# Siblings of Children with Autism:

# Sibling Support Intervention Program

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### **ABSTRACT**

Siblings of Children with Autism: Sibling Support Intervention Program

#### Keisha Gafoor

The Sibling Support Intervention Program (SSIP) was created specifically for siblings of children with autism to provide these children with the opportunity to voice their perspective and needs, and to empower them within their family dynamics by developing stronger and more understanding relationships within their family (e.g., D'Arcy et al., 2005; Dyson, 1998; Evans et al., 2001). Six children (3 in control group and 3 in experimental group) between 7- and 13-yearsold participated in six weekly, two and a half hour sessions. The perceptions and experiences of the children and their parents of the SSIP were obtained through the use of semi-structured interviews, the Piers-Harris Children's Self-Concept Scale (Piers & Herzberg, 2002), the Behavioural Assessment System for Children (Reynolds & Kamphaus, 1988; 2004), as well as video-taped group observations. Descriptive findings suggest that children often benefitted from information about autism, and the strategies were deemed somewhat beneficial to sibling interactions and helped typically developing children to recognize their sibling's abilities and limitations. In addition, children's self-concept and their parents' reports of internalizing and externalizing behaviors of the experimental group showed improvements from the pre-group session interview and the post-group session interviews. However, there were no consistent changes noted for the control group. The parents' perceptions of family dynamics indicated little change between preand post-group.

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### Introduction

Siblings spend a significant amount of time interacting with each other which in turn helps to develop understanding of each other as well as aiding in each other's development of language skills through play and conflict (Howe & Recchia, 2006; Larson & Richards, 1994). Therefore, the sibling relationship is one of the most complex and longest lasting relationships for many individuals, as they provide each other with important tools to facilitate their social, moral, emotional, and cognitive development. The sibling relationship is also a fundamental relationship when considering the entire family. According to Minuchin's (1985) family systems theory, family members are interconnected and as a result each member can have direct effects on the lives of each. Consequently, when one child is diagnosed with Autism Spectrum Disorder, the interactions amongst family members can present several challenges.

According to current research, one in 68 children is diagnosed with autism each year and the number continues to increase. Autism Spectrum Disorder (ASD) is a neurological disability with a wide range of complex behavioral, cognitive, communication, and emotional difficulties. These challenges and constant adjustments can have a direct impact on the quality of life of children with ASD, their parents, and siblings. As a result, parents of a child with ASD are at risk for depressive and stressful symptoms which can affect their ability to interact with their child with ASD (Meirsschaut, Roeyers, & Warreyn, 2010). Parents, and in particular mothers, have been shown to be concerned and even guilty about the impact the diagnosis will have on their children without ASD who are typically developing (TD) (Meirsschaut et al., 2010). Thus, these changes to the family dynamics may cause disruption to the family system and can result in the TD siblings being at risk for adjustment and socio-emotional development (Petalas et al., 2009). For example, researchers have suggested that these TD siblings may have limited knowledge of the disability (Rawson, 2009), have insufficient tools to interact with their sibling with ASD (Hastings, 2003), and perceive pressure and the burden of having to be their sibling's caretaker in the future (Benderix & Sivberg, 2007). Unfortunately, Giallo and Gavidia-Payne (2006) reported that the typically developing (TD) siblings' needs and concerns are sometimes overlooked in research. Therefore, investigating these issues further may provide these children with the opportunity to voice their perspective about their unique family dynamics and roles as siblings of children with ASD.

The parent-child bi-directional interaction is also an important element of the family

dynamics. Parents do not necessarily treat siblings equally within the same family as they cater to the needs and ages of each individual child. While at the same time, each child interacts differently with their parents because of those needs and their developmental level. Therefore this differential parenting can result in conflicts amongst siblings, fewer prosocial behaviors, and greater competition (Rivers & Stoneman, 2008). According to previous research, a child with special needs requires additional attention and more support than a TD child because of the limitations of the former's developmental level (Rivers & Stoneman, 2008). As a result, the TD sibling may feel that the differential parenting not only impacts how they interact with their parents, but also their relationship with their sibling with a disability. This relationship is an important component that may be important to address within a sibling support group.

