognitive appraisal* with the exception of the Parent Autism Communication Scale (PACS)  $r = -.530, p = .008$  (CBCL total scale). In other words, high quality communication is associated with fewer parent reported autism worries. Some of the *background factors* significantly correlated with the *adaptational outcome*. The child Autism Communication Scale (ACSR) was significantly correlated with the externalizing scale on the CBCL score,  $r = -.469, p = .024$ . The Parent Autism Communication Scale (PACS) was also significantly correlated with both internalizing  $r = -.419, p = .041$ , and externalizing subscales on the CBCL,  $r = -.469, p = .024$ . In other words, high quality of

communication as reported by both children and parents correlated with parent reports of lower amounts of child externalizing problems.

Finally, some of the *cognitive appraisal* variables were significantly correlated with the child's *adaptational outcome*. Specifically, the parent report of number of child autism worries (AWS-Parent;  $r = .451, p = .027$ ) and the child Coping Appraisal Scale ( $r = -.586, p = .003$ ) are both correlated with the internal CBCL scale, such that high internalizing scores are associated with both a high amount of autism worries and a low coping appraisal score.

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Insert Table 7 here  
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### *Treatment Acceptability*

Results indicated that both child and parent participants rated activities favorably, with differences by activity for child but not parent reports. The children's Activity Evaluation Scale was based on a 4-point scale. For both groups, the means describe the children rating the activity between a '4' on the scale corresponding to "I really like it" and a '3' on the scale corresponding to "I liked it somewhat" (workbook  $M = 3.61, SD = .42$ ; games  $M = 3.93, SD = .19$ ). The Parent Activity Evaluation Form was based on a 5-item scale. The means describe the parents as rating both activities near the "agree" or '4' on the scale to questions similar to the example: "I believe that this activity is likely to be effective as a way to decrease my child's worries" (workbook  $M = 4.05, SD = .52$ ; games  $M = 3.93, SD = .43$ ). A significant difference was found between the workbook and the games conditions for child assessment of treatment acceptability,  $t(23)$

$= -2.348, p = .031$ . The children rated the games activity higher than the workbook activity. There were no group differences between the workbook or games condition for the parents' assessment of treatment acceptability,  $t(23) = .630, p = .535$

## Discussion

Typical siblings of autistic children can be at-risk for problems inherent to having a brother or sister with autism. However, there is a lack of theoretical explanations for the variability in sibling outcome, as well as a dearth of objective and experimental intervention studies that recruit a large number of heterogeneous participants. Most descriptive research has involved siblings of children with multiple chronic disabilities, not limiting the study to autism. Further, sibling interventions have been developed and reported, however, these lack sufficient empirical support of effectiveness. A stress and coping model of typical child adjustment, such as the one presented in the introduction to this report, may help researchers and clinicians better understand risk factors, make sense of the many contextual variables, identify siblings more at-risk for difficulties, and better design and implement sibling intervention programs.

The reported study was designed using logic from the stress and coping model of typical child reaction to an autistic sibling in an effort to address gaps in the autistic sibling literature, primarily through addressing child autism worries, using an experimental and objective intervention design, and involving parents. The experimental group used an autism worries workbook and the control group played games together. The number and intensity of child autism worries, the accuracy of the child and parent reports of child autism worries, and the parent and child autism communication report

were the main variables examined in this study. In addition, exploratory analysis studied the effectiveness of the proposed stress and coping model.

### *Child Worries*

The first hypothesis predicted that the typical child's autism related worries would be lower in the workbook condition in comparison to the games condition. However, several analyses conducted immediately after the intervention and three week follow-up showed that the workbook and games did not significantly differ in the amount or intensity of worries that the typical sibling reported about the intervention activity. Therefore, the results suggest that the workbook intervention was not effective in changing the immediate child or parent perception of typical child autism-related worries. This finding is not surprising based on the relative brevity of the intervention. Perhaps perceptions of autism worries do not change after a brief one-time intervention. It may be possible to obtain significant results across similar, yet longer, interventions.

