A SIBLING SUPPORT GROUP FOR CHILDREN WITH A SIBLING WITH AUTISM

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A SIBLING SUPPORT GROUP FOR CHILDREN
WITH A SIBLING WITH AUTISM

A Project
Presented to the
Faculty of
California State University,
San Bernardino

In Partial Fulfillment
of the Requirements for the Degree

Master of Arts
in
Child Development

by
Audrey Grace Venegas

June 2015
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June 2015

Approved by:

Dr. Laura Kamptner, Committee Chair, Psychology
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ABSTRACT
The purpose of this project was to create a research-based sibling support group for 7 to 12 year-old children who have a sibling with autism. Typically-developing children (N = 3) and their parents attended a four-week, once-weekly sibling support group. The program focused on topics found to be the key issues of typically-developing siblings who have a sibling with autism: discovering that others share similar family circumstances, learning about their sibling with autism’s special needs, discussing issues and problems children with siblings who have ASD typically face (and developing effective coping strategies to deal with these issues), and having an opportunity to express who they are as individuals. Pre- and post- assessments showed that the group only slightly increased their knowledge about autism. Feedback from the children suggested that they especially enjoyed the opportunity to speak openly about their sibling with autism and having the opportunity to share activities and items that were important to them. The children reported that they did not enjoy having to complete worksheets related to information about autism spectrum disorder. Additionally, they did not understand the information that was presented about the programs and interventions that some children with ASD may use. Overall, the sibling support group provided an opportunity for children with a sibling with autism to share feelings and experiences about their sibling, including problems they face.
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CHAPTER ONE

INTRODUCTION

Autism Spectrum Disorder (ASD) has a profound impact on all family members, including typically-developing siblings. The purpose of the current project is to create a sibling support group for typically-developing siblings of children with ASD. The aim of this group is to help increase the typically-developing siblings’ knowledge about their sibling’s disorder. Additionally, providing typically-developing siblings with a place to meet new children who have similar life experiences and encourage open discussions about issues and problems faced due to having a sibling with ASD and how to cope with these problems are goals of this support group.

Autism Spectrum Disorder (ASD) is the fastest-growing serious developmental disability in the U.S. (“What is Autism?”, 2014). ASD is defined as a group of neurodevelopmental disorders with a strong genetic basis that occurs during early brain development and causes significant social and communication problems, restricted activities and interests, and behavioral difficulties (American Psychiatric Association, 2013; National Institute of Neurological Disorders and Stroke [NINDS]: “Autism Fact Sheet”, 2014; Rosenblatt & Carbone, 2012). The Diagnostic and Statistical Manual of Mental Disorders (5th ed.; DSM-5; American Psychiatric Association, 2013) criteria state that individuals with ASD must show signs from early childhood even if
those symptoms aren’t recognized until later when social demands exceed their capacity (American Psychiatric Association, 2013).

Current research from the Center for Disease Control and Prevention reports that the prevalence of ASD is now 1 in 68 children (Centers for Disease Control and Prevention [CDC]: “Data & Statistics”, 2014), with boys being 5 times more likely than girls to be diagnosed with an ASD (1 in 42 vs. 1 in 189) (American Psychiatric Association, 2013; CDC: “Data & Statistics”, 2014). Possible explanations for this increase in prevalence could be due to the fact that the diagnosis criteria has changed and also parents and doctors are becoming more knowledgeable about ASD so parents are more likely to take their children to get diagnosed and doctors are able to better diagnose these children (National Institute of Mental Health [NIMH]: “Who Is At Risk?”, n.d.). They occur in all racial, ethnic, and socioeconomic groups, and as “spectrum disorders,” each person can be affected in different ways ranging from very mild to severe (CDC: “Data & Statistics”, 2014). While these conditions may be chronic and last a lifetime, studies show that 3%-25% improve to a point where they no longer meet the diagnostic criteria for ASD (Rosenblatt & Carbone, 2012).

The Center for Disease Control and Prevention (2013) described three subtypes of autism spectrum disorder including Autistic disorder (“classic” autism), Asperger’s Disorder, and Pervasive Developmental Disorder- Not Otherwise Specified (PDD-NOS; “atypical autism”). However, with the

**Autism Spectrum Disorder**

Common characteristics of autism spectrum disorder include significant social, emotional, and communication challenges, bodily problems, behavior problems, restricted interests, unusual interests, and unusual sensory behaviors and responses (American Psychiatric Association, 2013; Rosenblatt & Carbone, 2012).

**Social, Emotional, and Communication Challenges**

Individuals with ASD generally have trouble understanding other people’s feelings and emotional cues (Rosenblatt & Carbone, 2012), and they often avoid eye contact and want to be alone, and have difficulty forming relationships (American Psychiatric Association, 2013; CDC: “Signs & Symptoms”, 2014; Rosenblatt & Carbone, 2012). Abnormal mood or affect is also common, and may include such behaviors as weeping or giggling for no apparent reason, excessive fearfulness of harmless objects, or not fearing objects that may cause harm (American Psychiatric Association, 2013). Language deficits of children with ASD may include delays in speech and language skills, repeating words and/or phrases (echolalia), giving unrelated
answers to questions, or saying words that have no apparent relevance to their current situation (i.e., pop-up words) (CDC: “Signs & Symptoms”, 2014; Rosenblatt & Carbone, 2012). In addition, difficulty expressing their wants and needs is a common communication challenge (Rosenblatt & Carbone, 2012).

**Bodily Problems**

There are a number of physical issues that children with ASD may suffer from including tics, sleep problems, seizures, gastrointestinal problems, and motor delays.

First, many children with ASD suffer from tics, which are involuntary movements and sounds. These tend to be similar to those who have Tourette syndrome, and medical treatment can help those who have moderate to severe cases (Rosenblatt & Carbone, 2012).

Second, sleep problems are also common among children with ASD (American Psychiatric Association, 2013). Between 40%-80% of children with ASD have trouble falling asleep, staying asleep, or waking up early which may decrease their attention and functioning ability. This may in turn result in more behavior problems (NINDS: “Autism Fact Sheet”, 2014; Norton & Drew, 1994; Rosenblatt & Carbone, 2012). Fortunately, sleep problems can be treated through the formation of schedules or medication (NIMH: “Sleep Problems”, n.d.).

Third, some young children and teenagers with ASD may also suffer from seizures which may be caused by lack of sleep or high fevers (American

Finally, gastrointestinal (GI) or digestion problems, including stomach pain, diarrhea, constipation, acid reflux, vomiting, or bloating are also common (NIMH: “Gastrointestinal problems”, n.d.; Solomon & Chung, 2012) as are food allergies. (While it’s unclear whether children with ASD are more likely to have GI problems than typically-developing children, certain diets may lead to an increase in GI problems) (NIMH: “Gastrointestinal problems”, n.d.).

Delayed and sometimes unusual motor skills are also common in children with ASD. Delays may be seen in both fine motor and gross motor skills, or in one motor skill while the individual excels at the other (Rosenblatt & Carbone, 2012). Unusual motor skills may be apparent in terms of children’s facial expressions, gestures, and body movements being vague or not matching what they are saying (American Psychiatric Association, 2013; NIMH: “Social impairment”, n.d.; “Symptoms”, 2014).

Behavior Problems

There are a number of behavior problems that individuals with ASD may display, including hyperactivity, a short attention span, impulsivity, and temper tantrums in young children (American Psychiatric Association, 2013). Aggression and self-injurious behaviors (e.g., finger, hand, or wrist biting) are also common in children with ASD (American Psychiatric Association, 2013).
Such behaviors may arise due to an inability to express their wants and needs, and difficulty controlling their impulses and emotions (Rosenblatt & Carbone, 2012). Since there may be many a number of different causes for such behaviors (e.g., banging their head on a wall due to an ear infection or being aggressive due to anxiety), such behaviors should be closely analyzed to determine the cause (Rosenblatt & Carbone, 2012).

**Restricted and Unusual Interests**

Children with ASD may also display restricted interests, e.g., getting upset by minor changes such as taking a different route to a certain place or changing a television station or movie they were watching (C. Hernandez, personal communication, December 2012). In addition, some children with ASD show unusual interests such as developing a strong attachment to hard objects (i.e., pens) and not wanting to let it go (Rosenblatt & Carbone, 2012).

**Unusual Sensory Behaviors and Responses**

Children with ASD may also display unusual behaviors or have unusual responses to sensory input. For example, a child with ASD may display unusual sensory-seeking behaviors through such activities as flapping their hands, walking on their tip toes, rocking their body, and spinning in circles (CDC: “Signs & Symptoms”, 2014; NIMH: “Repetitive & stereotyped behaviors”, n.d.; Norton & Drew, 1994; Rosenblatt & Carbone, 2012; Solomon & Chung, 2012). In addition, unusual responses to sensory stimuli may include having a high threshold for pain or being oversensitive to sounds, smells,

Early Signs/Symptoms of Autism

There are a number of early signs and symptoms of ASD that may foretell future problems including decreased interest in social functioning between 2 and 3 years of age (e.g., delayed/lack of joint attention, less likely to look in someone’s direction, pay less attention to new faces, and resist physical closeness); not responding to one’s own name by 12 months of age; not pointing at objects to show interest by 14 months; and/or not playing “pretend” games by 18 months (American Psychiatric Association, 2013; Rosenblatt & Carbone, 2012). While young children with ASD engage less in pretend play, they may be skilled at constructive play (i.e., assembling puzzles) and may use ritualistic play (i.e., lining up objects repeatedly) (Rosenblatt & Carbone, 2012). Other early signs and symptoms include rarely responding to loud noises or smiling at others (Rosenblatt & Carbone, 2012). In addition, vocalizations may be limited and these individuals may have difficulty supporting their head (Rosenblatt & Carbone, 2012).
Causes of Autism

The cause of ASD has not been determined, although a number of risk factors have been identified including genetic, biological, and environmental factors.

Most scientists agree that genes are one of the risk factors that can make a person more likely to develop ASD (CDC: “Facts About ASD”, 2014; Rosenblatt & Carbone, 2012). Parents who have a child with ASD have a 2%-18% chance of having a second child who is also affected (American Psychiatric Association, 2013). Having certain genetic or chromosomal conditions also puts a person at a higher risk for ASD. For example, about 10% of children with autism are also identified as having Down syndrome, fragile X syndrome (which is the most common known genetic cause of ASD in boys), tuberous sclerosis complex, and other genetic and chromosomal disorders (CDC: “Facts About ASD”, 2014; Rosenblatt & Carbone, 2012).

A number of biological risk factors have also been identified. First, being born to older parents is a risk factor thought to be related to the hormonal changes that older mothers may experience and the impact of such changes on fetal brain development (Rosenblatt & Carbone, 2012). Second, being born to a mother with rheumatoid arthritis or celiac disease is another risk factor as evidence indicates that the production of antibodies during pregnancy negatively impacts fetal brain development (Rosenblatt & Carbone, 2012). Third, Type 1 diabetes in the family history also puts a child at a higher
risk for ASD (Rosenblatt & Carbone, 2012). Fourth, the amount of time between pregnancies is also a risk factor: having children within a year of one another puts the next child at an increased risk for having ASD (about 3 times more likely). Similarly, having the next child between one to two years may put that child at 2 times the risk to have ASD (Rosenblatt & Carbone, 2012).

Research on brain development and brain functioning highlights areas in which the brains of individuals with ASD differ from their typically-developing counterparts. First, in terms of early brain growth, research has found an increase in brain size, by measuring head circumference, for very young children who have ASD (Courchesne, 2002; Mak-Fan, Morris, Vidal, Anagnostou, Roberts, & Taylor, 2013; Williams, 2008). More specifically, research has found that head circumference at birth is smaller for children with ASD compared to typically-developing children, but between birth and 6-14 months of age there is an increase in head circumference (Courchesne, Carper, & Akshoomoff, 2003). Second, increased brain volume, surface area, and cortical thickness have all been found in younger individuals with ASD compared to their typically-developing counterparts, but as children age, there is decreased or similar brain volume, surface area, and cortical thickness (Mak-Fan et al., 2013; Mak-Fan, Taylor, Roberts, & Lerch, 2012).

Both white and gray matter in the brain are increased in younger individuals with ASD compared to their typically-developing counterparts, but this volume decreases as the individuals grow older (Mak-Fan et al., 2012;
Williams, 2008). These overgrowths of white matter affect processing in the frontal lobes, temporal lobes, and frontal regions as well as communication between different parts of the brain. This in turn is believed to negatively impact language, cognition, social, and emotional functioning (Williams, 2008). Additionally, both communication and brain organization between and within regions of the brain are affected in individuals with ASD (Williams, 2008). Also, the corpus callosum has been found to be reduced in size in individuals with autism as compared to typically-developing individuals in some studies, thus suggesting that hemispheric communication in individuals with autism may be impaired as well (Casanova, El-Baz, Elnakib, Switala, Williams, Williams, Minshew, & Conturo, 2011; Williams, 2008). While these individuals use the same brain regions as typically-developing individuals to process various types of information (i.e., language and visual areas to process language and visual information), brain activation patterns show a different use of cognitive resources (i.e., more cognitive resources are used for more simple tasks, thus leaving little to no additional resources for more difficult tasks) (Williams, 2008). In light of what is known about brain development and functioning of individuals with autism, those who live with and work with individuals with ASD should learn ways to shape the environment so that it can help the brain learn (Williams, 2008).

A number of environmental risk factors have also been identified as potential causes of autism. These environmental risk factors may result from
interactions between environmental exposure and a person’s genes, suggesting that a person may be born with a genetic predisposition for ASD and as they are exposed to events in the environment (either in or outside of the womb), a gene is activated (Rosenblatt & Carbone, 2012). For example, concerns about vaccines and infections have led researchers to consider risk factors before and after birth. Studies have found, however, that there is no evidence that vaccines cause ASD (Rosenblatt & Carbone, 2012). In addition, taking the prescription drugs valproic acid and thalidomide during the early trimesters of pregnancy have been linked with a higher risk of having ASD (Rosenblatt & Carbone, 2012). Thalidomide is less of a risk factor, however, since it has been banned for use on pregnant women due to the finding decades ago that it causes birth defects (Rosenblatt & Carbone, 2012). Finally, chemicals found in the environment (i.e., toxins such as inorganic mercury, heavy metals, pesticides, substances in plastics, and human-created chemicals like polychlorinated biphenyls) may also be environmental risk factors; however, there is not yet enough research to substantiate this (Rosenblatt & Carbone, 2012).

Treatments and Interventions

There are many different types of treatments that have been used on children with ASD including medication, behavioral, relational, educational, and skill development intervention approaches, and complementary and alternative medicines.
Medication

While there are no medications that can cure or treat the main symptoms of ASD, there are medications that can help control some of the symptoms. For example, medication can help manage high energy levels, an inability to focus, depression, tics, gastrointestinal problems, and seizures (CDC: “Treatment”, 2014). The use of risperidone and aripiprazole, which are antipsychotic drugs, have been approved by the U.S. Food and Drug Administration to treat children of certain ages with ASD who experience severe tantrums, aggression, and self-injurious behaviors (CDC: “Treatment”, 2014). Similarly, some medications have also been found to help with sleep disturbances (Rosenblatt & Carbone, 2012).

Behavioral Treatment Intervention

The primary behavioral treatment approach used for individuals with ASD is called Applied Behavior Analysis (ABA), and it has become widely accepted among health care professionals and used in many schools and treatment clinics. ABA is an intensive and systematic method that uses behavioral principles to teach individuals by using reinforcement to motivate and shape desired behaviors (Rosenblatt & Carbone, 2012). The goal of ABA is to increase positive/desirable behaviors and decrease negative/undesirable behaviors in order to improve a variety of skills (Rosenblatt & Carbone, 2012). There are different types of ABA including discrete trial training (i.e., a series of trials to teach desired steps of a certain behavior, paying attention, or
response), incidental teaching (i.e., a child acquires skills without direct instructions), pivotal response training (i.e., used to increase a child’s motivation to learn, monitor his own behavior, and initiate communication with others), and verbal behavior intervention (i.e., a type of ABA to teach verbal skills) (Rosenblatt & Carbone, 2012). ABA services can help young children learn to talk, walk, interact and play with others, develop self-help skills, and learn to function more effectively in the community (Rosenblatt & Carbone, 2012).

**Relationship-Building Intervention**

A relationship-building intervention that has been used with children with ASD is called “Developmental, Individual Differences, Relationship-Based Approach” (DIR; also called “Floortime”). This technique focuses on relational development (building a relationship) and how a child deals with sensory input. In short, this treatment is tailored to the child’s developmental level and the therapist follows the child’s lead during therapy sessions (Rosenblatt & Carbone, 2012).

**Educational Intervention**

An educational approach for teaching children with ASD is “Treatment and Education of Autistic and related Communication-handicapped Children” (TEACCH). This program focuses on identifying the strengths and weaknesses of children with ASD and using that information to teach the child (Rosenblatt & Carbone, 2012). Visual cues are used to help the child
understand directions and information more clearly (Rosenblatt & Carbone, 2012). The four main areas of focus to enhance learning are the organization of the child’s physical environment, predictable though flexible routines, structured activity systems, and an emphasis on visual learning (Rosenblatt & Carbone, 2012).

**Skill Development Interventions**

There are a few well-known skill development interventions that are used with children with ASD. One such intervention is occupational therapy, a treatment approach that focuses on teaching a person with ASD how to live as independently as possible. This is done by evaluating the individual to see what their fine motor and sensory processing deficits are, and also developing and teaching strategies for learning tasks that they will use in their everyday lives (Rosenblatt & Carbone, 2012).

Two other well-known skill development interventions are speech-language therapy and the Picture Exchange Communication System (PECS) which are used to improve communication skills for children with autism due to their communication difficulties (Rosenblatt & Carbone, 2012). Teaching the child to use speech and language in natural settings with all people is the purpose of speech-language therapy (Rosenblatt & Carbone, 2012). Similarly, the PECS program is an augmentative communication technique that can help teach children how to effectively communicate through the use of pictures (Rosenblatt & Carbone, 2012).
Complementary and Alternative Medicine Interventions

A final group of interventions include Complementary and Alternative Medicine (CAM). These types of treatments are controversial due to a lack of sufficient and generalizable findings (many based on personal experiences) and may include special diets, therapies, and treatments that are used with (complementary) or in place of (alternative) conventional medicine (Rosenblatt & Carbone, 2012).