Currently, many studies have found advantages and disadvantages concerning children's socio-emotional development when they have a sibling with special needs. On one hand, research has shown that the siblings with ASD negatively affects TD siblings because of differential parental treatment, embarrassment about their sibling's behavior, invisibility of the disorder, and restrictions on family outings (Moyson & Roeyers, 2011; Orfus & Howe, 2008; Pilowsky, Yirmiya, Doppelt, Gross-Tsur, & Shaley, 2004). On the other hand however, siblings of children with ASD have been demonstrated as being more empathetic and may have a higher self-concept because they compare themselves to their sibling and the increased responsibility given to them by their parents (Macks & Reeve, 2007). These findings may suggest that children who have a sibling with a disability may benefit from sibling support groups that may allow them to discuss their role with their siblings, as well as empower them to deal with any possible challenges related to their relationship with their sibling. The literature on sibling support groups has shown such groups to be responsive to the needs of TD children and recognized the unique experiences of siblings with autism (Dyson, 1998; Evans 2001; Smith & Perry, 2004). According to Lobato and Kao (2005), providing increased knowledge can help children to adjust better to their exceptional family situation. Current research on sibling support groups has been implemented with siblings of children with a variety of disabilities and although the groups have been effective in addressing their concerns, these groups were less focused on the specific concerns and issues of siblings of children with ASD. Consequently, the purpose of the proposed study is to systematically investigate sibling support groups for children who have a sibling with autism and help them in understanding and responding to their sibling with autism.

### **Definition and Characteristics of ASD and Intellectual Disabilities**

Most of the current research on sibling support for children has focused on children who have siblings with intellectual disabilities and there is limited research on siblings of children with autism. According to the DSM-IV-TR, mental retardation, which is used instead of the term intellectual disability, is defined as "a state of functioning that typically begins in childhood and is characterized by limitations in intelligence and adaptive skills" (DSM-IV-TR, 2000). As this diagnosis includes such a broad spectrum of autistic disabilities, the needs and impact can vary for these families.

The DSM-IV-TR defines autism as a neurobiological disability with three main characteristics: (a) delayed and disordered communication (language impairment), (b) impaired social interaction, and (c) restricted and/or repetitive behavior (DSM-IV-TR, 2000). The stereotypical, repetitive, and unpredictable behaviors, as well as the limited cognitive and social development of a child with autism, pose additional challenges for their TD siblings. A child with ASD may appear physically normal, but the invisibility of this disorder may result in the impression that an individual with ASD is able to control their behaviors and that the disorder can be sporadic depending on the situation at hand (Moyson & Roeyers, 2011). This in turn can be difficult for TD siblings to explain to others that their sibling has a disability, as well as for parents who may be reluctant to tell others because of fear of being misunderstood or prejudiced (Moyson & Roeyers, 2011). According to Kaminsky and Dewey (2001), TD siblings of children with autism revealed lower levels of cohesion, prosocial behavior, and support by their sibling with ASD when compared to siblings of children with Down's syndrome. As a result, invisibility as well as the daily unpredictable struggles to partake in typical activities, the rigidity, and obsessive compulsive tendencies of children with autism, may result in the sibling relationships being very different and not comparable to siblings with a different disability (Beyer, 2009; Morgan, 1988; Roeyers & Mycke, 1995).

## **Review of Literature**

The current literature review will summarize the following questions: what areas of concern regarding TD sibling's needs have been deemed beneficial in previous intervention research and why? What were the drawbacks or concerns raised when using these interventions? How well were these issues addressed in support groups? Lastly, how the areas of concern maybe beneficial in support groups for siblings of children with ASD? As a result, this review of literature will

discuss some of the current findings regarding the advantages and disadvantages of implementing these types of support groups with families with a child with ASD. In addition, a review of the activities that have been implemented with siblings who need support will be described to try to understand how they may be useful for helping siblings of children with ASD.