### *Parent-Child Accuracy*

The second hypothesis was that parents would be able to more accurately predict their children's worries in the workbook condition as compared to the games condition. The correlation between child and parent report of child worries was very strong and significant in the workbook condition, but weak and non-significant in the games condition. Thus, the workbook increased parent accuracy in predicting child worries compared to the games group, supporting the idea that the workbook was useful in making parents more aware of their children's autism-specific worries. Follow-up data was in agreement with the initial results regarding increased agreement in the parent and child report of worries in the workbook condition compared to the games condition. This



data suggests that the results may be a lasting positive effect of the study, or at least persistent for the short follow-up period. Theoretically, parent-child agreement is related to the parent-child relationship, family communication, and child autism-specific knowledge, all background factors described in the stress and coping model. Increased parent-child agreement may help typical children to be more resistant to negative adaptational outcomes of having an autistic sibling, including problematic internalizing and externalizing behaviors.

### *Autism Communication*

The third hypothesis predicted that parents and children would report improved autism-specific communication in the workbook condition as compared to the games condition. However, the results did not support the conclusion based on the initial post-test data. The immediate communication data suggests that the brief intervention was not sufficient for improving immediate perception of global autism communication.

On the other hand, exploratory analyses of the follow-up data suggests that the intervention was successful at provoking some autism-specific communication within the family following the workshop for both the workbook and games groups. Almost all of the parents and the majority of children surveyed at the follow-up times described talking with their typical child about autism-specific worries following the study, even a year later and especially in the workbook group. The follow-up data suggests that the workshop may help give parents and siblings language to discuss autism-specific worries, an opportunity to bring up such issues, and a one-on-one parent-child connection which allows the participants to “open-up” to one another. The overall similarity between the workbook and games participants’ communication responses in the follow-up surveys

may be a reflection of the types of questions asked on the post-test survey, or a result of spending quality time with each other.

### *Stress and Coping Model*

Exploratory correlational analyses of the effectiveness of the stress and coping model of typical child reaction to an autistic sibling offered preliminary support for this type of theoretical framework. A large number of non-significant correlations were found, however, some significant results linked specific pieces of the model. An important and significant background factor measured in this study was autism communication. Increased amount and quality of family autism communication is related to an improved report of both the typical child's *cognitive appraisal* and to the child's *adaptational outcome*. In addition, number of worries and cognitive appraisal variables were related to the child's *adaptational outcome*, as well. On the other hand, non-significant data helps to identify factors that may not play a role in predicting a child's *adaptational outcome*. Interestingly, intrinsic factors such as age, sibling relationship, and severity of autism did not play a role in predicting sibling outcome. Future research may choose to study different pieces of the stress and coping model in an effort to better identify the significant contextual and mediating variables and to assess the overall effectiveness of the model. A larger sample size would allow for the use of a regression analysis/path analysis of the model. In addition, better measures could more effectively focus on different aspects of the model.

### *Treatment Acceptability*

In conclusion, both parent and child participants rated the activities in a very positive way. This demonstrates the acceptability of the activities, and that they are

perceived as fun or enjoyable for both parents and children. This is crucial as it shows that the children react positively to participating, and that there are no harmful effects as a result of the study. In addition, these results lend evidence that the parents viewed that games condition as an equally rewarding treatment to the workbook condition, suggesting that this was a stringent control condition.

### *Strengths and Limitations*

This study attempted to improve on many of the limitations of previous sibling intervention studies. First, one of its strengths was the use of an experimental design with matched random assignment to groups. Second, the sample was larger than many previous studies and perhaps more important this study focused only on typical siblings of children with autism spectrum diagnoses without including additional chronic disabilities. Third, this study took advantage of the Autism Worries survey as an objective measure with high internal consistency and evidence of construct validity rather than solely relying on subjective measures of sibling adaptational outcome. This allowed for multiple informant measures of child's worries. Fourth, the intervention involved parents, which may improve the typical child's adaptational outcome to the experience of having an autistic sibling. Finally, this study provides limited support for the effectiveness of a theoretical framework to help predict sibling outcome, to organize the contextual variables placing siblings at-risk for problems, and to guide the creation of successful intervention techniques.

This study is not without limitations. It is very important to note that the intervention was a brief one-time activity. Future research may attempt to expand on the intervention duration in order to examine the important effects of repeated exposure and

increased developmental understanding. Another limitation comes from the homogeneity of the sample. Most of the child participants were Caucasian, from intact and highly educated families, and were boys with male autistic siblings. This study suffered from a very high self-selectivity for participation. An estimated 500 to 1,000 total families were contacted about the study, however, only 25 families responded. Future studies may reach out to a more diverse population to get a more accurate sampling of sibling worries and contextual background factors contributing to different adaptational outcomes. Finally, this study was not designed to specifically assess the stress and coping model of typical child reactions to an autistic sibling. Future studies need to expand on the initial exploratory analyses to gain a better understanding of the factors involved in typical sibling coping and outcome.