While dietary approaches aimed at treating ASD have been developed, they are still not widespread because while one approach may work for one child, it may not work for another (Rosenblatt & Carbone, 2012). Many biomedical interventions call for changes in diet. Such changes include removing certain types of foods from a child’s diet and using vitamins or mineral supplements (Rosenblatt & Carbone, 2012). A popular dietary approach is the gluten-free/casein-free diet (GFCF). While research has not yet verified that this type of diet improves social skills or communication, there may be benefits for those with gastrointestinal problems (Rosenblatt & Carbone, 2012). In addition, using dietary supplements (i.e., multivitamins, the most common CAM treatment) has become a popular CAM treatment for parents of children with ASD (Rosenblatt & Carbone, 2012).

Sensory Integration Therapy is a treatment approach that despite not being considered a popular therapy for ASD, has been found to help some children with ASD manage sensory information. These therapy sessions are
play-oriented and include the use of trampolines, slides, deep pressure, weighted vests, and swinging (Rosenblatt & Carbone, 2012). Reports show that these therapies may calm a child who is anxious and may increase their tolerance for environments that have a lot of sensory information while also helping to reinforce positive behaviors (e.g., dealing with transitions in a more positive way) (Rosenblatt & Carbone, 2012). However, other research has shown that this type of therapy may cause problem behaviors to get worse (R. Gutierrez, personal communication, March, 2013).

Mind-body therapies have also been suggested as CAM treatments. While these therapies may help a child regulate their emotions and stay calm, there is no scientific research to support such findings. However, they may be alternatives to using medications (Rosenblatt & Carbone, 2012). Some of these therapies include yoga (which has been found to be a safe activity for some children with certain disabilities), neurofeedback (which has been found to improve behavior and reduce symptoms for some children with ASD), and music therapy (which has been found in some studies to help children with ASD gain new skills in communication and expression) (Rosenblatt & Carbone, 2012).

A few CAM treatments that are no longer used in treating individuals with ASD include treatments involving chelation and secretin. Treatments involving chelation (a treatment to remove heavy metals like lead from the body) are not approved for autism and should be avoided due to the fact that it
bends to other metals in the body like iron and calcium which are necessary nutrients (Rosenblatt & Carbone, 2012). In addition, it is not necessary due to the fact that thimerosal, a preservative used in vaccines that contains mercury, is not used in vaccines anymore (Rosenblatt & Carbone, 2012). Similarly, secretin is no longer considered a treatment for autism due to a lack of benefits for children with ASD (Rosenblatt & Carbone, 2012).

Impact of a Child with Autism Spectrum Disorder on Family Functioning

Having a child with ASD significantly impacts family functioning in a number of ways including increasing parental and marital stress, and restricting family activities.

Parental Stress

Research has found that parents of children with ASD report higher levels of stress than parents of typically-developing children or even Down syndrome (Dabrowska & Pisula, 2010). Stress comes from a number of sources, including the feelings parents may have in reaction to learning their child’s diagnosis, the unique parenting demands associated with having a child with ASD, the ASD child’s social and communication deficits, and issues relating to the child’s treatments.

First, parents of children with ASD may experience a mix of many different feelings starting from the time their child is diagnosed. The diagnosis of autism can be a very stressful time for parents as it can cause feelings of
pain, hurt, intense fear, sadness, anger, helplessness, and less interest in social interactions (Bloch & Weinstein, 2010; Davis & Carter, 2008). Parents may even react to the diagnosis by denying the existence of a problem (Bloch & Weinstein, 2010). Worry, anxiety, and uncertainty over their child’s future and the subsequent alteration of their previous expectations for that child’s future are also feelings these parents may have to overcome (Gray, 2002; Hock, Timm, & Ramisch, 2012; Tehee, Honan, & Hevey, 2009).

Second, the unique parenting demands of having a child with ASD add to parental stress levels (Hock et al., 2012). Dealing with their ASD child’s unpredictable and inappropriate behavior is stressful (Tehee et al., 2009), and the higher the intensity of behavior problems, the greater the parental stress (Brobst, Clopton, & Hendrick, 2009). Externalizing “public” behaviors (e.g., physical aggression towards others or repetitive vocalizations and behaviors) often cause unwanted attention and are difficult for parents to manage when they are out in public, thus increasing parental stress (Davis & Carter, 2008). Similarly, the unique parenting demands associated with dealing with their ASD child’s deficits with self-regulation (i.e., eating, sleeping, and emotion regulation) can be especially stressful on a daily basis for mothers (Davis & Carter, 2008) since the parent is typically the person responsible for taking care of the child’s daily needs (Bloch & Weinstein, 2010; Davis & Carter, 2008; Nealy, O’Hare, Powers, & Swick, 2012; Rosenblatt & Carbone, 2012; Tehee et al., 2009). In addition, some mothers’ inability to take on a different role...
Besides caregiver (e.g., bread-winner) can also increase maternal stress levels (Gray, 2002).

Third, parents of children with ASD may experience greater stress because they feel unable to turn to extended family and friends for help due to their inexperience with taking care of a child with ASD (Hock et al., 2012).

Fourth, social and communication deficits of children with ASD are also sources of stress for parents (Davis & Carter, 2008). Their lack of social skills, which may also take the form of a lack of affection towards and communication with parents, not only adds to parental stress (Bloch & Weinstein, 2010) but may also put a strain on the parent-child relationship by causing parents to question their parenting abilities (Davis & Carter, 2008; Hock et al., 2012). Because the child with ASD may be unable to express/show appreciation for what their parents do for them, parents may become more stressed since they do not receive any confirmation that they are parenting effectively (Davis & Carter, 2008).

Fifth, parents may experience many different sources of stress that relate to their child’s treatments. Mothers have reported stress that is related to seeking financial assistance for their ASD child’s therapies, finding providers to develop their child’s treatment program, and scheduling issues as they relate to services for their child with ASD (Nealy et al., 2012). Similarly, having multiple therapists visiting the ASD child’s home unannounced may be especially stressful for some parents because they may be caught off-guard.
and unprepared to participate in their child’s therapy as much as they would prefer (C. Hernandez, personal communication, March 2013).

**Marital Stress**

Parents of children with ASD have reported both positive effects (i.e., factors that have been found to help the marriage relationship) and negative effects (i.e., factors that have been found to cause strain on the marriage relationship) related to having a child with ASD.

The research literature suggests several factors related to having a child with ASD that may have a positive effect on the marriage relationship. One such factor is that parents may be able to spend more time with one another due to not being able to go out as much with others (Brobst et al., 2009). Similarly, this increase in time together might allow couples to be sources of support for one another (Brobst et al., 2009). In addition, parents have reported finding resilience in their marital relationship due to parenting their child with ASD (Hock et al., 2012). These factors may lead to less conflict and help spouses use each other to cope with stress (Hock et al., 2012).

More commonly, having a child with ASD in the family has generally been found to cause strain on and add pressure to the marriage relationship and decrease marital satisfaction (Brobst et al., 2009; Cassidy, McConkey, Truesdale-Kennedy, & Slevin, 2008; Hock et al., 2012). One source of stress is the added daily stressors often displayed through partners’ physical exhaustion and having to make difficult parenting decisions (e.g., what
programs to seek treatment from and how to pay for them) while dealing with little sleep or respite help (Hock et al., 2012). These daily stressors can also cause partners to have a difficult time communicating with each other (Hock et al., 2012) which may contribute to lower marital satisfaction. Similarly, financial strain, which often results from a mother being forced to quit her job due to having to invest so much time into taking care of the child with ASD, may cause the other partner to have to work more hours to make up for the loss in income (Hock et al., 2012). This may in turn lead to rigid sex roles (i.e., bread-winner or caregiver) and more dissatisfaction, resentment, and conflict in the marriage relationship (Hock et al., 2012). In addition, the strain of having a child with ASD in the family may result in the dissolution of the marriage. Research has shown that parents of children with ASD have almost two times higher divorce rates compared to families of typically-developing children (Hartley, Seltzer, Head, & Abbeduto, 2012). These higher divorce rates may be due in part to an extended period of risk for divorce for parents of children with ASD because of the increased likelihood that their child will stay in the home longer (Hartley et al., 2012; Rosenblatt & Carbone, 2012). Although many couples succumb to divorce, other couples find that their commitment to their child and their identity as parents holds them together (Hock et al., 2012).

**Restrictions on Family Activities**

Having a child with ASD in the family can restrict family activities in many ways including causing financial strain, fear of judgment from others due
to the child’s atypical behaviors in public, inability to find adequate childcare, and strained relationships with extended family members.

First, financial strain due to mothers of children with ASD tending not to work or work less due to having to take care of the child can cause restrictions on the ability of their family to participate in family outings and activities (Gray, 2002; Nealy et al., 2012). This decrease in family income also results from expenses related to the care of the child with ASD which may include having to pay for the child’s services out of pocket due to limits on insurance coverage, traveling far distances to receive services, the higher cost of qualified childcare providers, specific diets children with ASD may be on (i.e., gluten-free diets), and the installment of security devices in the home (Nealy et al., 2012).

Second, parents may also fear judgment or rejection from those who do not know about their child’s special needs such as their atypical behaviors (e.g., repetitive motor behaviors, vocalizations, and outbursts) (Gray, 2002). As time passes, however, social rejection tends to bother parents less as they tend to socialize more with those who are understanding of their child’s special needs (Gray, 2002). Although families may spend more time with others who understand what they are going through, they may still choose to restrict their family outings (i.e., running errands, going to church, going to a friend’s house, going out to dinner, or even going on a vacation) in order to reduce the risk of judgment from strangers (Bloch & Weinstein, 2012; Cassidy et al., 2008; Hock
et al., 2012; Nealy et al., 2012). The behavior of the child with ASD may cause families to only go to places the child with ASD likes to help reduce the chance of behavior problems occurring (and thus other family members may not get to go places or do activities they prefer) (Cassidy et al., 2008).

Third, the inability to find adequate childcare also makes it difficult for the parents (or parents and their typically-developing children) to engage in out of home activities (Cassidy et al., 2008; Nealy et al., 2012). Fear of leaving their child with someone who does not know how to work with children with ASD may make parents uneasy, and this may make it more difficult for them to find someone suitable to watch their child (C. Hernandez, personal communication, December, 2012). Even when a suitable childcare provider is found, it may be too expensive for families to afford (Nealy et al., 2012).

Fourth, tension and distance from extended family members may also make it difficult to participate in extended family activities. The inability of the ASD child’s family to spend time with and go places with extended family members on a regular basis has been reported by mothers to cause distance between family members (Nealy et al., 2012). One such reason for the distance may be due to the fact that extended family members may not understand what the child’s immediate family is going through (i.e., not being able to go just any place they want due to how their child with ASD may react, but extended family members feeling that personal reasons are keeping the ASD child’s family from participating in extended family activities) (C.
Fortunately, longitudinal research has found that as children with ASD grow older, relationships with extended family members improve perhaps due to family members making more of an effort to understand the needs of the child and by providing more support for their families (Gray, 2002).

Adjustment Outcomes of Children Who Have a Sibling with Autism Spectrum Disorder

While family functioning is impacted by having a child with ASD in the family, the typically-developing siblings of children with ASD are also personally impacted. Overall, some typically-developing siblings show positive effects (such as having high levels of self-concept) and some experience no ill effects. Others experience negative effects such as low levels of pro-social behavior, increased levels of loneliness, and slower acquisition of socialization skills. Thus, findings are mixed (Meadan, Stoner & Angell, 2010). Age, gender, socioeconomic status, family size, and coping styles all influence how a typically-developing sibling will be affected by having a sibling with ASD (Benson & Karlof, 2008; Hastings, 2007; Meadan et al., 2010; Pilowsky, Yirmiya, Doppelt, Gross-Tsur, & Shalev, 2004; Ross & Cuskelly, 2006).

Positive Effects

Positive social and emotional adjustment effects for typically-developing siblings of children with ASD have been found in terms of self-concept, behavior, intelligence, academics, and anxiety compared to children with
nondisabled siblings (Macks & Reeve, 2007). Possible reasons for these findings include the fact that these children may be comparing themselves to their sibling with autism or they may be more mature compared to other children their age without a disabled sibling (Macks & Reeve, 2007). While the siblings of children with autism tend to score significantly higher compared to siblings of nondisabled children on social and emotional adjustment, both groups in Macks and Reeve’s (2007) study scored within the average range for self-concept and depression.

**No Ill Effects**

Several studies have found no ill effects for siblings of children with autism regarding their adjustment and social competence (Benson & Karlof, 2008; Kaminsky & Dewey, 2002). Some studies have found that typically-developing siblings of children with ASD are well functioning in terms of social skills when compared to a normative sample (e.g., Pilowsky et al., 2004), suggesting that siblings of children with ASD are reasonably well adjusted and socially competent (Kaminsky & Dewey, 2002; Rodrigue, Geffken & Morgan, 1993).

Similarly, in a study of adolescents between 8 to 18 years old who had a sibling with ASD, Down syndrome, or no known disability, Kaminsky and Dewey (2002) found low levels of loneliness in all three groups and all sibs were well adjusted.
Negative Effects

There is some evidence that typically-developing siblings of children with ASD experience may be at a heightened risk for behavioral and social adjustment problems during childhood and adolescence (Orsmond & Seltzer, 2007). Siblings of children with ASD tend to show more problem behaviors and may experience more relationship difficulties; in addition, they may be at more of a risk for developing internalizing (i.e., depression) and externalizing (i.e., aggression) behaviors (Rodrigue et al., 1993; Ross & Cuskelly, 2006).

The behavioral adjustment of typically-developing siblings of children with ASD has been found to be similar to siblings of children diagnosed with Down syndrome and other intellectual disabilities (Hastings, 2007). These typically-developing siblings tend to show more behavior problems (i.e., emotional and conduct problems, hyperactivity and peer problems) and fewer pro-social behaviors compared to a normal sample (Hastings, 2003; Kaminsky & Dewey, 2001). Typically-developing boys with autistic siblings and those younger than their sibling with ASD have been especially likely to show fewer pro-social behaviors (Hastings, 2003).

Demographic Risk Factors

When demographic risk factors are considered, mixed results have been found for typically-developing siblings (Macks & Reeve, 2007). When demographic risk factors are minimal (i.e., being female, coming from high SES, having more than one sibling, and being younger than the sibling with
ASD), nondisabled siblings of a child with ASD tend to show enhanced emotional and psychological development (Macks & Reeve, 2007). When risk factors are more numerous (i.e., being male, coming from low SES, only having one sibling, being older than the sibling with ASD), the impact on the nondisabled sibling was less favorable since these risk factors have been found to add more stress and challenges to the typically-developing sibling.

Interestingly, Kaminsky and Dewey (2002) found that the more siblings in a family, the better the psychosocial adjustment of typically-developing siblings. Possible reasons for this could be that having additional siblings in the family helps the siblings to not be so worried about future responsibilities for their sibling and/or the provisions of more siblings to engage in social activities with (and giving them more opportunities to develop their socialization skills). Other studies, however, have found that the larger the family size, the greater the delay in the typically-developing children’s socialization skills (Pilowsky et al., 2004), perhaps due to the fact that having a child with ASD requires a great deal of parental time and attention. Thus, most of the parents’ time is directed toward taking care of the child with ASD and not providing their typically-developing child with opportunities to develop better socialization skills (Barak-Levy, Goldstein, & Weinstock, 2010).

Negative Impact of Parental Differential Treatment

Parental time and attention is usually unequally distributed between children with ASD and their typically-developing siblings, with children with
ASD tending to receive far more of their parent’s time than their siblings (Dodd, 2004; Naylor & Prescott, 2004; Nealy et al., 2012; Tsao, Davenport, & Schmiege, 2012). This unequal amount of time and attention is due to the fact that some children with ASD are unable to effectively take care of themselves and they may need extra help with everyday tasks. In addition, they may need to be watched more closely to make sure they are safe (McHale & Gamble, 1989). This unequal distribution of parental time and attention can have negative influences on the typically-developing sibling, including increasing their risk of displaying internalizing and externalizing behaviors, increasing their household responsibilities, and negatively impacting their relationship with their sibling with ASD.

Internalizing and Externalizing Behavior Problems

When children have a sibling with a disability who receives more parental time and attention, anger, resentment, anxiety, depression, and guilt are common feelings of the typically-developing sibling (Harris, 2008; Rodrigue et al., 1993; Rossiter & Sharpe, 2001). These feelings may result from misunderstanding the reasons for getting less parental time and attention, jealousy, and/or guilt from having negative feelings about their sibling with ASD (McHale & Pawletko, 1992). Feelings of depression may result from the fact that the disabled sibling cannot do the same activities as the typically-developing sibling, and so the typically-developing sibling is left feeling lonely and without a peer to play with (Naylor & Prescott, 2004).
Increases in aggressive behaviors of older typically-developing siblings of children with ASD have also been reported (Rodrigue et al., 1993). This may result from the abrupt changes that these typically-developing siblings experience due to having a disabled sibling, the increase in household responsibilities, or even the fact that parents may place higher expectations on them while not giving them more time and attention (Rodrigue et al., 1993).

**Increase in Household Responsibilities**

Siblings of children with ASD may experience an increase in their household responsibilities since parents need to spend a great deal of their own time with the child with ASD (McHale & Gamble, 1989). In particular, older female siblings of a child with ASD tend to take on more of the responsibility of household chores and sibling caregiving (McHale & Gamble, 1989). This increase in home responsibilities can in turn lead to a decrease in the amount of time those siblings can spend outside of the home socializing with their peers and participating in extracurricular activities (which are important for their social and cognitive development) (Barak-Levy et al., 2010; McHale & Gamble, 1989; Nealy et al., 2012).

**Negative Perception of Sibling with Autism Spectrum Disorder**

In general, previous research has found that differential parenting can also lead to sibling competition, less positive engagement between the siblings, and more conflict in the sibling relationship (McHale, Crouter, McGuire, & Updegraff, 1995; Tsao et al., 2012). These feelings may be a
result of children feeling that their parents favor the sibling with ASD over them and although the typically-developing child may understand the need for their sibling with ASD to receive more attention, they may still feel neglected (McHale & Pawletko, 1992). This can result in the typically-developing child interacting with their sibling in a more negative manner (McHale & Pawletko, 1992). Due to the fact that mothers are typically the ones who take care of the children, especially the child with special needs, when typically-developing children experience differential treatment from their mothers, they may experience dissatisfaction with the sibling relationship. This in turn may lead to less positive experiences between siblings due to some jealousy (McHale & Gamble, 1989; Rivers & Stoneman, 2008).