Typical siblings of children with autism face daily challenges that may play a role in increasing the amount of worries they have relative to other children. This study was one attempt to help ease these worries and to increase parental awareness of these worries. In addition, the review for this study attempted to organize information relevant to siblings of children with autism in order to help identify which variables place a child at-risk for problems, to explain the variation in sibling outcome and to help guide intervention designs. Initial results provide promising support for the effectiveness of the workbook intervention activity. This study showed that parents were able to better predict their children's worries after the workbook activity. Future research should expand on this intervention with repeated exposure to a similar design with a more heterogeneous sample of siblings of children with autism, as guided by the stress and coping model of typical child reaction to a sibling with autism.

## References

- Abramson, R., Wright, H., Cuccaro, M, Lawrence, L, et. al. (1992). Biological liability in families with autism. *Journal of the American Academy of Child & Adolescent Psychiatry*, 31, 370-371.
- American Psychiatric Association. Diagnostic and statistical manual of mental disorders. 4<sup>th</sup> ed. Washington (DC): American Psychiatric Association; 1994.
- Bagenholm, A. & Gillberg, C. (1992). Psychosocial effects on sibling sof children with autism and mental retardation: A population-based study. *Journal of Mental Deficiency Research*, 35, 291-307.
- Bagenholm & Gillberg, C. (1991). Psychosocial effects on siblings of children with autism and mental retardation: a population-based study. *Journal of Mental Deficiency Research*, 35, 291-307.
- Bank, S., Kahn, M., (1982). *The Sibling Bond*. New York: Basic Books.
- Bebko, J., Konstantareas, M., Springer, J. (1987). Parent and professional evaluations of family stress associated with characteristics of autism. *Journal of Autism & Developmental Disorders*, 17, 565-576.
- Bolton, P., Pickles, A., Murphey, M, & Rutter, M., (1998). Autism, affective and other psychiatric disorders: Pattern of familial aggregation. *Psychological Medicine*, 28, 385-395.
- Breslau, N., Weitzman, M., & Messenger, K. (1981). Psychologic functioning of siblings of disabled children. *Pediatrics*, 67, 344-353.
- Brody, G. H. (1998). Sibling relationship quality: Its causes and consequences. *Annual Reviews of Psychology*, 49, 1-24.

- Brody, G., Stoneman, Z., McCoy, J. (1994). Contributions of family relationships and child temperaments to longitudinal variations in sibling relationship quality and sibling relationship styles. *Journal of Family Psychology*, 8, 274-286.
- Brodzinsky, D. (1990). *The Psychology of Adoption*. Rutgers U, New Brunswick, NJ.
- Bryson, S.E., Clark, B.S., & Smith, I.M. (1988). First report of a Canadian epidemiological study of autistic syndromes. *Journal of Child Psychology and Psychiatry*, 29, 433-446.
- Buhrmeister, D., & Furman, W. (1990). Perceptions of sibling relationships during middle childhood and adolescence. *Child Development*, 61, 1387-1398.
- Burack, J.A., Charman, T., Yirmiya, N., & Zelazo, P.R. (2001). *The Development of Autism: Perspectives from Theory and Research*. Lawrence Erlbaum Associates, Inc.: Mahwah, NJ.
- Caro, P., & Derevensky, J. (1997). An exploratory study using the sibling interaction scale: observing interactions between siblings with and without disabilities. *Education and Treatment of Children*, 20, 383-403.
- Celiberti, D.A. & Harris, S.L. (1993). Behavioral intervention for siblings of children with autism: A focus on skills to enhance play. *Behavior Therapy*, 24, 573-599.
- Clark, M., Cunningham, L., Cunningham, C. (1989). Improving the social behavior of siblings of autistic children using a group problem solving approach. *Child & Family Behavior Therapy*, 11, 19-33.
- Deal, S.N., & MacLean, W.E. (1995). Disrupted lives: siblings of disturbed adolescents. *American Journal of Orthopsychiatry*, 65, 274-281.

- Dellve, L., Cernerud, L., Hallbery, L. (2000). Harmonizing Delemmas: Siblings of children with DAMP and asberger syndrome's experiences of coping with their life situations. *Scandinavian Journal of Caring Sciences*, 14, 172-178.
- Delong, G., Dwyer, J., (1988). Correlation of family history with specific autistic subgroups: Asperger's syndrome and bipolar affective disease. *Journal of Autism & Developmental Disorder*, 18, 593-600.
- Knott, F., Lewis, C., Williams, T. (1996). Sibling interaction of children with learning disabilities: A comparison of autism and Down's syndrome. *Journal of Child Psychology & Psychiatry & Allied Disciplines*, 36, 965-976.
- Kunce, L., Groh, G. (2000). Anxiety in siblings of children with autism. Unpublished senior thesis, Illinois Wesleyan University.
- Kunce, L., Irwin, S. (2002). *The effects of a parent-child communication activity on the worries of siblings of children with autism*. Unpublished senior thesis, Illinois Wesleyan University.
- Folstein, S.E. & Rutter, M.L. (1988). Autism: familial aggregation and genetic implications. *Journal of Autism & Developmental Disorders*, 18(1), 3-30.
- Gamble, W.C. & McHale, S.M. (1989). Coping with stress in sibling relationships: a comparison of children with disabled and nondisabled siblings. *Journal of Applied Developmental Psychology*, 10, 355-373.
- Garcia, M., Shaw, D., Winslow, E. (2000). Destructive sibling conflict and the development of conduct problems in young boys. *Developmental Psychology*, 36, 44-53.

- Glasberg, B.A. (2000). The development of siblings' understanding of autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 30, 143-156.
- Gold, N. (1993). Depression and social adjustment in siblings of boys with autism. *Journal of Autism and Developmental Disorders*, 23, 147-162.
- Harris, S.L. (1994) *Siblings of Children with Autism*. Bethesda, MD: Woodbine House.
- Helps, S., Newson-Davis, I., Callias, M. (1999). Autism: The teacher's view. *Autism*, 3, 287-298.
- Howlin, P. (1988). Living with impairment: the effects on children of having an autistic sibling. *Child: care, health and development*, 14, 395-408.
- Howlin, P. & Yates, P. (1989). *Diagnosis and treatment of autism*. University of London, Institute of Psychiatry, Maudsley Hospital, London.
- Jenkins, J. & Smith, M. (1990). Factors protecting children living in disharmonious homes: Maternal reports. *Journal of the American Academy of Child & Adolescent Psychiatry*, 29, 60-69.
- Kaminskey, L. & Dewey, D. (2001). Siblings' relationships of children with autism. *Journal of Autism and Developmental Disorders*, 31, 399-410.
- Kaminskey, L. & Dewey, D. (2002). Psychosocial adjustment in siblings of children with autism. *Journal of Child Psychology & Psychiatry & Allied Disciplines*, 43, 225-232.
- Kaplan, F., Fox, E. (1968). Siblings of the retardate: An adolescent group experience. *Community Mental Health Journal*, 4, 499-508.



- Koegel, R., Schreibman, L, O'Neill, R. & Burke, J. (1983). The personality and family-interaction characteristics of parents of autistic children. *Journal of Consulting & Clinical Psychology*, 51, 683-692.
- Konstantareas, M., Homatidis, S. (1989). Assessing child symptom severity and stress in parents of autistic children. *Journal of Child Psychology & Psychiatry & Allied Disciplines*, 30(3), 459-470.
- Lainhart, J. (1999). Psychiatric problems in individuals with autism, their parents and siblings. *International Review of Psychiatry*, 11, 278-299.
- Lazarus, R., and Folkman, S. (1984). *Stress, Appraisal and Coping*. New York, NY. Springer Publishing Company, Inc.
- Lobato, D. (1985). Brief report: preschool siblings of handicapped children- impact of peer support and training. *Journal of Autism and Developmental Disorders*, 15, 345-350.
- Lobato, D., Tlaker, A. (1985). Sibling intervention with a retarded child. *Education & Treatment of Children*, 8, 221-228.
- Mates, T.E. (1990). Siblings of autistic children: their adjustment and performance at home and in school. *Journal of Autism and Developmental Disorders*, 20, 545-553.
- McHale, S.M., Sloan, J., & Simeonsson, R.J. (1986). Sibling relationships of children with autistic, mentally retarded, and nonhandicapped brothers and sisters. *Journal of Autism and Developmental Disorders*, 16, 399-413.
- McLinden, S.E., Miller, L.M., & Deprey, J.M. (1991). Effects of a support group for siblings of children with special needs. *Psychology in the Schools*, 28, 230-237.