Additional Findings

Findings show that it is not so much that siblings mind being treated differently as long as they feel that it is fair, and that they understand why it is occurring (Harris & Glasberg, 2012; Powell, Gallagher, & Rhodes, 2006). In spite of understanding, however, typically-developing siblings often feel left out (McHale & Pawletko, 1992). If parents can explain to their typically-developing child why they are spending more time with the child with ASD, there is a better chance that their differential parenting will have less of a negative effect on the typically-developing child and the sibling relationship (McHale & Pawletko, 1992).
Sibling Support Groups

Since typically-developing siblings of children with autism are affected in multiple ways, they may need additional support that is specifically geared toward helping them deal with issues that arise from having a sibling with autism. Studies have found, in fact, that sibling support groups can be helpful for the typically-developing siblings of children with ASD. These children tend to feel isolated from peers who also have a sibling with ASD because they do not usually get the opportunity to spend time and form friendships with them. One way these siblings can come together to form friendships with one another is to join a support group (Naylor & Prescott, 2004). Being part of a support group may be their first chance to talk with other children in similar situations, thus helping alleviate some of their feelings of isolation and showing them that there are other children who have siblings with ASD (Dodd, 2004; McCullough & Simon, 2011). In addition, the research literature has also found that it is beneficial for typically-developing siblings to have the opportunity to be with peers because it helps them learn better socialization skills (since having a sibling with ASD often does not provide adequate or appropriate opportunities for typically-developing siblings to learn appropriate social skills) (McCullough & Simon, 2011; Orsmond & Seltzer, 2007).

Topics for Sibling Support Groups

The research literature on sibling support groups suggests a number of relevant topics that should be addressed in these groups including
age-appropriate information concerning their sibling’s disability, issues and problems encountered in everyday life due to having a sibling with ASD, effective ways to cope with having a sibling with ASD, and the importance of having opportunities to “express themselves” (i.e., engage in their own interests and activities).

First, typically-developing siblings tend to lack adequate information about their sibling with ASD (Dodd, 2004; Harris, 2008; Lock & Feinstein, 2009; McCullough & Simon, 2011; Petalas, Hastings, Nash, Dowey, & Reilly, 2009; Smith & Perry, 2004; Tsao et al., 2012). This lack of information has been found to have a negative impact on the typically-developing sibling’s understanding of their sibling with ASD and their relationship with this sibling (Dyson, 1998; McCullough & Simon, 2011). Providing different types of information (i.e., explaining the disability, explaining how their sibling is affected by the disability, and teaching them ways to better interact with the disabled sibling) has been found to combat the negative effects of having inadequate information by helping siblings become more empathetic and understanding towards their sibling and others with ASD. (This also teaches them how to be more helpful towards disabled people in general [e.g., Dyson, 1998; McCullough & Simon, 2011] and to better understand the struggles that such individuals encounter) [McCullough & Simon, 2011]).

Studies have found that directly exposing typically-developing siblings to the activities and interventions that their sibling with ASD uses (by engaging
in role play activities aimed at mimicking what a certain disability is like, teaching them how to use their sibling’s special equipment, or observing their sibling at school or during a therapy session) can help them better understand how their sibling with ASD lives (Dyson, 1998; McCullough & Simon, 2011; Powell et al., 2006).

Second, discussing issues and problems that typically-developing siblings encounter with others who have siblings with ASD has also been identified as an important topic for sibling support groups (Powell et al., 2006; Scelles, Bouteyre, Dayan, & Picon, 2012). These discussions provide children with a safe place where they feel supported and free to openly express their concerns, feelings, and emotions about their sibling with ASD as well as their own personal problems with this sibling (Dodd, 2004; Dyson, 1998; Harris, 2008; Lock & Feinstein, 2009; Naylor & Prescott, 2004; Smith & Perry, 2004; Tsao et al., 2012). Similarly, being around peers who also have siblings with ASD may assist typically-developing siblings to speak out in an honest manner (Rodrigue et al., 1993). Having the opportunity to speak openly about their feelings and share solutions with one another is beneficial because it may help combat the problem behaviors some siblings of children with ASD may experience (Dodd, 2004; Dyson, 1998; McCullough & Simon, 2011; Rodrigue et al., 1993; Ross & Cuskelley, 2006) such as experiencing rivalry with this sibling due to receiving less attention from parents and feeling isolated from peers due to limited opportunities for peer play. Also, typically-developing
siblings may fear bringing friends home due to the uncertainty of how their sibling may behave. Discomfort or embarrassment over going out in public with their sibling with ASD due to unpredictable, atypical behavior is also an issue expressed by typically-developing siblings. In addition, they may experience resentment due to the restrictions on activities and places the family can go. Typically-developing siblings may also experience anger due to the teasing or bullying they may receive from their peers and from feeling unappreciated by parents (Dodd, 2004; Harris, 2008; McCullough & Simon, 2011; Naylor & Prescott, 2004; Petalas et al., 2009; Powell et al., 2006).

Typically-developing siblings may also experience hurt feelings due to a lack of communication and/or emotion reciprocation from their sibling with ASD (McCullough & Simon, 2011).

Third, typically-developing siblings often need help in developing effective coping strategies to deal with such issues as being teased by peers due to their sibling’s atypical public behaviors and learning alternative ways to deal with their ASD sibling’s physical aggression (Dyson, 1998). Being teased can lead to more behavior problems for the typically-developing sibling because they may not know effective ways to deal with the hurt or anger they may feel from being teased (Rodrigue et al., 1993). One possible coping strategy that has been highlighted in the research literature for dealing with having a sibling with ASD which may help combat teasing by peers would be to have children act as “advice” givers to others who are dealing with similar
situations (i.e., “Dear Aunt Blabby,” Meyer & Vadaszy, 2008). This format has been found to be successful because it allows the siblings of children with ASD to see that they are not the only ones with such problems (Dyson, 1998). Another coping strategy to combat teasing about the ASD sibling’s atypical behaviors is to teach children ways to explain and answer questions about their sibling’s special needs and atypical behaviors (Dyson, 1998; Lock & Feinstein, 2009; Powell et al., 2006; Smith & Perry, 2004). Questions that peers may ask include “What’s the matter with that dumb old brother of yours…?”, “How come he always acts so weird?”, or “What’s wrong with him?” (Harris & Glasberg, 2012; Petalas et al., 2009). Learning ways to answer these questions can help alleviate feelings of anger, embarrassment, and resentment that these siblings may experience due to other people’s lack of knowledge about their sibling’s ASD (Petalas et al., 2009). Learning these answers may also help typically-developing siblings better understand their sibling’s behaviors (Petalas et al., 2009). Finally, teaching children ways to help deter their sibling with ASD from displaying atypical behaviors in public, e.g., giving them other items to occupy their hands in order to cut down on the amount of hand flapping (C. Cochran, personal communication, September 2012) is also helpful.

The research literature has highlighted the difficulty that some children have in not retaliating to the physical aggression of their sibling with ASD (Petalas et al., 2009). This is problematic since typically-developing siblings
may begin to feel frustrated as they are told not to retaliate, and they may not understand why (Dodd, 2004). One technique that is helpful is to explain the reasons why they cannot retaliate because it will help them learn that their sibling is not being aggressive toward them due to personal reasons, but perhaps due to their sibling’s lack of communication skills or their sensory sensitivity (Dodd, 2004). Another coping strategy is to help typically-developing siblings recognize the positive qualities of, and experiences they have had with, their sibling with ASD (Petalas et al., 2009) rather than the negative qualities of their sibling with ASD (e.g., aggressive behaviors). Studies have also found that wishful thinking and emotional regulation are common coping strategies used by typically-developing siblings of children with ASD to combat aggressive behaviors (Ross & Cuskelly, 2006). A possible reason for the use of emotional regulation may be due to the fact that these typically-developing siblings know how angry they can get when someone is aggressive toward them, thus they choose to regulate their emotions when their sibling with ASD is aggressive with them rather than get angry (Ross & Cuskelly, 2006). Wishing that their sibling was different or that their circumstances were different might be a possible explanation for the use of wishful thinking as a coping strategy for typically-developing siblings (Ross & Cuskelly, 2006).

Fourth, since siblings of children with disabilities have been found to conform to rigid roles in families due to expectations that parents may have for
them, they may lack the opportunity to engage in their own interests and preferred activities (Dyson, 1996). The stress and pressure of having to live up to others’ expectations may stifle their ability to become individuals who have unique experiences (McCullough & Simon, 2011). When support group leaders can promote self-reflection about leadership roles the children may possess, promote discussions about uniqueness, and provide children with the opportunity to explore their personal strengths, talents, and interests, it helps these children combat stress, develop healthy views of themselves, and minimize negative internalizing and externalizing behaviors (i.e., depression and aggression) (Lock & Feinstein, 2009; McCullough & Simon, 2011; Tsao et al., 2012).

Guidelines for Conducting Sibling Support Groups

The research literature on sibling support groups also suggests a few guidelines for conducting groups including keeping parents informed about what is being discussed, exploring personal and demographic similarities between participants which can support the development of new friendships, and easing typically-developing siblings’ hesitation about joining a group.

First, keeping in close communication with parents is important for several reasons. It helps to ensure that parents are aware of the topics that are going to be discussed in the group (and so can allow them to make topic suggestions); it helps them feel included; it keeps them informed of issues that arise (and that may that they may need to address further with their child); and
it can help alleviate some of the apprehension that parents may feel about having their child participate in a support group (i.e., worrying about their child being exposed to information that doesn’t relate to their personal situation) (Powell et al., 2006; Scelles et al., 2012; Tsao et al., 2012). Keeping in close contact with parents also encourages children and their parents to speak openly and honestly with each other about the child’s disability because it encourages open lines of communication (Scelles et al., 2012).

Second, helping the children in the support group see how similar they are to one another is important. Research studies have found that children feel more relaxed and more willing to participate when their demographic characteristics are similar (e.g., their sibling’s ASD severity and age range of group participants) (McCullough & Simon, 2011; McLinden, Miller, & Deprey, 1991; Scelles et al., 2012; Tsao et al., 2012) since children of the same age tend to have similar experiences and understand or interpret situations based on their cognitive development (Ferraioli & Harris, 2010). These similarities are also helpful for developing new friendships that may last outside of the support group (Dyson, 1998; Lock & Feinstein, 2009; McCullough & Simon, 2011; Naylor & Prescott, 2004). Once the support group is over, the use of information packets can provide ways for the children to get in touch with one another to help facilitate the continued development of their new friendships (Dodd, 2004; Dyson, 1998).
Lastly, children may be hesitant about joining a sibling support group because they may be unsure of what is going to be discussed in the group or what they will be required to do as a participant. They may also worry about making their schedules busier, being in an unknown location with unknown people and having to discuss personal feelings, and having to drive long distances to participate (Lock & Feinstein, 2009). One way to alleviate such hesitation about joining a group is to include other children from the child’s geographic area (Lock & Feinstein, 2009). In addition, taking time to discuss in-person the specifics of the group (i.e., what participants will have the opportunity to do and what information they will receive and discuss about having a sibling with ASD) has also been found to alleviate some hesitation (Lock & Feinstein, 2009).

Shortcomings of Current Autism Spectrum Disorder Sibling Groups

While the research literature discusses how typically-developing siblings may benefit from participating in a sibling support group, most of the current research has been done on sibling support groups developed for typically-developing siblings of children with developmental disabilities; there is less research on the development and effectiveness of support groups specifically created for typically-developing siblings of children with ASD (e.g., Lock & Finstein, 2009; Petalas et al., 2009; Smith & Perry, 2004). Toward that end, the proposed sibling support group will focus solely on reaching children
who have siblings who have been diagnosed with ASD as their primary
diagnosis.

Another shortcoming of current interventions is that they typically do not
include parents in the group sessions. The proposed sibling group, by
contrast, will invite parents to participate in the first session (i.e., the parent
meeting) where they will learn about the need for the sibling group as well as
what will be discussed with the children. In addition, parents will be
encouraged to work with their child(ren) to create a simple presentation for the
group that expresses who the child is as a unique individual. Parents will also
be given family activity guides that include information for families and how
they can continue to work with their typically-developing child once the sibling
group is over. In addition, the parents will receive information about managing
their own stress (as they are a group that is known to experience increased
amounts of stress).

Summary and Purpose of Project

The research literature has found that the typically-developing siblings
of children with ASD may benefit even more from participating in sibling
support groups than siblings of children with other disabilities (or no
disabilities) due to the unique challenges they may face (Smith & Perry, 2004).

Unlike interventions in the past which have focused primarily on siblings
and have not included parents, the current project will be a research-based
sibling support group for seven to twelve year old siblings of children with ASD and at least one of their parents.

The goals for this project include increasing the siblings’ knowledge about ASD; providing opportunities for them to express themselves; helping to assist the siblings in developing friendships with other children who have siblings with autism and increase the development of their socialization skills; and provide ways to cope with problems related to having a sibling with autism. Group discussions, games, handouts, and video clips will be used to meet these goals.

Findings of this project will contribute to previous research literature by highlighting activities and information that typically-developing siblings of children with ASD find to be informative and helpful when dealing with issues and/or concerns that may arise as they live and grow up with a sibling with autism. Results from this intervention will also contribute to the effectiveness of future support groups for siblings of children with ASD.
CHAPTER TWO

METHOD

Overview

The purpose of this project was to develop a research-based sibling support group for 7 to 12 year-old children who have a sibling with autism. Typically-developing siblings and their parents attended a four-week, once-weekly sibling support group. The four-week program focused on the four topics found to be the key issues of typically-developing siblings who have a sibling with autism: discovering that others share similar family circumstances, learning about their sibling with autism’s special needs, discussing issues and problems which children with siblings who have ASD typically face (and developing effective coping strategies to deal with these issues), and having an opportunity to express who they are as individuals. Table 1 shows the general outline for the four sessions.
Table 1. Session Breakdown

<table>
<thead>
<tr>
<th>SESSION/DURATION</th>
<th>INFORMATION COVERED</th>
</tr>
</thead>
<tbody>
<tr>
<td>Session #1</td>
<td>Parent Meeting (<em>for parents</em>)</td>
</tr>
</tbody>
</table>
| Duration: 1hr. 30min. | - Overview of how family functioning and typically-developing siblings are impacted  
|                   | - Purpose of current sibling group  
|                   | - Family Activities Guide: How to help siblings of ASD children and parental stress information |
| Session #2       | Understanding Your Sibling with Autism (*for siblings*) |
| Duration: 1hr. 30min. | - Getting to know one another  
|                   | - Definition and causes of autism  
|                   | - Characteristics of children with autism  
|                   | - Programs and interventions for children with autism |
| Session #3       | Everyday Issues, Problems and Coping Skills (*for siblings*) |
| Duration: 1hr. 30min. | - Issues and problems faced  
|                   | - Discussion of autistic behaviors  
|                   | - Discussion of effective coping skills to deal with these issues and problems  
|                   | - Dear Aunt Blabby letters |
| Session #4       | You are Special! (*for siblings and parents*) |
| Duration: 1hr. 30min. | - Comprehension Game  
|                   | - Group discussion of how each child is special and about growing up in a family with a special-needs child  
|                   | - Show and Tell of unique talents and interests |

Participants

A total of three children (two boys and one girl) who have a sibling with autism and their parents signed up for the sibling group. Originally five children signed up, but one family with two children failed to show up for any of the sessions. Participants were ultimately recruited from Applied Behavior
Consultants, Inc., the UCDD parent group, and by word of mouth. The children’s ages ranged from 7 to 11 years (m = 8.7 yrs.); one child was Asian, one was Hispanic, and one was Caucasian. The parents in the group were all mothers who ranged in age from 37 to 45 years (m = 41 yrs.). Two mothers reported having a graduate or professional degree, while one mother had some college/trade school. Each family had one child in the family diagnosed with ASD (two 11 year-old females and one 5 year-old male). Two families had one other child in the family without a disability, while the other family had three other children without a disability. All families had two adults living in the home. Two of the parents had previously attended classes or orientations for parents who have a child with autism (e.g., a parental support group and an orientation for ABA services); one parent had not attended any previous classes or orientations.

Measures

**Autism Knowledge Measure for Young Children**

The Autism Knowledge Measure for Young Children (Perry, 1989) (APPENDIX A) was completed by children attending the sibling group both before and upon completion of the support group to evaluate whether they increased their knowledge about autism. This 20-item measure is intended to assess children’s basic knowledge of the characteristics and causes of autism (e.g., “Do autistic kids like to be by themselves a lot?”). The language is simple and suitable for children. The children respond “yes”, “no”, or “not sure” to the
items. Internal consistency for this measure was computed from the initial sample of siblings (N=30) using their pre-test scores. The coefficient alpha was .68, indicating fair reliability (Smith & Perry, 2004).

**Post-Class Parent Evaluation Form**

Parents completed the Post-class Parent Evaluation Form (APPENDIX B) at the end of the 4-week program. This evaluation form was created by the researcher to evaluate whether parents who had participated in the initial parent meeting felt more equipped to help their typically-developing child cope with issues and problems they may face due to having a sibling with autism. Additionally, parents provided feedback as to the most helpful aspects of the support group, what they learned, what they thought could be added/changed in future groups, and how likely they were to incorporate information they learned into their everyday lives.

**Post-Class Child Evaluation Form**

The post-class Child Evaluation Form (Dyson, 1998) (APPENDIX C) was used to assess the effectiveness of the program for the children at the end of the four sessions. Some questions from this evaluation form were adapted from Dyson’s (1998) Workshop Evaluation Questionnaire. For the purpose of this project, the evaluation form asked the children what they learned from the program, what program components they enjoyed and didn’t enjoy, and other information they would have liked to have learned.
Having a Brother/Sister with Autism Measure

The Having a Brother/Sister with Autism measure (APPENDIX D) was created by the researcher to determine the issues and problems that the children may be facing due to having a sibling with autism. The items in this measure were created based off of issues and problems discussed in the research literature. This measure was completed by the children and returned by the parents at the parent meeting during Session #1. It is an eight item measure written in child-friendly terms. Children circled the answer that best described how they felt about each question. The information obtained from this measure was used to help the facilitator determine if there were certain issues that should be included in the group discussions based on how many children identified it as an issue they often deal with in their everyday lives.