- Meyer, K.F. & Vadasy, P.F. (1994). *Sibshops: Workshops for Siblings of Children with Special Needs*. Baltimore: Paul H. Brookes Publishing Co.
- Piven, J. (1999). Genetic liability for autism: the behavioural expressions in relatives. *International Review of Psychiatry*, 11(4), 299-309.
- Piven, J., Palmer, P. (1999). Psychiatric disorder and the broad autism phenotype: Evidence from a family study of multiple-incidence autism families. *American Journal of Psychiatry*, 156, 1999, 557-563.
- Piven, J., Palmer, P., Jacobi, D., & Childress, D., (1997). Broader autism phenotype: evidence from a family history study of multiple-incidence autism families. *American Journal of Psychiatry*, 154(2), 185-190.
- Powers, M.D. (Ed.). (2000). *Children with Autism: A Parent's Guide*. Bethesda, MD: Woodbine House.
- Rodrigue, J.R., Geffken, G.R., & Morgan, S.B. (1990). Families of autistic children: Psychological functioning of mothers. *Journal of Clinical Child Psychology*, 19, 371-379.
- Rodrigue, J.R., Geffken, G.R., & Morgan, S.B. (1993) Perceived competence and behavioral adjustment of siblings of children with autism. *Journal of Autism and Developmental Disorders*, 23, 665-674.
- Schopler, E., Yirmiya, N., Shulman, C., & Marcus, L. (2001). *The Research Basis for Autism Intervention*. Kluwer Academic / Plenum Publishers, New York, NY.
- Siegel, B. & Silverstein, S. (1994). *What About Me? Growing Up with a Developmentally Disabled Sibling*. New York: Insight Books.

- Seligman, M. (1983). Sources of psychological disturbance among siblings of handicapped children. *Personnel and Guidance Journal*, 61, 529-531.
- Sharpley, C., Bitsika, V., Efremidis, B. (1997). Influence of gender, parental health, and perceived expertise of assistance upon stress, anxiety, and depression among parents of children with autism. *Journal of Intellectual & Developmental Disability*, 22(1), 19-28.
- Stormshak, E., Bellanti, C., and Bierman, K. (1996) The quality of sibling relationships and the development of social competence and behavioral control in aggressive children. *Developmental Psychology*, 32, 79-89.
- Trevino, F. (1979). Siblings of handicapped children: identifying those at risk. *The Journal of Contemporary Social Work*, X, 488-493.
- Tunali, B., Power, T. (1995). Creating satisfaction: A psychologic perspective on stress and coping in families of handicapped children. *Journal of Child Psychology and Psychiatry*, 34, 945-957.
- Williams, P. (1997). Siblings and pediatric chronic illness: a review of the literature. *International Journal of Nursing Studies*, 34, 312-323.
- Wilson, J., Blacher, J., Baker, B. (1989). Siblings of children with severe handicaps. *Mental Retardation*, 27, 167-173.
- Wolf, L., Fishman, S., Ellison, D., & Freeman, T. (1998). Effect of sibling perception of differential parental treatment in sibling dyads with one disabled child. *Journal of the American Academy of Child and Adolescent Psychiatry*, 37(2), 1317-1326.

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Table 1

*Workbook and Games Group Means, Standard Deviations and Gender Ratios Prior to Experiment*

	Workbook Means (SD)	Games Means (SD)	Overall Number/ Ratio/ Mean (SD)	T-Test
<u>Typical Child Data</u>				
Boys : Girls	9:4	8:4	17:8	--
Age Typical Child	10.13 (1.92)	9.1 (1.77)	9.63 (1.83)	$t(23) = -.652, ns$
Child Behavior Problems	49.1 (10.70)	51.0 (12.41)	50.0 (11.37)	$t(22) = -.405, ns$
Child AWS-Short Form-Number	4.69 (2.90)	6.25 (2.30)	5.40 (2.69)	$t(23) = -1.48, ns$
<u>Parent Data</u>				
Fathers : Mothers	4:9	4:8	8:17	--
Years Parent Education	15.46 (2.44)	15.91 (1.87)	15.67 (2.16)	$t(23) = 1.43, ns$
Age Parent:				
Under 31	0	1	0:1	--
31-40	5	6	5:6	--
40 or older	8	5	8:5	--
<u>Sibling with Autism</u>				
Age Autistic Child	11.04 (4.37)	9.00 (2.65)	10.06 (3.7)	$t(23) = 1.42, ns$
Age: Sibling-Autistic Child	-.90 (4.47)	.08 (2.96)	-.43 (3.78)	$t(23) = -.652, ns$
<u>Other</u>				
Sib Support Groups (per year)	5.38 (14.2)	3.42 (5.2)	4.44 (10.71)	$t(23) = 2.08, ns$
Support Groups (per year)	11.4 (8.14)	5.27 (5.68)	8.48 (7.59)	$t(23) = .516, ns$