Background Information

A background information form (APPENDIX E) was used to gather information about the parent’s age, gender, ethnicity, relationship to the child in the sibling group, highest educational level of both parents, the child’s age, gender, ethnicity, the age and sex of the child diagnosed with an ASD, the number of other children in the family, and the major issues and problems that the children and parents are currently facing related to having a sibling and child with autism. The background information form was completed by the parent before the first session.
Procedure

While it was originally planned to recruit participants from the CSUSB student parent population and/or Applied Behavior Consultants, Inc., it was difficult to recruit families so attempts to recruit were made at community groups including Ability First-Claremont, Parents Place-West Covina, and an online autism group called Redlands Autism Parents. Flyers (APPENDIX F) were posted, handed out, and at some locations, in-person talks were given to participants who expressed interest in the group. These flyers outlined information about the group and how to sign up. Once parents confirmed their participation, they were emailed forms to complete to bring to the first session of the group (i.e., Background information [APPENDIX E], Autism Knowledge Measure for Young Children [APPENDIX A], Having a Brother/Sister with Autism Measure [APPENDIX D], Informed consent form [APPENDIX G], and Child Assent [APPENDIX H]).

Throughout each of the four sessions, participants had opportunities for open discussion. A student volunteer from California State University, San Bernardino sat in the back of the meeting room during each session and wrote down key points that were brought up. These responses helped guide future discussions and provided useful information about what to consider for future sibling groups (see below).

The presenter arrived early for each of the four sessions in order to make sure that the session area was set up and that any necessary
multi-media aspects of the session were ready. The presenter also set out beverages (water and juice) and small snacks (bread or fruit snacks) for participants. In addition, the presenter set out any necessary materials (folders and writing utensils) that the participants would need to pick up on their way in.

Development of Project Materials

Session 1: Parent Meeting

The outline for Session #1, which covers the parent meeting, is provided in APPENDIX I. The purpose of this session was to familiarize parents with information about the support group, including how families are impacted by having a child with autism. It is important for parents to know this information so they are aware of how typically-developing siblings may be affected, thus allowing them to tailor their parenting style to assist their child as needed. Research shows that it is important to include parents to some degree in a sibling support group so they have a clear idea of what is being discussed in order to continue to work with their child once the sibling support group is over (Scelles et al., 2012).

The plan for this session was to begin with a PowerPoint presentation that would provide parents with current information about how families, including typically-developing siblings, may be impacted by having a child with autism (APPENDIX I-1). Next, the organization and purpose of the sibling support group was to be discussed. Parents were to be informed of what was to be discussed with the children and the activities the children would
participate in so they would be aware of what was going to occur in the group. Parents were also to be given copies of the children's curriculum as well as information about stress and ways to combat it (APPENDIX I-2). Finally, parents were to be given a family activities guide that included information from the book “Siblings of Children with Autism: A Guide for Families” by Harris and Glasberg (2012) (APPENDIX I-3). This information includes suggestions for ways to balance family time so that the needs of all family members are met, and how parents can encourage and help their children play effectively with one another. The facilitator was going to review the two-page handout with parents, briefly touching on points discussed in the book. Parents would be encouraged to obtain a copy of the book and to discuss and utilize the tips with their families.

This was the only session of the support group that the parents attended. One family brought their child who was going to participate in the group to this meeting, and the child had an electronic game to occupy his attention. While each session was expected to be 1.5 hours, Session #1 lasted one hour due to covering all the necessary information in that amount of time. The facilitator first collected the completed forms and then distributed folders to the parents which had the handouts that were to be discussed (e.g., a copy of the PowerPoint presentation for them to take notes on, copies of the handouts that would be given to the children, the family activity guide, and information about dealing with stress). The presenter and participants
introduced themselves, and parents were asked to mention why they were attending the group. Answers included the following: their typically-developing child wanting to play with their sibling with ASD, but not being able to; the typically-developing sibling feeling upset and wanting another sibling; and the typically-developing sibling needing to be around people who understand what they are going through by having a sibling with autism. The presenter went through all of the information in the folder beginning with the PowerPoint presentation. After each topic was discussed, the presenter allowed for question/answer time. Next, the presenter asked for any questions about what was discussed or about the group in general. Lastly, once there were no more questions, the presenter thanked the parents for their time and willingness to participate in the group, made sure the parents had the presenter’s contact information in case they had any other questions, and reminded them of the next meeting that was the following week at the same place and time. Overall, parents seemed glad to learn about how the group was going to be run, what was going to be covered, and were eager for their children to participate.

Session 2: Understanding Your Sibling with Autism

The outline for Session #2, which covers Understanding Your Sibling with Autism, is provided in APPENDIX J. The purpose of this session was to help the children become more familiar with their siblings’ special needs.

The plan for this session was to begin with the children introducing themselves and talking about their sibling with autism to the group to help
each child understand that they are not the only one who has a sibling with autism. The facilitator planned to ask specific questions to help facilitate the children’s introductions (APPENDIX J-1). The purpose of this activity was to allow the children to become more familiar with one another which would help them feel more comfortable around one another. Research findings show that typically-developing siblings tend to lack adequate information about their sibling with autism (e.g., Dodd, 2004; Harris, 2008; Lock & Feinstein, 2009; McCullough & Simon, 2011; Petalas et al., 2009; Smith & Perry, 2004; Tsao et al., 2012), which has a negative impact on the child’s understanding of their sibling with autism and their relationship with this sibling (Dyson, 1998; McCullough & Simon, 2011). Therefore, the definition and causes of autism (APPENDIX J-2 & J-3) as well as the characteristics that children with autism may display were to be discussed next (APPENDIX J-4 & J-5). Studies have also found that directly exposing children to the activities and interventions that their sibling with autism uses (by engaging in role play activities aimed at mimicking what a certain disability is like, teaching children how to use their ASD sibling’s special equipment, or observing their sibling at school or during a therapy session) can help them better understand how their sibling with autism lives (Dyson, 1998; McCullough & Simon, 2011; Powell et al., 2006). Therefore, programs and interventions for children with autism were to be discussed next (APPENDIX J-6 & J-7). Children were to be given worksheets, created by the researcher, with this information that they were to complete as
the facilitator discussed this information. The group facilitator also planned to show video clips to the children to help them better understand the causes, characteristics, programs, and interventions for children with autism.

This was the first session that the children attended. On the day of the session, only one of the two families who said they were planning to attend showed up on time. (One family couldn’t make it due to a previous commitment). The family who arrived on-time chose to wait for the other family to arrive before the session began. Due to the late start, the session only lasted an hour and ran about thirty minutes past the scheduled end time. Session #2 began with the children receiving folders that had the handouts they would be completing during that session. The parents were then shown to the parent room where they could wait for the session to finish. Once the group began, the presenter first introduced herself and facilitated introductions between the two participants. The presenter then told the children where the restrooms were, that they could feel free to speak whenever they felt like it (as long as no one else was speaking), and that they could sit or stand--whatever made them the most comfortable. The presenter then gave a quick overview of what the next three sessions would cover, and asked the children if they had any questions (and if they had any questions or comments during the session to feel free to ask them at any time). The information that was to be presented in Session #2 was then discussed, and the children completed their handouts by calling out the answers. The presenter either confirmed or gave
the correct answer and wrote it on the whiteboard. YouTube videos were also presented as they related to the information that was covered. Table 2 summarizes comments made by the children about their sibling with autism while the information about characteristics of ASD were being discussed.

Table 2. Session #2: Comments Made By Children about Their Sibling with Autism during the Discussion about Characteristics of Children with Autism Spectrum Disorder

<table>
<thead>
<tr>
<th>“Theme”:</th>
<th>Children’s Comments:</th>
</tr>
</thead>
</table>
| Behaviors/Characteristics of sibling with autism | 1. Hitting typically-developing sibling  
2. Screaming to get food child is allergic to  
3. Repeating words/phrases  
4. Talking with words no sentences  
5. Hand flapping  
6. Singing/spitting at inappropriate times  
7. Poor balance |
| Role of typically-developing sibling | 1. Typically-developing siblings need to help teach ASD siblings about the world |
| Understanding sibling with ASD | 1. Sibling doesn’t understand typically-developing child’s feelings and that’s why sibling takes things |

Due to the late start of this session and having the children guess and write down the answers, only the Definition and Causes and Characteristics were covered during this session. The presenter ended the session by answering questions, mentioning what would be covered the following week, and having the children collect their folders and choose a “treat” (e.g., stickers,
pens, Silly Putty) from a “grab bag”. The children then went to the parent room where the presenter thanked the families for attending the session and reminded them of the day and time of the next session. The presenter also sent out an email during the week before the next session as a friendly reminder for the families.

**Session 3: Everyday Issues, Problems and Coping Strategies**

The outline for Session #3, which covers everyday issues, problems, and coping strategies is provided in APPENDIX K. The purpose of this session was to provide the children with the opportunity to talk about and answer questions about everyday issues and problems they face due to having a sibling with autism. The plan for this session was to begin with participant introductions, a review of the previous week, and a discussion of the programs and interventions for children with autism.

First, the research literature shows that discussing the issues and problems that children encounter with others who have a sibling with autism is an important topic for sibling support groups (Powell et al., 2006; Scelles et al., 2012). Having the opportunity to speak openly about their feelings and share solutions with one another is beneficial because it may help combat the problem behaviors experienced by children who have a sibling with autism (e.g., Dodd, 2004; Dyson, 1998; McCullough & Simon, 2011; Rodrigue et al., 1993; Ross & Cuskelley, 2006). Therefore, the children were to answer and discuss open-ended questions related to issues and problems they face by
having a sibling with autism (APPENDIX K-1). During this time, the children would be asked what problems they encounter. They would also discuss atypical behaviors their sibling with autism displays. In addition, they would have the opportunity to discuss more typical behaviors they may be able to teach their sibling with autism (APPENDIX K-2). (Although it is not their responsibility to teach their sibling with autism more typical behaviors, some siblings may find that doing so helps them feel that they are helping their sibling).

Second, the research literature shows that children often need help in developing effective coping strategies to deal with such issues as being teased by peers due to their ASD sibling’s atypical public behaviors and also learning alternative ways to deal with their ASD sibling’s physical aggression (Dyson, 1998). Therefore, effective coping skills to help manage these issues and problems were to be discussed (APPENDIX K-3). Afterwards, the children were to act as advice-givers for other children who have written to “Aunt Blabby” about their issues and problems (Meyer & Vadasy, 2008) (APPENDIX K-4).

At the conclusion of Session #3, children were to be given a handout to give to their parents that described ways the parents can help their children prepare for the Show and Tell part of Session #4 (APPENDIX K-5). A primary purpose of this activity was to give children and their parents some quality time to work on a simple project together.
This was the second session the children attended. Parents once again spent this session in the parent room. This session began with the presenter giving the child who was absent from the previous session the folder with the handouts already filled in so that this child would have the information that was covered the week before. The presenter then did introductions again so that all participants had a chance to introduce themselves, and then did a quick review of the information that was covered the previous week. Information about commonly-used programs and interventions for ASD children was then discussed. The children worked with the presenter to complete the matching handout by trying to guess which programs/interventions went with what description. Next, there was an open discussion about everyday issues and problems they may face due to having a sibling with autism as well as ways they dealt with these issues and problems. The presenter asked open-ended questions to give the children ideas of what to talk about. This was the time in the group when the children freely spoke and shared the most about their sibling with autism. Table 3 highlights comments the children made during this time. One child said that she liked this day because it let her complain about her sibling with autism, and she was glad the parents were not in the same room because if they were then she would have lied about the things she was saying. During this time, the presenter would only comment or ask another question once the children seemed to be finished talking about the topic in order to keep the discussion child-centered and child-led. To summarize the children’s comments, the presenter briefly reiterated some of the issues and problems faced and some of the coping strategies that the children mentioned.
Table 3. Session #3: Problems Mentioned By Children Due to Having a Sibling with Autism

<table>
<thead>
<tr>
<th>“Theme”:</th>
<th>Children’s Comments:</th>
</tr>
</thead>
</table>
| “Getting away” with things | 1. When sibling with ASD acts out or takes things from typically-developing sibling adults say “it’s okay” and try to lessen impact  
2. Having to let sibling with autism come into bedroom because child is sibling |
| Friends | 1. Siblings expressed mixed experiences relating to time spent with friends: plenty of time vs. not enough time  
2. Not many real friends/get made fun of |
| Play with Sibling | 1. Typically-developing sibling never wanting to play with sibling with autism  
2. Sibling with autism playing ASD games on IPod and typically-developing sibling finding them boring so not playing together |
| Anger/Frustration | 1. When sibling with autism cries; typically-developing sibling yells and gets frustrated and that doesn’t make situation any better  
2. Leaving situation when possible when sibling with autism is causing problems  
3. Typically-developing sibling feels parents don’t think they have feelings and says that sibling should be proud to have an ASD sibling  
4. ASD sibling pulling participants’ hair causes these feelings |
| Restricted Outings | 1. Sibling with autism makes it so they can’t go out to certain places  
2. Embarrassed by sibling with autism when out in public  
3. Have to go where sibling with autism wants to go |
| Reactions of others | 1. Feeling bad for typically-developing sibling  
2. Asking a lot of questions  
3. People looking when sibling acting out |
| Coping Strategies | 1. Reading, watching television, going to own room and being left alone  
2. Telling parent when sibling with autism is doing something they shouldn’t |
Due to the children having a lot to say on this topic, there was no time to do the “Dear Aunt Blabby” letters. At the conclusion of this session the children again went to the “grab bag”, were thanked for their participation, and were given the paper to give to their parents about the Show and Tell activity that was going to occur during the fourth (and final) session. The presenter thanked the parents, briefly explained the Show and Tell activity, and reminded the parents about the day and time for the last meeting.

**Session 4: You Are Special!**

The outline for Session #4 is shown in APPENDIX L. The purpose of this session was to discuss with the children how each child is special, why their sibling with autism requires a lot of their parents’ time and attention, and to provide them with an opportunity to share their unique talents and interests with others.

The plan for this session was to have the children first play a comprehension game to sum up and review, in an entertaining way, the information that was presented about autism in Sessions #2 and #3 (APPENDIX L-1). Since the research literature shows that siblings of children with disabilities tend to conform more to rigid roles in families due to expectations that parents may have for them, they may lack opportunities to express their “true” selves (Dyson, 1996). When group leaders can promote self-reflection about leadership roles the children may possess, discuss their special skills, and provide children with the opportunity to explore their
personal strengths, talents, and interests, it can assist these children in combating stress, developing healthy views of themselves, and minimizing negative internalizing and externalizing behaviors (i.e., depression and aggression) (Lock & Feinstein, 2009; McCullough & Simon, 2011; Tsao et al., 2012). Therefore, the plan was to have the children participate in a group discussion about how unique they each are and why their sibling with autism requires so much of their parents’ time (such that their parents may have little time left in the day to attend to all of their needs on a daily basis). APPENDIX L-2 outlines how the group discussion can be facilitated.

This was the fourth and final session of the group and all participants attended and were on time. The children brought in items they were going to share with the group during the Show and Tell time. The parents were given the Post-class Parent Evaluation Form (APPENDIX B) to fill out while they were waiting in the parent room, and they also received the handouts that had information about additional resources that they might find useful (e.g., websites, books, places to possibly find other parent and/or child support groups) (APPENDIX L-3). Session #4 began with the presenter first doing a brief review of what was discussed in the previous session. The presenter then gave an overview of how this session would go. Next the group played the comprehension game that covered information discussed in the previous sessions. The children recorded their individual answers on small index cards and then held them up and called out their answer to see if everyone got the
same answer. All of the children answered all of the questions except for the last question about programs and interventions, which none of them was sure about. One of the participants mentioned that the programs and interventions section was difficult to understand and that they still didn’t really get it. The presenter provided the answer for that question and briefly explained that intervention (i.e., functional communication-PECS) once again. The presenter then began a discussion about how the participants’ parents may not be able to give them much of their time and attention on a daily basis. This discussion focused on why this may be and what kinds of things their sibling with autism needed help with on a daily basis. By the end of this discussion one of the participants mentioned that it made sense that the parents had to help the sibling with autism more than him/her, but that the parents should still give him/her attention as well. Table 4 shows the comments made by the children during this session.
Table 4. Session #4: Children’s Comments about Parental Treatment, the Sibling Relationship, and the Importance of Their Independence

<table>
<thead>
<tr>
<th>“Theme”:</th>
<th>Children’s Comments:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unfair parental treatment</td>
<td>1. Sibling with autism treated “so nicely” and then parents yell at typically-developing sibling and say he/she is lucky because he/she don’t have autism</td>
</tr>
<tr>
<td>Unequal parental time/attention</td>
<td>1. All agree ASD sibling needs extra help to do things (e.g., participate in play, do certain activities), but all the extra time and attention can be annoying</td>
</tr>
<tr>
<td></td>
<td>2. Parents preoccupied doing research related to having a child with autism, helping the child with autism, or doing household things</td>
</tr>
<tr>
<td></td>
<td>3. Would like parents to play and spend more time with them even if it is only one parent</td>
</tr>
<tr>
<td>Sibling relationship</td>
<td>1. Want siblings who they can play with because other family members live far</td>
</tr>
<tr>
<td></td>
<td>2. Don’t have things in common and don’t think they will</td>
</tr>
<tr>
<td></td>
<td>3. Feel that sibling with autism does things to bother them on purpose</td>
</tr>
<tr>
<td></td>
<td>4. Annoyed to hear people say that siblings will get along better when they’re older</td>
</tr>
<tr>
<td></td>
<td>5. While the siblings may not have a lot in common, there are some activities they find to do together (e.g., trampoline, catch, video games)</td>
</tr>
<tr>
<td>Importance of being an individual</td>
<td>1. Time to go off on own when in public and then meeting up with parents and sibling with autism is nice</td>
</tr>
<tr>
<td></td>
<td>2. Sibling expressed the need to be known as their own person rather than being known as the sibling of the person with autism</td>
</tr>
<tr>
<td></td>
<td>3. Personal identity is key</td>
</tr>
</tbody>
</table>

Note: Themes are listed in the order they were discussed during Session #4.
Next, the presenter discussed how all the participants were unique, and mentioned that for the rest of this session, the conversation was only going to be about them and what they liked to do and not about their sibling with autism. At the start of the Show and Tell activity, the presenter asked if the children wanted to invite their parents into the room and all three children said they would rather just share with one another, so the parents stayed in the parent room. During Show and Tell, the children volunteered to share and they also chose where in the room they wanted to share (e.g., in the front of the room or by their seat). Each child took a turn talking about the items they brought in and why they were important. The children brought in a collection of items that included their favorite toys (e.g., Legos), their favorite electronics (e.g., video game/music player), their favorite items purchased from a recent school trip (e.g., a mood ring and beanie), and their favorite things to do during their alone time (e.g., movies/shows they enjoyed—Harry Potter; or books they enjoyed). Lastly, before the children were dismissed to their parents they were given the post-class measures (Autism Knowledge Measure for Young Children (Perry, 1989) [APPENDIX A] and the Post-class Child Evaluation form [APPENDIX C]). Once the children were finished, the presenter and children went to the parent room where the presenter collected the Post-class Parent Evaluation forms and thanked the families for their willingness to participate in the group. The presenter also let the parents know that they could contact her in the future if they needed anything and the parents asked
the presenter to let them know if another sibling group formed so that they could participate.
CHAPTER THREE

RESULTS

Results for the pre-post assessment, the pre-class questionnaires, the post-class questionnaires, and feedback from the parents in Session 1 and the children in Sessions 2-4 are discussed below.

Pre-and Post-Assessments

Pre-Post Assessment

To determine whether participation in the sibling group increased the children’s knowledge about autism, pre-post scores from the Autism Knowledge Measure for Young Children (Perry, 1989) were compared. Results showed that the pre-test mean for the group was 12 (out of a possible 20), while the post-test mean was only slightly higher (12.7).

Pre-Class Questionnaires

The issues which the typically-developing siblings reported on the pre-class questionnaire, “Having a Brother/Sister with Autism” are shown below (Table 5). In general, the results show that the children had some negative feelings towards their sibling with autism, and having less of their parent’s time was an issue for them.
Table 5. Results of “Having A Brother/Sister with Autism” Measure

<table>
<thead>
<tr>
<th>Measure</th>
<th>Very Well (n=0)</th>
<th>Okay (n=2)</th>
<th>Not Very Well (n=1)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. “How well do you get along with your brother/sister with autism?”</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. “Do you often feel angry at your brother/sister with autism?”</td>
<td>Often (n=2)</td>
<td>Sometimes (n=1)</td>
<td>Never (n=0)</td>
</tr>
<tr>
<td>4. “Do you often feel upset with him/her?”</td>
<td>Often (n=2)</td>
<td>Sometimes (n=1)</td>
<td>Never (n=0)</td>
</tr>
<tr>
<td>7. “Do you ever feel like you don’t know what to say when other kids make fun of your brother/sister with autism?”</td>
<td>Often (n=1)</td>
<td>Sometimes (n=1)</td>
<td>Never (n=1)</td>
</tr>
<tr>
<td>8. “Do you feel like your brother/sister with autism takes up a lot of your mother’s/father’s time?”</td>
<td>Often (n=1)</td>
<td>Sometimes (n=2)</td>
<td>Never (n=0)</td>
</tr>
</tbody>
</table>

The concerns, stressors, or problems the parents reported on the background information form due to parenting their typically-developing child and concerns, stressors, or problems that their typically-developing child faced are outlined below in Table 6. Parents reported their challenge with dividing their time and attention and facilitating social contact for their typically-developing child, and other concerns, with parenting their typically-developing children. Anger, irritation, grief, feeling like an only sibling, and difficulty socializing with peers were concerns reported by parents which their typically-developing child was facing. (Information about these concerns, stressors, or problems would have been used to guide discussions during the
subsequent sessions if the children had needed ideas of things to discuss; however, they brought up many of these issues on their own).

Table 6. Concerns, Stressors, and Problems Parents and Their Typically-Developing Child Face

Concerns, stressors, or problems due to parenting typically-developing children:

P 1: “Not giving enough attention; worried [child] will develop anxiety like me.” (P1, personal communication, January 2015)
P 2: “Fairly dividing my time between both kids, since one has much higher needs. Helping my (child) find other children who know what (my child) is going through. Helping (my child) with the sadness of not having a typical sibling (my child) can play with in ways (my child) enjoys.” (P2, personal communication, January 2015)
P 3: “To facilitate their daily social contact.” (P3, personal communication, January 2015)

Concerns, stressors, or problems typically-developing child is facing:

P 1: “I feel (my child) is having difficulty socializing with peers.” (P1, personal communication, January 2015)
P 2: “Anger over…sibling’s frequent crying. Irritation over the loud way (sibling) eats. Grief of not having a sibling to play with.” (P2, personal communication, January 2015)
P 3: “(My child) feels like (my child) does not have any siblings and always wishes that (my child) was an only child.” (P3, personal communication, January 2015)

Post-Class Child Evaluation Form

Results from the Post-class Child Evaluation Form are shown below (Table 7). In general, results showed that the children mentioned the group discussions and their presentations to the group about themselves as what they liked the best about the group. The children mentioned doing “work” (e.g., filling out worksheets) as their least favorite part. In terms of the activities they
liked the best, the interactive activities and watching the video clips were mentioned. The children also indicated a desire to play more games and do certain activities (e.g., Show and Tell) in an earlier session as things they would have liked to have done. In terms of what they learned from the group, the children named some characteristics of children with autism and hearing that other children feel the same way they do.

Table 7. Results of Post-Class Child Evaluation Form

<table>
<thead>
<tr>
<th>Question 1: The part of the group that I liked the most was:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Responses: C 1: “When we had Show and Tell” (C1, personal communication, January 2015)</td>
</tr>
<tr>
<td>C 2: “Talking about embarrassing things” (C2, personal communication, January 2015)</td>
</tr>
<tr>
<td>C 3: “When we complained about our sibling” (C3, personal communication, January 2015)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Question 2: The part of the group that I didn’t like was:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Responses: C 1: “When we had to do work” (C1, personal communication, January 2015)</td>
</tr>
<tr>
<td>C 2: “When we did worksheets” (C2, personal communication, January 2015)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Question 3: The activities I liked the best were:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Responses: C 1: “Watching the YouTube videos” (C1, personal communication, January 2015)</td>
</tr>
<tr>
<td>C 2: “Show and Tell” (C2, personal communication, January 2015)</td>
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<tr>
<td>C 3: “The game” (C3, personal communication, January 2015)</td>
</tr>
</tbody>
</table>
Question 4: The activities I would have liked to do but didn’t were:
Responses: C 1: “Do Show and Tell in the beginning of the class (first meeting)” (C1, personal communication, January 2015)
C 3: “More games” (C3, personal communication, January 2015)

Question 5: What I learned from the group that I didn’t know before:
Responses: C 1: “The temper tantrums. Also the flapping of the hands” (C1, personal communication, January 2015)
C 2: “Some people feel the same way as I about their sibling” (C2, personal communication, January 2015)
C 3: “…that most autistic children are boys” (C3, personal communication, January 2015)

Question 6: What I would have liked to learn from the group about my brother or sister with autism:
Responses: C 1: “How to get him to be good and better. I want my (sibling) to be the best” (C1, personal communication, January 2015)
C 2: “How to deal with their behavior and feelings” (C2, personal communication, January 2015)

Post-Class Parent Evaluation Form

Results from the Post-class Parent Evaluation Form are shown below (Table 8). In general, feedback from the parents was positive, and they indicated that they had good experiences with the support group and found it useful for both themselves and their child. Results showed that parents found receiving information about additional resources and having a place for the child to express themselves as some of the key reasons they found the group to be useful. Parents identified realizing they needed to invest more time in their typically-developing child and that they are not alone in their unique family situation as important things they learned. (A disruptive child was the
only thing mentioned as the least valuable part of the group). All parents
mentioned a desire for more kids to be in the group as something that could
be changed to improve the support group. All parents mentioned they would
likely use the information they obtained in the group.

Table 8. Results of Post-Class Parent Evaluation Form

Question 1: Was this support group useful for you and your child(ren)? Why or why not?

Responses: P 1: “Yes. For me all that I have learned is a refresh and
remind of information I already knew. Also, info
received will be very useful in finding other programs
for my family and myself. My (child) is very happy with
being involved with his peers who are in the same
situation. He has become more talkative and engages
even more with his sibling.” (P1, personal
communication, January 2015)

P 2: “Yes. It helped my (child) to hear another
(participant’s) experiences with (participant’s sibling)-
(my child) related a story (participant) told and thought
it was funny. So I think that helped (my child) feel less
alone in (my child’s) experience. And (my child)
wanted to go back.” (P2, personal communication, January 2015)

P 3: “Very useful. My (child) has a chance to express all
(my child’s) feelings about (their sibling). I have better
understanding of (my child’s) frustration.” (P3,
personal communication, January 2015)

Question 2: What is the most important thing you learned from the support group?

Responses: P 1: “How important and special my (child) is. Also we are
not alone in our special situation.” (P1, personal
communication, January 2015)

P 2: “Just talking with the moms reminds me I’m not alone
in this experience, which is always validating and nice
to not be alone. And I gained information from
someone with a physical therapy background.” (P2,
personal communication, January 2015)

P 3: “I need to start investing more time with my typical
child.” (P3, personal communication, January 2015)
Question 3: What was the least valuable part of the support group?

Responses: P 2: “(My child) had some trouble with a (child) who was ‘off topic’ and kept talking to (my child) when (my child) as trying to participate.” (P2, personal communication, January 2015)

Question 4: What do you think can be added or changed to improve the support group?

Responses: P 1: “Maybe more participants. I was a bit surprised there wasn’t more families here.” (P1, personal communication, January 2015)

P 2: “More kids. My son was interested in talking with some kids his own age. Maybe dividing up the kids by age.” (P2, personal communication, January 2015)

P 3: “I wish there were more children in the support group.” (P3, personal communication, January 2015)

Question 5: Will you use the information you learned from the group? Why or why not?

Responses: P 1: “Yes. We have reviewed the info at home. (Just a little) and we have all this wonderful information to review and keep and most importantly share with family.” (P1, personal communication, January 2015)

P 2: “Hopefully. I would like to. My only concern is ‘life’ getting in the way! It helps to have a structured activity like a group to keep us on task.” (P2, personal communication, January 2015)

P 3: “Yes. Very useful.” (P3, personal communication, January 2015)

Question 6: To what extent do you plan to incorporate the ideas/suggestions from the group? [Circle one] (1 = “not at all”, 7 = “definitely yes”)

Responses: P 1: “7” (P1, personal communication, January 2015)

P 2: “5” (P2, personal communication, January 2015)

P 3: “7” (P3, personal communication, January 2015)
CHAPTER FOUR
DISCUSSION

The purpose of this project was to develop a research-based sibling support group for seven to twelve year old children who have a sibling with autism. The primary reason the group was created was because there is a lack of sibling support groups specifically for typically-developing children who have a sibling with Autism Spectrum Disorder. Research suggests that typically-developing children who have a sibling with autism may benefit more from participating in a support group compared to siblings of children with other disabilities (or no disabilities) due to the unique challenges they face (Smith & Perry, 2004).

Pre-Post Assessments, the Pre-Class Questionnaire, and the Post-Class Evaluations

Results from the Autism Knowledge Measure for Young Children (Perry, 1989) indicated that the sibling support group only slightly increased the children’s knowledge about autism. One possible explanation for this finding could be that this support group covered in-depth information about ASD during the second session when only two of the three participants attended, so the third child missed out on hearing and discussing this information. Also, while the children were completing the post-test on this measure, they made such comments as, “my (sibling) doesn’t do that”; thus, some of the children may have answered some of the questions on the
post-test about *their own* sibling rather than children with ASD in general, even though the facilitator explained that they should consider what *most* children with ASD are like. Another possible explanation could be that during the comprehension game in Session 4, the children said that they didn’t really understand the section about Programs/Interventions that children with ASD may use.

The Having a Brother/Sister with Autism measure showed that the children had some negative feelings towards their sibling with autism, and that they felt they received less of their parents’ time. These findings are consistent with research studies that have found that differential parenting may lead typically-developing children to feel that their parents favor their sibling with ASD over them, and this can lead to feelings of sibling competition and more conflict in the sibling relationship (McHale, Crouter, McGuire, & Updegraff, 1995; Tsao et al., 2012). These findings are also consistent with research studies that have found that parental time and attention is usually unequally divided between children with ASD and their typically-developing siblings (Dodd, 2004; Naylor & Prescott, 2004; Nealy et al., 2012; Tsao et al., 2012). Although the children did express negative feelings toward their sibling with autism during the group sessions, they were also able to express ways they choose to deal with these issues and problems they face (e.g., going to their own room to be alone until they are ready to come out or telling their parents
when their sibling with ASD is doing something they shouldn’t be doing or that is bothering them).

The Post-class Child Evaluation Form showed that the children enjoyed talking about their sibling with autism and the things he/she does, and also sharing with the group items and activities (e.g., favorite books, toys, or items they purchased) that are important to them (e.g., clothing items bought from a recent school trip, Legos, books). It is likely that these children do not get many opportunities to speak openly about their sibling with autism and how he/she affects their life. Similarly, the opportunity to talk about themselves and things they like may be something that they do not get many opportunities to do. These findings are consistent with research studies that have found that being part of a support group may be their first opportunity to talk with other children who are in their situation (Dodd, 2004; McCullough & Simon, 2011). Future groups should consider adding more information on dealing with their sibling’s behaviors and ways to get their sibling to “be better.”

The Post-class Parent Evaluation Form showed that the parents found receiving information about additional resources as an important component of the group. A possible explanation for this result could be that due to these parents leading such busy lives, it may be easier for them to utilize resources if they are clearly organized and easily accessible. Additionally, a larger group size was mentioned as something the parents would change about the current support group. A larger group size would be ideal for allowing the children to
get the perspective of *many* other children, and it would also give them the opportunity to meet and form friendships with other children with similar life experiences.

**Session Notes**

The findings of Session 1, i.e., the reasons parents gave as to why they wanted their typically-developing child to be part of the support group, are consistent with research studies that have found that being part of a support group may help alleviate some feelings of isolation that typically-developing children experience, and it can also show them that there are other children who have siblings with ASD (Dodd, 2004; McCullough & Simon, 2011). All parents seemed eager for their typically-developing child to participate in the support group. This eagerness could be related to the fact that there are few groups like this to meet these children’s needs.

In Session 2, the comments made by the children regarding the behaviors their sibling with autism displayed (e.g., hitting their sibling, screaming to get what they want, repeating words, hand-flapping, poor balance) are consistent with the research literature that describes common characteristics and behaviors of children with autism spectrum disorder (American Psychiatric Association, 2013; Rosenblatt & Carbone, 2013). The finding that the children knew that their sibling with ASD didn’t understand their feelings and that is why their sibling takes their things is consistent with research studies that have found that when these children receive adequate
information about their sibling with autism, it can help them to become more empathetic and understand toward their sibling and others with ASD (McCullough & Simon, 2011).

In Session 3, children identified problems they face due to having a sibling with autism (e.g., inability to play with their sibling in the way they want; frustration and anger over some of the things their sibling does to them). The opportunity for these children to speak about these problems was important because research studies have found that discussing issues and problems that typically-developing siblings encounter with others who have siblings with ASD is important as it provides children with a safe place where they can openly express their concerns, feelings, and emotions about their sibling with ASD (Dodd, 2004; Dyson, 1998; Harris, 2008; Lock & Feinstein, 2009; Powell et al., 2006; Scelles, Bouteyre, Dayan, & Picon, 2012). While the children did express many problems they face, they also identified coping strategies they use to deal with these problems. Having the opportunity to share these strategies was an important component of the support group because research studies have found that sharing solutions with one another is beneficial for siblings of children with ASD because it may help them combat problem behaviors they may experience (Dodd, 2004; Dyson, 1998; McCullough & Simon, 2011; Rodrigue et al., 1993; Ross & Cuskelly, 2006).

In Session 4, children provided feedback about parent treatment, the sibling relationship, and the importance of their independence. Findings from
this session are consistent with research studies that have found that parental

time and attention is usually unevenly distributed (Dodd, 2004; Naylor &
Prescott, 2004; Nealy et al., 2012; Tsao et al., 2012), and that
typically-developing siblings understand why this occurs (Harris & Glasberg,
2012; Powell, Gallagher, & Rhodes, 2006). Children mentioned more than
once during the fourth session that it was important for them to be considered
their own person rather than the sibling of a child with autism. This finding is
consistent with research studies that have found that providing children with
opportunities to explore their personal strengths, talents, and interests is
important because it helps them to become individuals with unique
experiences (Lock & Feinstein, 2009; McCullough & Simon, 2011; Tsao et al.,
2012).

Overall, the notes from all four sessions provided information as to what
was important to the participants (e.g., having the opportunity to speak openly
about their sibling with autism, and sharing activities and other items that are
important to them), and they also provided useful information that could be
used in the future to teach information and guide discussions (e.g., finding
other ways to provide the children with information about ASD and how it
affects their siblings, such as role playing activities and interactive games).

Lessons Learned and Advice for Future Support Groups

Overall, there were several topics that were found to be very useful in
the group. First, allowing the children to have time to “vent” and speak freely
about their sibling with autism seemed to be one of the most enjoyable parts for the children. Second, incorporating opportunities for the children to talk with one another and describe issues they were facing due to having a sibling with autism helped them relate to one another. Third, having the opportunity to share things that made them unique and that they enjoyed was also important because it allowed the attention to be on them and as one of the children in the group mentioned on more than one occasion, “… they are individuals and want to be known as their own person and not the sibling of someone who has ASD.”

Findings from the current sibling support group provide additional suggestions for future sibling support groups, including future group formats, narrowing the age range of participants, and the recruitment of participants (including session days and times).

First, while the children enjoyed the open discussion format and getting a chance to express their feelings about issues as they relate to their sibling with autism, incorporating more interactive games should be considered for future groups. Due to the hour and a half session times, there was not enough time in the current support group to incorporate many interactive games. Future support groups should consider ways to incorporate these types of activities into each session (i.e., increase session length by 30 minutes so that each session is 2 hours). Interactive/cooperative games would give the children a chance to work with one another closely while encouraging team
work; plus the children enjoyed the interactive comprehension game that was played during the current group.

Also, coming up with new ways to present the information on programs and interventions their sibling with autism may use would be helpful since the children in the current group had a hard time understanding this information. Suggestions might include having the children role play these programs/interventions, as role play activities can help them to better understand how their sibling with ASD lives (Dyson, 1998; McCullough & Simon, 2011; Powell et al., 2006). Showing additional video clips of these interventions and programs being run would also be helpful.

Additionally, having the children write notes or letters (anonymously) to their parents about topics or information that they think parents should know related to how they feel about and deal with having a sibling with autism would be helpful (e.g., “The things I wish my parent knew I was feeling” or “The things I wish my parents would do more or less of”). The children in the current group had a lot of interesting information to share and even though they may not want to share everything with their parents, it could be helpful for both the parents and the children if the children wrote some of their thoughts down and the facilitator created a handout for the parents with this information.

Second, it became clear that having children from a broad age range can make it difficult for children to relate to one another. Future sibling support groups should consider narrowing the age range of the group which could
increase what children have in common and help them to relate better to one another.