Table 2

*Pretest, Post-test, and Follow-up Measures for Parents and Children*

Procedure ( <i>N</i> = 25)	Workbook Group	
	Children	Parents
Pretest Forms		
1	Assent	Consent
2	AWS-Short	Activity Tips
Intervention		
1	Workbook	Workbook
Post-Test Measures		
1	--	Demographics
2	AWS	AWS(P)
3	SRQ-R	SRQ-R(P)
4	ACS	ACS
5	Coping Appraisal Scale	Parent Coping Appraisal Scale
6	Child Activity Evaluation Form	Parent Activity Evaluation Form
7	--	CBCL
Follow-Up Measures		
1 (3 weeks, <i>N</i> = 21)	Phone Survey I	Phone Survey I
2 (1 year, <i>N</i> = 14)	Phone Survey II	Phone Survey II

Table 3

*Typical Child and Parent Means and Standard Deviations for Total Number and Intensity of Child worries (AWS).*

	Child Mean (SD)	Parent Mean (SD)
Number		
Workbook:	22.6 (13.8)	24.1 (13)
Games:	23.8 (10.4)	23.9 (8.89)
Intensity		
Workbook:	1.73 (.57)	1.77 (.55)
Games:	2.00 (.65)	1.89 (.42)
Follow-Up (Time 1)		
Workbook:	4.7 (.965)	5.70 (2.58)
Games:	5.45 (.920)	6.45 (2.42)

*Note:* Number represents the number of endorsed (yes/no) worries (maximum of 50).

Intensity represents the mean intensity of worries on a 4-point scale, with 4 representing the highest degree or worry.

Follow-Up represents the number of endorsed (yes/no) worries (maximum of 10).

Table 4

*Parent-Child Accuracy of Number of Worries Immediately Following Intervention (AWS)  
and at Three Week Follow-Up (MAWS)*

	Parent-Child Accuracy	Parent-Child Accuracy Follow-Up
Workbook:	$r = 0.888^{**}, p < 0.000$	$r = .836^{**}, p = .003$
Games:	$r = -.197, p = .540$	$r = .134, p = .695$
Significance:	$F = 2.65, p < 0.05.$	$F = 2.37, p < 0.05.$

*Note:* Number (AWS) represents the number or endorsed (yes/no) worries (maximum of 50).

Number (MAWS) represents the number or endorsed (yes/no) worries (maximum of 10).



Table 5

*Selected Parent-Child Follow-Up I Communication Data for Workbook and Games*

	Mean (SD) or % Workbook	Mean (SD) or % Games
<u>First Parent Follow-Up:</u>	(N = 10)	(N = 11)
1. Did you talk about child's autism related worries? (% Yes)	100	73
2. Times talked about worries?	5.6 (5.99)	4.00 (1.63)
3. Who initiated the talks?		
Child Only?	10	27
Parent Only?	80	54
Both?	10	0
3. What topics discussed?		
Social	10	36
Caretaking	10	27
Sibling Relationships	20	0
Autism Differences	30	18
Sibling Future	20	9
Other Sibling Worries	30	18
4. Any positive consequences from participating in the study? (% Yes)	90	100
Increased Awareness	40	18
Communication	50	36
Time with Sibling	10	36
Exposure to Similar Others	20	9
Impact Behavior/Feelings	20	27
5. Learn anything new about child? (%Yes)	60	18
<u>First Child Follow-Up</u>		
1. Did you talk to parent about autism worries since the study? (% Yes)	40	73
2. Was anything good? (% Yes)	90	91
What?: (N = 7 Workbook, 9 Games; not asked of all families)		
Prizes	0	18
Fun and Games	10	45
Questions Asked	20	18
Talking About Sibling	20	0
Increased Understanding	20	27