Third, future sibling support groups should consider running groups during the week and on weekends due to varying family availabilities. Parents of the current group had been asked when would be the ideal time to have a sibling support group, and responses included having it during the summer in a camp-type format, Saturday mornings in the summer, once a month, and scheduling it around their child’s sports team’s games and practices. Additionally, leaving the recruitment window open for a longer period of time would likely yield more participants. Once the current group had finished, the facilitator received an email from a family who was interested in signing up. One way might be to start recruiting participants for a summer support group in the spring, when children first come back to school from winter break. This would give the parents ample time to rearrange schedules and plan other summer extracurricular activities around the support group if they so choose. Another way might be to hold the support group on school grounds as an after-school activity.

Although the sibling group had only three participants, the feedback and comments will be very useful for making changes to the support group should it be run again and for other support groups for children who have a sibling with autism. A mother of one of the children in the group sent the presenter an email once the group was over, and mentioned that her child told her that he
enjoyed the group and was sad that it was over. This positive feedback suggests that even with only a few participants, sibling support groups are valuable and can make a difference.

Limitations

The major limitation of the current project was the number of families who participated. It was difficult to find a sufficient number of families who were able and willing to participate in the group during its scheduled days and times. Two major barriers to recruitment included the time of the scheduled group, and the difficulty the facilitator had with disseminating the information about the group in person.

When families showed an interest in the group, they were asked what day and time would work best for them (weekdays in the evening or weekends in the morning). Based on their responses, the session was ultimately run on four consecutive Saturday mornings. This ultimately made it impossible for some families to attend due to having extracurricular activities on Saturday mornings, or the children not being able to make every session because they were with a different parent every other weekend. Another family who was initially interested said they could not attend because the child with autism’s therapy was during the week in the evening, and other extracurricular activities for the other siblings were scheduled on the weekends. Regarding the dissemination of information about the group in person, in some locations the facilitator was able to speak directly to parents who were already members of
a parent support group and also to staff members who could get the information about the support group to the families they work with. However, in some locations this option was either not available (e.g., an online support group page or a facility where there were no parents in the program’s group to speak to) or a program did not want the facilitator to come in and speak to the parents directly. In these cases, the facilitator sent out copies of the flyer to the groups so that they could be put out so that interested families could contact the facilitator to sign-up.

Conclusion

In conclusion, this research-based sibling support group was created to benefit the typically-developing siblings of children with autism. Findings of this project were consistent with previous research literature that has highlighted activities and information that typically-developing sibling of children with ASD find to be informative and helpful when dealing with issues and concerns that may arise as they live and grow up with a sibling with autism. In the current group, allowing the children to engage in open-ended discussions about topics worked really well. Once one child started talking about something their sibling did or an issue they faced, the other siblings would also talk about related issues. Including children who were not at the same developmental level didn’t work well for this group. This was evident during discussions when the youngest sibling didn’t speak much, but the other two siblings had a back and
forth dialogue. Findings from this project can contribute to the effectiveness of future support groups for siblings of children with ASD.
APPENDIX A

AUTISM KNOWLEDGE MEASURE FOR YOUNG CHILDREN
Directions: You are going to read some questions about autism. I want you to answer as best you can by circling, either YES or NO. If you don’t know, try to guess what you think is the right answer. If you can’t guess, you can circle NOT SURE.

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

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

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

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

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

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

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

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

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

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

11. Are autistic kids usually developmentally delayed too?
    YES  NOT SURE  NO

12. Do autistic kids look at you when you talk to them?
    YES  NOT SURE  NO
13. Do autistic kids like to be by themselves a lot?
   YES      NOT SURE      NO

14. Are autistic kids usually born into rich families?
   YES      NOT SURE      NO

15. Have autistic kids been that way since they were very young?
   YES      NOT SURE      NO

16. Is autism common enough that there are lots of people on your street (or in your building) with an autistic kid in the family?
   YES      NOT SURE      NO

17. Do autistic kids sometimes hit themselves or bite their hand?
   YES      NOT SURE      NO

18. Do autistic kids get that way because of the way their parents treat them?
   YES      NOT SURE      NO

19. Do autistic kids do funny things like flapping their hands or bouncing up and down in their chair?
   YES      NOT SURE      NO

20. If a kid has an autistic brother or sister does that mean there’s something wrong with him/her too?
   YES      NOT SURE      NO

APPENDIX B

POST-CLASS PARENT EVALUATION FORM
Post-class Parent Evaluation Form

1. Was this support group useful for you and your child(ren)? Why or why not?

2. What is the most important thing you learned from the support group?

3. What was the least valuable part of the support group?

4. What do you think can be added or changed to improve the support group?

5. Will you use the information you learned from the group? Why or why not?

6. To what extent do you plan to incorporate the ideas/suggestions from the group? (circle one)

Not at all 1 2 3 4 5 Definitely Yes 6 7

Created by: Audrey Venegas
APPENDIX C

POST-CLASS CHILD EVALUATION FORM
Post-class Child Evaluation Form
(Source: Adapted from Workshop Evaluation Questionnaire- Dyson, 1998)

We have come to the end of our sibling group. We would like to know what you thought about this group so that we can make it better in the future. Please answer the following questions:

1. The part of the group that I liked the most was: ______________________
   ______________________
   ______________________

2. The part of the group that I didn’t like was: ______________________
   ______________________
   ______________________

3. The activities I liked the best were: ______________________
   ______________________
   ______________________

4. The activities I would have liked to do but didn’t were: ________________
   ______________________
   ______________________

5. What I learned from the group that I didn’t know before: ________________
   ______________________
   ______________________

6. What I would have liked to learn from the group about my brother or sister with autism: ________________
   ______________________
   ______________________

APPENDIX D

HAVING A BROTHER/SISTER WITH AUTISM
Having a Brother/Sister with Autism

Circle the answer that BEST describes how you feel.

1. How well do you get along with your brother/sister with autism?
   VERY WELL       OKAY       NOT VERY WELL

2. Do you wish you knew more about autism?
   YES              NO          I ALREADY KNOW ENOUGH

3. Do you often feel angry at your brother/sister with autism?
   OFTEN           SOMETIMES       NEVER

4. Do you often feel upset with him/her?
   OFTEN           SOMETIMES       NEVER

5. Do you ever get teased at school because you have a brother/sister with autism?
   OFTEN           SOMETIMES       NEVER

6. Do you have friends over to your house?
   OFTEN           SOMETIMES       NEVER

7. Do you ever feel like you don’t know what to say when other kids make fun of your brother/sister with autism?
   OFTEN           SOMETIMES       NEVER

8. Do you feel like your brother/sister with autism takes up a lot of your mother’s/father’s time?
   OFTEN           SOMETIMES       NEVER

Created by: Audrey Venegas
APPENDIX E

BACKGROUND INFORMATION
Background Information

Parent: Please complete the following items below:

1. Your age: _____ years
2. Your sex: _____ male  _____ female
3. Your relationship to the child in the sibling group: ______________________
4. Your ethnicity: _____ Hispanic   _____ African American
   _____ Asian    _____ Middle Eastern
   _____ Caucasian  _____ Bi-racial
   _____ Other: ______________________
5. The highest level of education you have completed:
   _____ Did not complete high school
   _____ High school graduate
   _____ Some college or trade school
   _____ Graduated with a Bachelor’s degree
   _____ Some graduate school
   _____ Graduate or professional degree
6. The highest level of education your child’s other parent has completed:
   _____ Did not complete high school
   _____ High school graduate
   _____ Some college or trade school
   _____ Graduated with a Bachelor’s degree
   _____ Some graduate school
   _____ Graduate or professional degree
7. Number of children diagnosed with an ASD? ________________
   a. Age: ________________________________
   b. Sex: ________________________________
   c. Ethnicity: ________________________________
8. Age ____ and gender ___ of child(ren) attending this sibling support group.
9. Number of children in family without a disability? _________________________
   a. Age: ________________________________
   b. Sex: ________________________________
   c. Ethnicity: ________________________________
10. Number of adults living in the home? ________________________________
11. Have you previously attended classes or orientations for parents who have a child with autism?  
   _____ yes     _____ no    if yes, please explain: ________________________________  

12. What concerns, stressors, or problems do you have in parenting your typically-developing child(ren)?

13. Are there any major concerns, stressors, or problems that your typically-developing child(ren) is (are) facing?

Created By: Audrey Venegas
APPENDIX F

FLYER
A Sibling Support Group for Children with a Sibling with Autism

FREE Workshop
For Children Ages 7-12 and Their Parent(s)
Being the sibling of a child with autism can be difficult for children. This is an opportunity for children to learn about their sibling’s special needs:

*Session 1: Parent Meeting (for parents)
- A time for the parents to learn about the information that will be presented during the sibling group

*Session 2: Understanding your Sibling with Autism (for siblings)
- Information about autism

*Session 3: Everyday Issues, Problems, and Coping Skills (for siblings)
- Group discussions about issues siblings face and how to cope with them

*Session 4: You are Special! (for siblings and parents)
- Show and Tell of unique talents/interests
**Group Dates:** 4 sessions (this group is made up of four different sessions); each session is 1½ hrs.; dates to be determined once participants have registered

**Time:** To be determined

**Location:** Applied Behavior Consultants, Inc.; Ontario Office
- 800 Ferrari Lane Suite 100
- Ontario, CA 91764

**Presenter:** Audrey Venegas, M.A. candidate in Child Development, California State University, San Bernardino; Behavioral Interventionist for 6 years with Applied Behavior Consultants, Inc.

*This is an independent project not affiliated with Applied Behavior Consultants, Inc. (ABC, Inc.). Participation is voluntary and ABC, Inc. is hereby released of all liabilities.*

**To register and for further information:**

Email Audrey Venegas at: vena311@coyote.csusb.edu

-In the email please include what day(s) of the week work best for you and your child(ren) to attend the group:

1. During the week after school (i.e., 4-5:30 p.m.)
2. Saturday mornings (i.e., 10-11:30 a.m.)
APPENDIX G

INFORMED CONSENT FORM
Informed Consent

The sibling support group which you and your child are invited to participate in is for typically-developing siblings of children who have been diagnosed with autism. This project is being conducted by Audrey Venegas, M.A. candidate in Child Development, under the supervision of Dr. Laura Kamptner, Department of Psychology, California State University, San Bernardino.

Participation for you consists of attending a parent meeting that outlines the purpose of the sibling support group, how a child with autism affects family functioning, what your child will be learning in the support group, and ways to handle parental stress. In addition, you will be asked to complete a brief (anonymous) background information form and a post-class parent evaluation form. Your child(ren)’s participation consists of attending three group sessions that will provide them with information about their sibling’s autism and help them learn coping skills to deal with issues they may face with having a sibling with autism. Additionally, they will be asked to complete a simple (anonymous) pre-post autism knowledge measure as well as a questionnaire about having a brother or sister with autism, and a post-class child evaluation form.

Participation is completely voluntary and you and your child(ren) may discontinue at any time without penalty. Information collected in the questionnaires and pre-post measures will be completely anonymous. No names or other identifying information will be reported.

All completed questionnaires and pre-post measures will be stored in a locked file drawer at CSUSB and only the researcher will have access to the data. The group’s results from this support group will be used for Audrey Venegas’ master’s thesis on helping siblings of children diagnosed with an ASD.

This study entails no foreseeable risks and may provide direct benefits to participating children and their parents by helping families learn more about their sibling/child with autism, coping strategies, and managing stress.

This project has been approved by the University Institutional Review Board. If you have any questions or concerns about the support group or participants’ rights, please contact Dr.
Laura Kamptner, Department of Psychology at (909) 537-5582 (SB-531). You may also contact the University Institutional Review Board (CSUSB) if you have any concerns about this support group. Thank you for your participation.

Sincerely,

Audrey Venegas  
M.A. candidate, Child Development

Laura Kamptner  
Professor, Psychology

I acknowledge that I have been informed of, and understand the true nature and purpose of this study, and I freely consent to participate. I acknowledge that I am at least 18 years of age. Please indicate your desire for you and your child(ren) to participate by placing an “X” on the line below.

Participant’s X _____
Date: _______________
I have created a group for children who have a brother or sister with autism. This group will be a way for you to meet and talk with other children who also have a brother or sister with autism.

There will be three group sessions for the kids. Your parents will come to the first and last sessions. Each will last 1 ½ hours. This group will give you a chance to learn more about autism and ways you can deal with problems that you may have because of your brother or sister with autism by talking as a group and playing games. During the last group session you will be invited to show and tell others in the group about things that you do that make you happy.

You do not have to talk about anything you do not want to in the group, and you can ask any questions you have. Also, you do not have to be in this group if you do not want to.

Sincerely,

Audrey Venegas
M.A. candidate, Child Development

If you decide you want to be in this group, please place an “X” here: 


APPENDIX I

SESSION #1: PARENT MEETING
Session #1: Parent Meeting

I. Welcome to Parents (10min.)
   1. Introductions:
      a. Facilitator will introduce him/herself to the parents (i.e., educational
         background/work information)
      b. Parents will introduce themselves and briefly discuss their families

II. Collection of Forms (10min.)
   1. Informed Consent: The parent(s) will return their informed consent form and
      their child’s assent (See Appendices G and H)
   2. Pre-assessment: Parent(s) will return the background information form and
      child’s pre-assessment measures
      a. Background Information Form (See Appendix A)
      b. The Autism Knowledge Measure for Young Children (See
         Appendix B)
      c. Having a Brother/Sister with Autism Measure (See Appendix E)

III. Powerpoint: Overview of impact of child with autism on families, including
      typically-developing sibling; purpose of sibling support group (20min.)
   1. The facilitator will present a powerpoint presentation (See Appendix I-1)
      that will include:
      a. Discussion of the impact of having a child with autism on families
      b. Impact of sibling with autism on typically-developing child
      c. Discussion of what the sibling support group will cover
      d. Parents will also receive copies of all of the handouts the children
         will be receiving as well as parental stress information (See
         Appendix I-2)

IV. Discussion (5min.)
   1. This will be a time for the parents to discuss information presented in the
      powerpoint presentation and ask any questions they may have.

V. Family Activities Guide (See Appendix I-3) (10min.)
   1. The facilitator will pass out and discuss information included in the
      information packets including:
      a. Ways to meet the needs of all members of the family
      b. Ways to facilitate effective play among the siblings
      *NOTE: Information in these packets can be obtained from the book “Siblings
      of Children with Autism: A Guide for Families” by Harris and
      Glasberg (2012)

VI. Question/Answer Period
   1. This will be a time for the parents to ask any additional questions they have
      about the sibling support group.
APPENDIX I-1
PowerPoint Presentation

105
IMPACT OF CHILD WITH AUTISM ON FAMILY FUNCTIONING

- Increased parental stress
  - Feelings in reaction to hearing of child's diagnosis
  - Unique parenting demands
  - ASD child's social and communication deficits
  - Issues relating to the child’s treatments (i.e. acceptance)

- Increased marital stress
  - Partner's physical exhaustion
  - Making difficult parenting decisions
  - Communication difficulties
  - Financial stress
  - Rapid role shifts and more resentment and dissatisfaction
  - Disease

- Restricted family activities
  - Financial stress
  - Fear of judgment from others
  - Difficulty finding adequate childcare
  - Strained relationships with extended family members
TYPICALLY-DEVELOPING CHILDREN WHO HAVE SIBLINGS WITH AUTISM:

- **Positive effects:**
  - High levels of self-esteem
  - Intelligence
  - Academics

- **Negative effects:**
  - Reasonably well adjusted and socially competent

  - Loss social time with peers
  - Conflict with peers who tease them about their sibling with autism
  - Loss parental time and attention
  - More household responsibilities
  - Possible feelings of anger and resentment toward their sibling with autism and in misunderstanding between for loss parental time and attention
  - Greater risk for anxiety and aggression

**Discussion Question:**

- Have you experienced these or any other related issues?
NEED FOR SIBLING SUPPORT GROUPS

- Typically-developing siblings of children with autism affected in multiple ways:
  - may need special support geared toward helping them deal with issues that arise from having a sibling with autism

SIBLING SUPPORT GROUP TOUGHS

- Four relevant topics that should be addressed in sibling support groups:
  - Age-appropriate information concerning their sibling's disability
  - Issues and problems encountered in everyday life due to having a sibling with autism
  - Effective ways to cope with having a sibling with autism
  - Importance of having opportunities to express themselves

A SIBLING SUPPORT GROUP FOR CHILDREN WITH A SIBLING WITH AUTISM
# A Sibling Support Group for Children with a Sibling with Autism

## Session #2
**Duration:** 1hr. 30min.

**Understanding Your Sibling with Autism (for siblings)**
- Getting to know one another
- Definition and causes of autism
- Characteristics of children with autism
- Programs and interventions for children with autism

## Session #3
**Duration:** 1hr. 30min.

**Everyday Issues, Problems and Coping Skills (for siblings)**
- Issues and problems faced
- Discussion of atypical behaviors of children with autism
- Discussion of effective coping skills to deal with these issues and problems
- Dear Aunt Blabby letters

## Session #4
**Duration:** 1hr. 30min.

**You are Special! (for siblings and parents)**
- Comprehension Game
- Group discussion of how each child is special and about growing up in a family with a special-needs child
- Show and Tell of unique talents and interests
APPENDIX I-2
Session #1: Children’s handouts (copies for parents)

The facilitator will pass out copies and discuss the following appendices with parents during the parent meeting so that they are aware of what will be discussed with their child(ren) during the subsequent group sessions:

1. APPENDIX J-3: Definition and causes of autism
2. APPENDIX J-5: Characteristics
3. APPENDIX J-7: Commonly used interventions and programs
4. APPENDIX K-1: Issues and problems faced
5. APPENDIX K-2: Discussing autistic behaviors
6. APPENDIX K-3: Effective coping skills
7. APPENDIX K-4: Dear Aunt Blabby letters
8. APPENDIX L-2: Group discussion

The facilitator will also pass out copies of the five pages of parental stress information and ways to combat it and will lead a brief discussion about this information as well. See next five pages.
Secrets of Parenting

Parental Stress Can Spill Over to the Kids

Imagine this: You get a speeding ticket on the way to work because you were thinking about the late charge on your electricity bill. You work hard most of the day on a huge report. But at 4:15, your computer crashes. You had saved only the changes made at the beginning of the work session. The clock is ticking, and you must pick up your son at school. Your co-worker stops by to chat, and you get angry and feel even more rushed. As you bend over to turn the computer off, your elbow catches on an open drawer. Although there is no blood, a welt begins to swell, and you wonder if you can take any more problems in one day. The phone rings. It is the school; your son has broken his arm on the playground.

The secret of parenting is to prevent your stress from spilling over and affecting your relationship with your child.

Adult stress can spill over and affect children. Life just keeps getting more and more rushed, money is tight, and you need to run to keep up with family, health needs, insurance plans, appointments, grocery shopping, being a good neighbor, getting the car inspected, taking the pets to the vet, remembering mother's birthday, and more. This is stress! But you must STOP and PAY ATTENTION to anything that causes you to lash out at your children. Is it really the children's actions, or did the children simply get in the way of a stressful adult day?

This is how stress works:

- Small things that bother you pile up, or an unexpected event occurs.
- You react and must think about how to deal with the stressor, which may involve the need for money, time, family support, or other resources.
- You react to the stress and take action.
- The event either turns into a crisis, or you make a plan to deal with it using your coping skills and resources.

It's up to you to recognize stress and confront the challenges it presents without taking out your frustrations on your children. By doing this, you can reduce the impact of the stressful event on your family. These guidelines can help you confront stress.
What to Do

Recognize the effects of stress in your children. Although some stress is normal and even healthy, children today seem to encounter many stressful life events at earlier ages. Stress shows itself in children through complaints about stomachaches, being nervous, trouble sleeping, flare-ups of anger, and infections.

Model and teach coping skills to your children. Children learn to cope by watching you cope. Learn a coping skill yourself, and be sure you model it for your children. Some positive ways to cope include exercise; calming techniques, such as sitting quietly while you take deep breaths; writing about your frustrations in a journal; and listening to music. Seek help from friends and family when you are in stressful situations, and teach your children to think through alternative ways to solve problems.

Take a break, and return refreshed. When you have had a stressful day, tell your children about your day and explain why you need a 10-minute break. Be sure they are supervised while you take time for yourself. Then take a 10-minute nap or sit quietly to let your heart rate slow down and your thoughts become calm. Then you will be able to calmly address issues with your children. The problem will still be there, but the spillover might not affect your interactions with your child.

Apologize. Apologize if you express anger at the children when your stress comes from something else. This provides a good example for them so they can learn to apologize, too.

Help children make sense of the world. Children and teenagers need to feel rooted in a world that makes sense to them. It makes sense to follow rules if you understand their purpose. Be an anchor in your children’s lives. They need someone they can count on. Explain why stressful things happen in simple terms.

Find help. Look at your support system. Do you have friends you can count on or family members who will help? Are there special services within the community that provide help to families under stress? Reach out to friends and family, and ask for help.

The North Carolina Cooperative Extension Service provides a free publication that provides more information about stress and parenting:

Helping Children Cope with Stress (FCS-457)

It is available from your county Extension Center, or it can be viewed online by visiting this Web site: www.ces.ncsu.edu/depts/fcs/humandev/pubs/copestress.html

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Dealing with the
Everyday Pressures
of Parenting

• **Stop** – Take time out to calm down and reflect.

• **Go for a walk or run** – Work off your frustration through exercise.

• If someone can watch the children, **get away**. Go outside, go in another room, give yourself a little time alone.

• Turn negative energy into **something productive**. Clean house, do yard work, tackle some other job you’ve been putting off.

• **Tune out**. Turn on some music, watch television, or read a book until you are ready to deal with the problem.

• **Talk** with someone else about your feelings. Call a friend or help line.

• **Write** your feelings down on paper.

  Don’t let your anger build and build.
  If your feelings don’t go away, get help.

San Bernardino County Child Abuse Hotline: 1-800-327-8724
THE BIG LIST OF PLEASURABLE ACTIVITIES

Check (✓) the ones you're willing to do, and then add any activities that you can think of:

- Talk to a friend on the telephone.
- Go out and visit a friend.
- Invite a friend to come to your home.
- Text message your friends.
- Organize a party.
- Exercise.
- Lift weights.
- Do yoga, tai chi, or Pilates, or take classes to learn.
- Stretch your muscles.
- Go for a long walk in a park or someplace else that's peaceful.
- Go outside and watch the clouds.
- Go jog.
- Ride your bike.
- Go for a swim.
- Go hiking.
- Do something exciting, like surfing, rock climbing, skiing, skydiving, motorcycle riding, or kayaking, or go learn how to do one of these things.
- Go to your local playground and join a game being played or watch a game.
- Go play something you can do by yourself if no one else is around, like basketball, bowling, handball, miniature golf, billiards, or hitting a tennis ball against the wall.
- Get a massage; this can also help soothe your emotions.
- Get out of your house, even if you just sit outside.
- Go for a drive in your car or go for a ride on public transportation.
- Plan a trip to a place you've never been before.
- Sleep or take a nap.
- Eat chocolate (it's good for you!) or eat something else you really like.
- Eat your favorite ice cream.
- Cook your favorite dish or meal.
- Cook a recipe that you've never tried before.
- Take a cooking class.
- Go out for something to eat.
- Go outside and play with your pet.
- Go borrow a friend's dog and take it to the park.
- Give your pet a bath.
- Go outside and watch the birds and other animals.
- Find something funny to do, like reading the Sunday comics.
- Watch a funny movie (start collecting funny movies to watch when you're feeling overwhelmed with pain).
- Go to the movie theater and watch whatever's playing.
- Watch television.
- Listen to the radio.
- Go to a sporting event, like a baseball or football game.
- Play a game with a friend.
- Play solitaire.
- Play video games.
- Go online to chat.
- Visit your favorite Web sites.
- Visit crazy Web sites and start keeping a list of them.
- Create your own Web site.
- Create your own online blog.
- Join an Internet dating service.
- Sell something you don't want on the Internet.
- Buy something on the Internet.
- Do a puzzle with a lot of pieces.
- Call a crisis or suicide hotline and talk to someone.
- Go shopping.
- Go get a haircut.
Go to a spa.

Go to a library.

Go to a bookstore and read.

Go to your favorite café for coffee or tea.

Visit a museum or local art gallery.

Go to the mall or the park and watch other people; try to imagine what they're thinking.

Pray or meditate.

Go to your church, synagogue, temple, or other place of worship.

Join a group as your place of worship.

Write a letter to God.

Call a family member you haven't spoken to in a long time.

Learn a new language.

Sing or learn how to sing.

Play a musical instrument or learn how to play one.

Write a song.

Listen to some upbeat, happy music (start collecting happy songs for times when you're feeling overwhelmed).

Turn on some loud music and dance in your room.

Memorize lines from your favorite movie, play, or song.

Make a movie or video with your camcorder.

Take photographs.

Join a public-speaking group and write a speech.

Participate in a local theater group.

Sing in a local choir.

Join a club.

Plant a garden.

Work outside.

Knit, crochet, or sew—or learn how to.

Make a scrapbook with pictures.

Paint your nails.

Change your hair color.

Take a bubble bath or shower.

Work on your car, truck, motorcycle, or bicycle.

Sign up for a class that excites you at a local college, adult school, or online.

Read your favorite book, magazine, paper, or poem.

Read a trashy celebrity magazine.

Write a letter to a friend or family member.

Write things you like about yourself on a picture of your body or draw them on a photograph of yourself.

Write a poem, story, movie, or play about your life or someone else's life.

Write in your journal or diary about what happened to you today.

Write a loving letter to yourself when you're feeling good and keep it with you to read when you're feeling upset.

Make a list of ten things you're good at or that you like about yourself when you're feeling good, and keep it with you to read when you're feeling upset.

Draw a picture.

Paint a picture with a brush or your fingers.

Masturbate.

Have sex with someone you care about.

Make a list of the people you admire and want to be like—it can be anyone real or fictional throughout history. Describe what you admire about these people.

Write a story about the craziest, funniest, or sexiest thing that has ever happened to you.

Make a list of ten things you would like to do before you die.

Make a list of ten celebrities you would like to be friends with and describe why.

Make a list of ten celebrities you would like to have sex with and describe why.

Write a letter to someone who has made your life better and tell them why. (You don't have to send the letter if you don't want to.)

Create your own list of pleasurable activities.

Other ideas: __________________________

______________________________

The Dialectical Behavior Therapy Skills Workbook

APPENDIX I-3
Session #1: Family Activities Guide

Purpose: To give parents suggestions for ways they can help meet the needs of everyone in their families and to give them suggestions for ways to help encourage their children to play together.

Reference: Siblings of children with autism: A guide for families (Harris & Glasberg, 2012)

I. The balancing act: Meeting everyone’s needs, including your own

A. You love him more: All children become aware of the different ways they are treated. When age difference is not a factor, differential treatment may be harder for children to understand (pp. 87-89).

B. Together or apart?: How do you feel about doing things as a family? While there are times that all family members should be included in family activities, there are times when it may be beneficial to do things separately (p. 89).
   1. Being together
   2. Avoiding embarrassment
   3. Choosing the right activities
   4. Private space

C. Everyone contributes to a family: While children should not act as secondary parents with a lot of responsibilities (i.e., disciplining and taking care of the autistic child on a full-time basis), they can issue some reprimands (i.e., “stop throwing my toys”) or give their sibling suggestions for other activities they can do. While it is important to make sure typically-developing children do not take on adult roles, they should still contribute to the family system in their own ways (i.e., doing chores and spending some time with their autistic sibling) (pp. 114-115).

D. Using resources
   1. Informal Support: Things your family, friends, members of your faith group, or people in the wider community do to help you with the problems you face in raising your child with ASD (pp. 98-100).
   2. Formal Support: Pediatrician, children’s dentist, speech therapist, teachers, behavior analysts, respite care, and other professionals who work with you and your child. Parent and sibling support groups can also be sources of support (pp. 101-105).

II. Children at play: Helping children play together

For children younger than seven years old, it may be more effective to have both children play games that include at least one parent because the typically-developing child may not be ready to be the “teacher” (p. 128).
A. Children as teachers: It is beneficial for children to have necessary skills to engage in reciprocal play with their ASD brother or sister and their sibling may be more responsive to these efforts (p. 112).

B. Behavioral techniques as teaching tools: These include: the use of rewards, well-delivered instructions that are brief and simple, physical, visual, and verbal guidance (prompts) (p. 114).

C. Teaching play skills:
   1. First, parents need to know how to give clear, simple instructions, how to reward good behavior, and how to help when the child needs a prompt in order to respond (p. 117).
   2. Then parents need to know three broad steps to take to teach their typically developing child to become an effective teacher and playmate (p. 118).
      i. First, remember to go slowly, do just a little each day, and be liberal in your praise of both of your children and take pride in yourself for what you are doing for them.
      ii. Second, create an attractive setting for teaching and play
      iii. Third, teach typically-developing child three basic skills:
          -giving instructions, rewarding good behavior, and prompting new skills

D. Setting the stage for play
   1. Select appropriate activities: colorful, attractive, of potential interest for both kids (i.e., soft balls that can be rolled/thrown, trucks or cars, dollhouses, toy airports, garages, barns with animals, and doctor kits). Start with toys that are familiar to your ASD child. Toys should encourage interaction and be age appropriate. Be sure to consider developmental level of children (pp. 118-119).
   2. Scheduling play sessions: Keep them short at the very beginning (p. 121).
   3. Modeling play skills: Begin by modeling the types of behaviors you want to see your child displaying with their ASD sibling (p. 121).

E. Giving clear instructions
   1. Make sure sibling has child’s attention and then they can give clear and uncomplicated instruction. Instructions should also be given at a slow enough pace so that the ASD child is able to respond. Avoid complicated, multiple commands (p. 124).

F. Being rewarding
   1. Part of being a good teacher is providing enthusiastic praise and affection to the learner. Praise can also be paired with small treats, but not necessary to use unless essential to getting started (pp. 124-125).

G. Giving help
   1. Providing verbal or physical help (also known as a prompt) may be helpful when first teaching an ASD child new skills. However, it is important that the ASD child does not become dependent on the prompt. Teaching your typically-developing child how to prompt may
be difficult and they may benefit from first practicing with you (pp. 126-127).
APPENDIX J

SESSION #2: UNDERSTANDING YOUR SIBLING WITH AUTISM
Session #2: Understanding Your Sibling with Autism

I. Snack Time (5min.)

II. Introductions/Icebreaker (15min.)
   1. The facilitator will introduce him/herself to the group and explain how the group works
   2. The children will introduce themselves to one another and talk about their sibling with autism (See Appendix J-1)

III. Current Autism Information (See Appendices J-2 to J-7) (60min.)
   1. Definition and causes of autism
   2. Characteristics (role playing; video clips)
   3. Commonly used interventions and programs (video clips)

IV. Question/Answer Time
APPENDIX J-1
Session #2: Introductions
FACILITATOR/LEADER COPY

Facilitators can utilize the following suggestions to help the children introduce themselves and their sibling with autism to the group:

1. To introduce themselves to the group: Encourage the children to say their name, age, and something that will help the group remember who they are (i.e., their favorite color, sport, food, a talent/hobby they enjoy, etc.).

2. To describe their sibling with autism to the group: Encourage the children to talk about their sibling with autism by saying their name, age, something they love about their sibling with autism or something they enjoy doing with their sibling with autism.
APPENDIX J-2
Session #2: Current Autism Information
Definition and causes of autism
FACILITATOR/LEADER COPY

DEFINITION OF AUTISM
Adapted from: “A Sibling’s Guide to Autism” (2011) and Everybody is Different (Bleach, 2002)

The word “autism” comes from the Greek word “autos” which means “self”. This is because many people with autism often prefer to be by themselves.

Autism is a complex brain disorder that affects the way a person’s brain works. It is referred to as Autism Spectrum Disorder or “ASD.” A spectrum disorder can include many symptoms.

Even though there are many people with autism (about 1 in 68 children; boys are diagnosed 5 times more than girls) each person is very different in terms of his or her challenges, abilities, and personality. Some people with autism may require a lot of help, while others need less assistance at home, school, and in the community.

CAUSES
Adapted from: “A Sibling’s Guide to Autism” (2011) and Everybody is Different (Bleach, 2002)

No one is certain what causes autism, but there are lots of different ideas about what causes it. Some believe it is caused by damage to the brain before birth or that part of the brain developed differently. There may be different chemicals in the autistic person’s brain. Some people believe autism is genetic, which means they may have gotten certain parts of who they are from your parents. There may also be things in the environment, the world we live in, that may cause autism. Doctors, scientists, and researchers are still looking for what might cause autism, however whatever it is that causes autism, it is nobody’s fault.

There is no cure for autism at the moment, but there are lots of ways in which you can help your brother or sister learn. This learning will help your brother or sister enjoy life and get the most out of it. Schools, therapies, and special ways of teaching all can help.
DEFINITION OF AUTISM

- The word “autism” comes from the ________________word “autos” which means “__________”. This is because many people with _________________ often prefer to be by themselves.

- Autism is a complex _________________ disorder that affects the way a person’s ______________works.

- It is referred to as “Autism _______________________Disorder” or “ASD.” A spectrum disorder can include many symptoms.

- Even though there are many people with autism (about 1 in _____children; __________ are diagnosed 5 times more than __________) each person is very different in terms of his or her challenges, abilities, and personality.

- Some people with autism may require a lot of help, while others need less help at home, __________________, and in the community.
CAUSES

- No one is certain what causes autism, but there are lots of different ideas about what causes it.
- Some believe it is caused by damage to the ______________ before birth or that part of the brain developed differently.
- There may be different __________________ in the autistic person’s brain.
- Some people believe autism is ______________, which means they may have gotten certain parts of who they are from their ________________.
- There may also be things in the environment, the world we live in, that may cause autism.
- Doctors, scientists, and researchers are still looking for what might cause autism, however whatever it is that causes autism, it is _________________ fault.
- There is no cure for autism at the moment, but there are lots of ways in which you can help your brother or sister __________________. This learning will help your brother or sister enjoy life and get the most out of it.
- __________________, therapies, and special ways of teaching all can help.

Created by: Audrey Venegas
APPENDIX J-4
Session #2: Current Autism Information- Characteristics
FACILITATOR/LEADER COPY
Child-friendly explanations to some of these characteristics can be found in Part 3 of “Everybody is Different” (Bleach, 2002)

CHARACTERISTICS:

1. Communication challenges:
   * hard to understand or say long sentences
   * using one or two words instead of a sentence
   * taking someone’s hand, pointing, or signing to show you what they want/need because they may be unable to say the right things
   * repeating words and/or phrases (echolalia)
     - Echolalia Video: http://www.youtube.com/watch?v=vGpF_GK42a0

2. Social and emotional challenges:
   * trouble understanding other people’s feelings
   * often avoids eye contact and want to be alone
   * difficulty with change
   * have difficulty forming friendships with others
   * trouble with sharing or taking turns while playing
   * weeping or giggling for no apparent reason
     - Laughing out of the blue video (2:15): http://www.youtube.com/watch?v=qYeYiDxfbB0

3. Imagination difficulties:
   * your brother/sister may find it hard to imagine what it is like to be you
   * trouble understanding why you like the things you do

4. Bodily problems:
   * tics: unwanted twitches, movements, or sounds that people make; sort of like a hiccup
     - Tics video: http://www.youtube.com/watch?v=-P6n-uNGzvA
   * sleep problems: having a hard time sleeping throughout the night or falling asleep
*seizures: when a person’s muscles tighten and relax rapidly or stop moving completely

*stomach problems: pain or discomfort in the stomach that may be caused by many different things

*motor (movement) difficulties (gross & fine motor): like having a hard time holding a pencil to write (fine motor-small muscles) or having trouble walking or climbing (gross motor-large muscles)
-1 min. 30sec. video of fine motor activity: http://www.youtube.com/watch?v=BTjUAJNAIDg

5. **Behavior problems:**

*temper tantrums in young children

*aggression: hurting the people around them (i.e., hitting)

*self-injurious (hurting themselves) behaviors (e.g., finger, hand, or wrist biting)
-1 min. video of tantrum/self-injury: http://www.youtube.com/watch?v=q4jc2OdxoP8

6. **Restricted and unusual interests:**

*few & specific interests (getting upset by minor changes such as taking a different route to a certain place or changing a television station or movie they were watching)

*developing a strong attachment to hard objects (i.e., pens) and not wanting to let it go

*skilled at play that involves putting smaller things together to make one big thing (i.e., assembling puzzles)

*always playing in a particular way (i.e., lining up objects repeatedly)

7. **Unusual sensory behaviors and responses:**

*unusual sensory-seeking behaviors through such activities as flapping their hands, walking on their tip toes, rocking their body, and spinning in circles (behaviors that give the person a certain feeling inside when they do the behavior)
  -Spinning video: http://www.youtube.com/watch?v=Y5QpsZTjQKo&list=PLA0BE821AA76D5122
  -Hand flapping, laughing out of the blue, tip toe walking video: http://www.youtube.com/watch?v=qYeYiDxFcB0