Table 6

*Selected Parent-Child Follow-Up II Communication Data for Workbook and Games*

		% or M (SD) Workbook	% or M (SD) Games Second
<u>Parent Follow-Up</u>		(N = 7)	(N = 7)
1.	Did you talk to child about autism worries? (%Yes)	100	86
2.	Times talked about worries?		
	More than one a week	14	0
	About once a week	14	14
	1-3 times a month	28	14
	1-5 times total	43	66
2.	What topics did you discuss?		
	Social Worries	14	57
	Care-taking worries	14	43
	Sibling Relationship	28	0
	Autism Differences	43	14
	Autistic Sibling Future	28	14
	Sibling Future	28	14
3.	Who initiated the talks?		
	Child Only?	43	14
	Parent Only?	14	43
	Both?	14	14
4.	Did you feel your family?		
	communication changed? (%Yes)	100	86
How?	Increased Awareness	28	28
	Increased Communication	57	43
<u>Second Child Follow-Up</u>			
1.	Did you talk to parent about autism worries since the study? (% Yes)	57	28
2.	Was anything good? (% Yes)	100	100
What?	Games	14	43
	Communication	57	43
	Self-Reflection	14	0

Table 7

*Significant Correlations from Exploratory Analyses of the Stress and Coping Model for Typical Children of Siblings with Autism*

	Cognitive Appraisal			Adaptational Outcome (CBCL)	
	AWS(C)	AWS(P)	CAS(C)	Internal	External
<u>Background Variables:</u>					
Age Kid	-.160	-.131	.199	.009	-.369
Age Difference	.296	.217	-.199	.053	.171
Autism Support	-.348	-.290	.201	.165	.231
Gender ( <i>t-test</i> )	1.058	.187	-.590	1.93	.378
Family Communication	-.152	-.046	.102	-.127	-.223
Severity of Autism	-.002	.238	-.230	-.084	-.159
Parent Autism Communication Scale	-.108	<b>-.462*</b>	.177	<b>-.419*</b>	<b>-.469*</b>
Autism Communication Scale (Child)	-.239	-.070	.037	-.159	<b>-.469*</b>
<u>Cognitive Appraisal Variables:</u>					
Autism Worries Survey- AWS (C)	--	--	--	.204	.302
Autism Worries Survey –AWS (P)	--	--	--	<b>.451*</b>	.229
Coping Appraisal Scale (Child)	--	--	--	<b>-.586*</b>	-.122

*\*Note:* AWS (C) refers to the Child Autism Worries Survey, AWS ( P) refers to the Parent Autism Worries Survey.

CAS (C) refers to the Child Coping Appraisal Scale.

CBCL scores are measured by both *Internal* and *External* subscales.

\*  $P < .05$ .

*Figure 1.* A stress and coping model of typical children's adjustment to an autistic sibling.