*high threshold for pain (they don’t get hurt easily; it may take a lot for them to feel physical pain)

*very sensitive to sounds, smells, tastes, touches, and the way things look/feel
CHARACTERISTICS:

1. **Communication challenges:**
   - *hard to understand or say long ____________________
   - * use one or two ______________ instead of a sentence
   - * take someone’s ________________, pointing, or signing to show
     you what they want/need because they may be unable to
     _______________ the right things
   - * ________________ words and/or phrases (echolalia)

2. **Social and emotional challenges:**
   - *trouble understanding other people’s ________________
   - *often avoid ____________ _______________ and want to be alone
   - * ________________ with change
   - *have ________________ forming friendships with others
   - *trouble with ________________ or taking turns while playing
   - *weeping or ________________ for no apparent reason

3. **Imagination difficulties:**
   - *your brother/sister may find it ________________ to imagine what it
     is like to be ________________
   - *trouble understanding why you like the things you do

4. **Bodily problems:**
   - *tics: unwanted twitches, movements, or ________________ that people
     make; sort of like a ________________
   - *sleep problems: having a hard time ________________ throughout
     the night or ________________ asleep
   - *seizures: when a person’s ________________ tighten and relax rapidly
     or stop moving completely
   - *stomach problems: pain or ________________ in the stomach that
     may be caused by many different things
*motor (movement) difficulties (gross & fine motor): like having a hard
time holding a pencil to write (___________motor-small
muscles) or having trouble ____________ or climbing (gross
motor-large muscles)

5. Behavior problems:

*temper _______________ in young children
*hurting the people around them (i.e., ________________)
*hurting themselves (i.e., finger, hand, or wrist biting)

6. Restricted and unusual interests:

*few & specific interests (getting upset by little changes such as going a
_______________ way to a certain place or changing a TV
station or movie they are watching)
*spending a lot of time playing with hard objects (i.e., ____________)
and not wanting to let it go
*being really good at playing with toys where you put smaller things
together to make one big thing (i.e., assembling
_______________)
*_______________ playing in a particular way (i.e., lining up
objects over and over again)

7. Unusual sensory behaviors and responses:

*unusual sensory behaviors like: flapping their _______________,
walking on their tip toes, _____________ their body, and spinning in
circles (behaviors that gives them a certain feeling inside when they do
the behavior)
*able to take a lot of _____________ (they don’t get hurt easily; it may
take a lot for them to feel physical ________________)
*very sensitive to sounds, _________________. ________________, touches,
and the way things look/feel

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COMMONLY USED INTERVENTIONS AND PROGRAMS:

* **Medications:** medicines that can help control some of the symptoms like high energy levels, aggression or self-injurious behaviors

* **Behavioral treatment intervention:** The primary behavioral treatment approach used for ASD individuals is called Applied Behavior Analysis (ABA). The goal of ABA is to increase positive/desirable behaviors and decrease negative/undesirable behaviors with the use of positive reinforcement (rewards) in order to improve a variety of skills (i.e., walk, talk, play with others, learn self-help skills).

  *Behavior Training video: http://www.youtube.com/watch?v=7pN6ydLE4EQ 1min. video of an example of a discrete trial in ABA. Just one component of ABA treatment.*

* **Relationship-building intervention:** A relationship-building intervention that has been used with children with ASD is called “Developmental, Individual Differences, Relationship-Based Approach” (DIR; also called “Floortime”). This treatment is tailored to the child’s developmental level and the therapist follows the child’s lead to help the child develop social interaction and communication skills.

  *Floortime video: http://www.youtube.com/watch?v=sQZ_6D6xGzc 1 min. video with explanations written on the screen from the autism educational video, The Early Learner at Home, copyright 2002 by Autism Teaching Tools TM. For more information, see www.autismteachingtools.com*

* **Educational intervention:** “Treatment and Education of Autistic and related Communication-handicapped Children” (TEACCH). This program focuses on identifying the strengths and weaknesses of ASD children and using that information to teach the child. Visual cues (pictures) are used to help the child understand directions and information more clearly.

  *TEACCH video: http://www.youtube.com/watch?v=PxLfIHPWITA 2 min. video of a tour around a TEACCH classroom that explains about visual cues and the importance in the classroom  http://www.youtube.com/watch?feature=player_embedded&v=ddGLJ2r4rcw 3 min. intro to TEACCH video from autismspeaks.org*

* **Skill development interventions:**

  Occupational therapy: used to help an ASD person learn how to live as independently as possible.

  * OT video: http://www.youtube.com/watch?v=4Fu4mJ_r-Y 30sec. to 1min. example from session shows work on hand/eye coordination and following instructions*
Speech-language therapy: Used to help people who have lost the ability to speak or have not learned how to use their voice or mouth to make sounds and talk.

*S-L Therapy video: http://www.youtube.com/watch?v=c7wp0JOPGVo
45sec. example of speech therapy session*

Picture Exchange Communication System (PECS): used to help teach children how to better communicate through the use of pictures.

*PECS video: http://www.youtube.com/watch?v=UfNJihQOJo0 1 min. example of how PHASE II of PECS works to request for desired item*
Appendix J-7
Session #2: Current Autism Information - Commonly used Interventions and Programs

Handout

Commonly Used Interventions/Programs:

Match the intervention or program name with the description. One intervention or program has more than one answer.

<table>
<thead>
<tr>
<th>Intervention/Program</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Medications</td>
<td>a) Applied Behavior Analysis: used to increase positive or desirable behaviors and decrease negative or undesirable behaviors</td>
</tr>
<tr>
<td>2. Behavioral Treatment Intervention</td>
<td>b) TEACCH: Focuses on the strengths and weaknesses of ASD children and using that information to teach them; visual cues (pictures) used</td>
</tr>
<tr>
<td>3. Relationship-building Intervention</td>
<td>c) Occupational Therapy: helps ASD children live as independently as possible</td>
</tr>
<tr>
<td>4. Educational Intervention</td>
<td>d) Speech-language Therapy: used to help people speak and/or learn to talk/make sounds</td>
</tr>
<tr>
<td>5. Skill Development Interventions</td>
<td>e) DIR/Floortime: therapist follows lead of child to help them develop social and communication skills</td>
</tr>
<tr>
<td></td>
<td>f) Picture Exchange Communication System (PECS): used to teach children how to better communicate through the use of pictures</td>
</tr>
<tr>
<td></td>
<td>g) Helps control some symptoms like high energy levels, aggression or self-injurious behaviors</td>
</tr>
</tbody>
</table>

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APPENDIX K

SESSION #3: EVERYDAY ISSUES, PROBLEMS
AND COPING SKILLS
APPENDIX K
Session #3: Everyday Issues, Problems and Coping Skills

I. Welcome/ Snack Time (10min.)

II. Issues and Coping Strategies (50min.)
   1. Issues and Problems faced: Open-ended questions or yes/no questions (i.e.,
      raise your hand if your sibling with autism sometimes makes you upset, sad
      or angry?) (See Appendix K-1)
   2. Discussing autistic behaviors (See Appendix K-2)
      a. Videos
      b. Discussing alternative behaviors the children can show their sibling
         with autism
   3. Effective coping skills (See Appendix K-3)
      a. Discussing answers for questions that peers may have about their
         sibling with autism
      b. Reasons for not retaliating to ASD sibling’s physical aggressions
      c. Talking about positive experiences with their sibling with autism

III. Dear Aunt Blabby letters (See Appendix K-4) (20min.)
   1. Children act as advice givers to other “children” with issues associated with
      having a sibling with autism

IV. Show and Tell preparation sheet (5min.)
   1. Children will be given a handout to give to their parents explaining ways
      parents can help their child(ren) prepare for the Show and Tell part of
      Session #4 (See Appendix K-5).

V. Question/Answer Time
APPENDIX K-1
Session #3: Issues and Problems Faced

1. Raise your hand if your sibling with autism sometimes makes you upset.
   a. What types of things does he/she do to make you upset?

2. Raise your hand if your sibling with autism has broken anything of yours.
   a. What did you do when this happened?

3. Raise your hand if you feel you don’t get very much time or many chances to play
   with your friends.
   a. Do you sometimes want to invite them over to your house but you are afraid
      to because of your sibling with autism?
   b. Are you sometimes not allowed to invite them over because of your sibling
      with autism?

4. How many of you sometimes feel that you and your family cannot go certain places
   because of your sibling with autism?
   a. What do your parents usually tell you when that happens? How does that
      make you feel?
APPENDIX K-2
Session #3: Discussing autistic behaviors

I. Main Question:
1. How many of you are sometimes embarrassed or bothered when going out in public with your sibling with autism because of the way they sometimes act? (i.e., hand flapping, rocking, spinning in circles, laughing or crying for no apparent reason)
   a. Who can explain/describe/act out some of the behaviors your sibling does?

II. Now that we’ve discussed some of the behaviors your sibling with autism engages in, let’s watch these short clips of some behaviors of children with autism:
   1. Autism. 2 1/2 year old boy. Non verbal. Autistic behavior. handflapping: [Link](http://www.youtube.com/watch?v=eVP9wN1Fqi8)
   2. Repetitive Autistic Behavior: [Link](http://www.youtube.com/watch?v=pSrPra1-ErY)

III. Now that you’ve seen some behaviors your sibling with autism might do, let’s talk about ways we can help them or other behaviors we can encourage them to engage in rather than the atypical behaviors, for the time being? (CHILDREN SHOULD BE ENCOURAGED TO SHARE ANY IDEAS THEY HAVE, BUT BELOW ARE A FEW SUGGESTIONS TO HELP GET THE BALL ROLLING.)

   1. If your sibling engages in hand flapping, what are some other things you can teach your sibling to do or something you can give them to prevent them from hand flapping?
      Possible Suggestions: 1. Give them a toy to play with
                                2. Hold their hand
                                3. Play a hand game with them (i.e., patty-cake)

   2. If your sibling engages in rocking their body back and forth or spinning in circles, what are some things you can teach your sibling to do or things you can give them to prevent it?
      Possible Suggestions: 1. Have them play a game with you to give them something else to do

NOTE: Be sure to mention to the kids that there are some behaviors that they can’t prevent and in those situations they may have to let their parents know. Sometimes just making sure their sibling stays out of harms’ way is the best/only thing they can do and that is okay. Also they should be told that some of these alternative behaviors may work for the time being, but they may not have lasting effects.
APPENDIX K-3
Session #3: Effective Coping Skills

I. Main Questions:
1. How many of you have been teased or bullied due to having a sibling with autism?
   a. What do some kids say or ask?
2. How many of you have a sibling with autism who sometimes hits or hurts you or others?
   a. What do you do in these situations?

II. Now that we see you all go through similar situations, we are going to discuss ways you can deal with some of these problems you experience.
1. Who can think of ways you can deal with being teased or bullied by other kids?
   Possible Suggestions: 1. Tell them they don’t know your sibling and that he has autism so he can’t talk well or he has a hard time playing with or being around a lot of people.
   2. If they ask you a question about your sibling that you don’t know the answer to, tell them you will check with your parents and get back to them.
2. Who can think of reasons you shouldn’t hit or hurt your sibling with autism when they hit or hurt you?
   Possible Suggestions: 1. Your sibling is not hitting or hurting you due to personal reasons, but it could be because they have a hard time talking with others or they may feel uncomfortable or unhappy in certain situations.

III. Now that we’ve talked about problems that you face in your daily life due to having a sibling with autism, let’s talk about fun or happy times you have had with your sibling with autism (i.e., family outings to favorite places, vacations, special dinners, special sibling time).
APPENDIX K-4
Session #3: Dear Aunt Blabby letters
(Adapted from Sibshops; Meyer & Vadasy, 2008, Appendix F)

Purpose: To give the children the opportunity to act as advice-givers to other children who have siblings with autism and who have questions about problems they are facing.

This activity can be an open group discussion and ideas can be written down. Present these letters in any way you choose. The idea is just to have the children act as “advice-givers.” Feel free to give them suggestions for advice based on the previous discussions you had if they need help getting started, use your own discretion.

1. Dear Aunt Blabby,
   Boy, am I mad! For the fifth time tonight my sister has bugged me while I’m trying to do my homework. She is always bugging me! Especially when my friends come over. Help!
   (signed)
   Fuming

2. Dear Aunt Blabby,
   Maybe you can help me. I really like my sister. She has autism, but I love her a lot. My problem is that I get bored just going for walks and watching TV with her. What else can I do with her that will be fun for both of us?
   (signed)
   Curious

3. Dear Aunt Blabby,
   I don’t know what to do. My little brother Mark has lots of problems learning. In September, Mark started going to my school. Some kids at my school make fun of the special education kids. I even heard them call my brother names and laugh at things he does. Aunt Blabby, what should I do?
   (signed)
   Confused

4. Dear Aunt Blabby,
   My brother always wants to play with my friends and me. He can’t hit the ball. He can’t catch the ball. He doesn’t understand the rules. My friends get mad. This is more than I can take!
   (signed)
   Caught Between

5. Dear Aunt Blabby,
   My brother, who has autism, sometimes hits kids when we are at the playground. These kids get mad and want to hit him back. What should I do?
   (signed)
   All Mixed Up

APPENDIX K-5
Session #3: Show and Tell

**Purpose:** To give the children the opportunity to display their unique talents and individual interests.

Children should be encouraged to bring in various items that may assist them in presenting/sharing this information with other group and family members. Such items may include: pictures, videos, trophies, certificates, etc. Each child should be given the opportunity to share whatever information they feel comfortable sharing with the group. Parents should be encouraged to work with their child to gather items or discuss what the child will say to the group.
APPENDIX L

SESSION #4: YOU ARE SPECIAL!
APPENDIX L
Session #4: You are Special!

I. Snack Time (10min.)

II. Welcome to parents and family members (5min.)

III. Comprehension Game- “Do you Remember?” (See Appendix L-1) (10min.)

IV. Group Discussion (See Appendix L-2) (15min.)
   1. Group discussion about how special and unique each child is and why their sibling with autism requires so much of their parents time, such that their parents have little time left in the day to attend to all of their needs on a daily basis

V. Show and Tell (See Appendix K-5) (35min.)
   1. Time for children to display unique talents/interests
      a. Can be done by bringing items, pictures, or showing videos of things they enjoy doing to the rest of the group members and family members

VI. Group Wrap-Up (15min.)
   1. Participants thanked for their participation
   2. Post assessments about group experience filled out:
      a. Parent(s) will complete the Post-class Parent Evaluation Form
      b. Children will again complete the Autism Knowledge Measure for Young Children and the Post-class Child Evaluation Form
      c. Families will be given information about resources they can utilize for additional support (See Appendix L-3)
APPENDIX L-1
Session #4: Comprehension Game- Do You Remember?
FACILITATOR/LEADER COPY

Materials: Dry erase boards, dry eraser makers, erasers, index cards (optional)

**Purpose:** The purpose of this game is to help the children remember some of the important information that was discussed earlier about autism.

Break children up into pairs (depending on the size of the group). Creative ways to break them up into pairs and prevent someone from feeling left out: by number of letters in their first name, height, first letter of their autistic sibling’s name, or age of their sibling with autism. The children will work together to answer the questions that are on the board. They will write their answers down on a dry erase board. Once each pair has written their answer and their board is turned over one pair will be chosen to give the correct answer. This will be a time to review the information while also encouraging cooperation among team members.

**Questions:** These questions can either be written on index cards, on a white board, or just vocally read out loud to the children.

**Definition/Causes**
1. True or False: There is a clear cause for autism that everyone knows about.
2. Autism is a disorder that affects a person’s what?

**Characteristics**
1. True or False: Being around a big group of people and socializing with others is easy for children with autism.
2. What is a type of play that some children with autism are especially good at?

**Interventions/Programs**
1. True or False: There are no interventions/programs that can help a child with autism.
2. Which communication technique helps children with autism communicate through the use of pictures and what does it mean?

**Answers:** Some answers may vary. Use your own discretion.

**Definitions/Causes**
1. False
2. Brain

**Characteristics**
1. False
2. constructive play (i.e., assembling puzzles) (answers may vary)

**Interventions/Programs**
1. False
2. PECS; Picture Exchange Communication System
APPENDIX L-2
Session #4: Group Discussion

**Purpose:** This will be a time for the facilitator to discuss with the group members how special and unique they each are and why their sibling with autism requires so much of their parents time, such that their parents have little time left in the day to attend to all of their needs on a daily basis.

Possible ways to lead this discussion include:

1. Ask the children if they ever feel like sometimes their sibling with autism requires a lot of their parent's time.
2. Facilitator should emphasize why siblings with autism require so much of their parents’ time, such that their parents have little time left in the day to attend to their needs on a daily basis.
   a. In order to encourage discussion with the children, the facilitator should ask the children for ideas for things that their sibling with autism needs that their parents take care of on a daily basis (i.e., feeding them, making sure they stay safe, helping them learn).
3. Once the discussion about why siblings with autism require so much time is completed, the facilitator should shift gears and begin a discussion about what the children can do to show their unique talents. This discussion should lead to or coincide with the Show and Tell presentations.
   Possible ways:
   a. Play sports
   b. Start new hobbies (i.e., drawing)
   c. Tell their parents that they want to spend more time with them doing things they enjoy

**NOTE:** The important part of this discussion is to help the children better understand why their sibling with autism requires a lot of their parents’ time and attention. Additionally, making sure that the children know that each of them is special and that the things that make them unique are important is another important part of this discussion. Encourage the children to openly speak about what makes them unique. Facilitators may be able to help the children think of things that make them special based off of experiences they have had with the children during the previous sessions.
APPENDIX L-3
Session #4: Additional Resources

Autism websites:
- Autism Speaks: www.autismspeaks.org – Resources Library
- Autism Society of America: www.autism-society.org
- Autism Web: www.autismweb.com
- Centers for Disease Control and Prevention: www.cdc.gov – Autism Spectrum Disorder

Publications for adults:
- Brothers and sisters: A special part of exceptional families (paperback) by Peggy Gallagher, Thomas H. Powell, and Cheryl Rhodes (2006)
- Siblings of children with autism: A guide for families by Sandra L. Harris and Beth A. Glasberg (2012)

Books for young readers:
- A Friend Like Simon - Autism / ASD - Special Stories Series 2 (Volume 1) (paperback) by Kate Gaynot (2009)
- My friend has autism (paperback) by Amanda Doering Tourville (2010)
- My brother Charlie (hardcover) by Holly Robinson Peete and Ryan Elizabeth Peete (2010)
REFERENCES