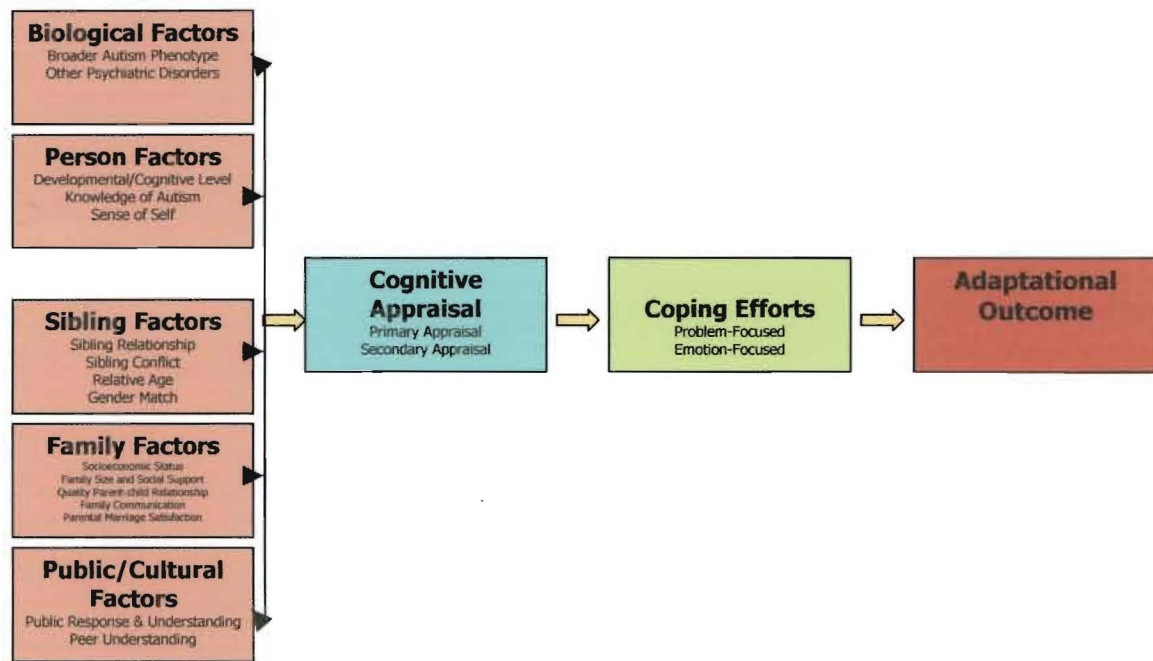


Figure 2. Example items from the child Autism Worries Survey (AWS).

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?*



11. Some kids worry that their brother or sister will get lost. (14)

12. Some kids worry that they do not get enough attention from their parents because their brother or sister needs so much attention. (16)

13. Some kids worry that they can't talk to their parents about their brother or sister with autism. (17)

14. Some kids worry that people say bad things about their brother or sister. (19)

Figure 3. Example items from part one of the workbook intervention activity.

### Worries About Being Treated Differently in Your Family

1. Some kids worry that their parents love their sister or brother more than them.



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 they don't get enough attention, time, or money from their parents because of 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?

Figure 4. Hypothesis two workbook: number reported worries child vs. parent.

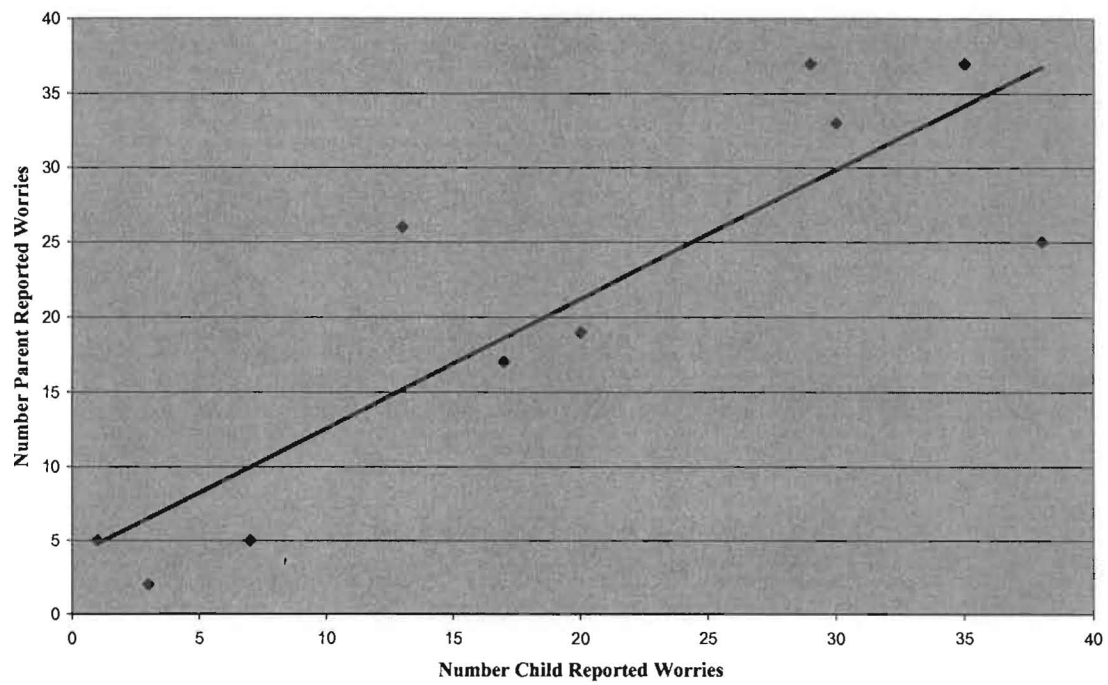


Figure 5. Hypothesis two games: number reported worries child vs. parent.