## **Knowledge and Education of the Disability**

Siblings of children with special needs sometimes feel isolated (Moysin & Roeyers, 2011). Once the disability is revealed these siblings tend to receive less attention within their family because of the increased demands that their sibling with a disability requires. TD siblings may also feel isolated from the outside world because of the restricted social outings and limited interaction with their peers. Part of the isolation may be due to their lack of sufficient knowledge about their sibling's diagnosis and perhaps, the limited information given to them by their parents, which in turn may affect their interaction and ability to explain the disability to their peers (Moyson & Roeyers, 2011). Siblings can be limited in the amount of information they receive or may not be aware of their sibling's diagnosis. In either case, they have difficulty interacting with their sibling and understanding their needs (Seligman, 1983). Some of the research on this topic is based on parents' personal accounts and case studies. According to the two case studies presented by Sage and Jegatheesan (2010), sibling relationships may vary from one family to another and may be influenced by family dynamics and culture. For example, in one case account, a family had limited the amount of information they provided to their TD child; their child was found to show a very distant relationship with their sibling with special needs and the siblings barely interacted with each other (Sage & Jegatheesan, 2010). This particular child only obtained knowledge when challenging issues arose. On the other hand, the other case study described a family dynamic in which the parents provided age appropriate information to their TD child and this resulted in a more positive and interactive relationship between the siblings (Sage & Jegatheesan, 2010). The authors concluded that providing children with information about their sibling could be beneficial not only to their relationship, but also conducive to positive dynamics between all members of the family. However, it was also revealed that the amount of information given might impact the level of stress and burden of responsibility that the TD child may feel, depending on the age and characteristics of both children.

As a result of the complex and challenging task of parenting a child with a disability, parents may be reluctant to share details about their siblings with a disability because it can be a

sensitive subject that many parents may not feel equipped to address with their TD child. Children may in turn also feel that discussing the disability with their parent may be uncomfortable and may refrain from seeking information from their parents (Kaminsky & Dewey, 2001). For those who feel comfortable enough to discuss the issue, parents themselves may not think that they are knowledgeable enough and are in the process themselves of trying to understand the diagnosis (Seligman, 1983). Therefore it is important that children are provided with information about what types of behaviors they may anticipate from their sibling, how their sibling was diagnosed, the role they will play in their sibling's life, and how their role may change over time (Featherstone, 1980). The goal of educating siblings is to improve their understanding of the disability, to help them recognize characteristics about the disability, to recognize their sibling's abilities and limitations, and to clarify any confusion and misunderstandings they may have (Kaminsky & Dewey, 2001).

Meyer (1990) created the original intervention programs for sibling support groups, known as Sibshops. Meyer created the group to improve and increase the peer support and information for siblings as well as for their family members. For over 20 years, researchers have used his ideas and continue to develop and implement their own sibling support groups. Currently the programs focusing on sibling support have attempted to address the concerns that children have received limited information and education about their sibling's disabilities (D'Arcy, Flynn, McCarthy, O'Connor & Tierney, 2005; Dyson, 1998; Evans, Jones, & Mansell, 2001; Lobato, 1985; Lobato & Kao, 2002, 2005; McCullough & Simon, 2011; Smith & Perry, 2004). In the following sections, I will describe the various activities and strategies used during research interventions to help TD siblings to acquire knowledge and a better understanding of their sibling with special needs. As stated earlier, research has shown that siblings of children with special needs may benefit from acquiring knowledge about their sibling's disability because in some studies, limited knowledge has shown to affect the TD siblings' adjustment (D'Arcy et al., 2005). One of the main goals of previous research was to help improve the TD siblings' knowledge and understanding of their sibling's disability, as well as to learn more about other disabilities. Some of the most popular activities included guided discussions and information sharing (Dyson, 1998; D'Acry et al., 2005; McCullough & Simon, 2001; Smith & Perry, 2004). An additional activity used in collaboration with the discussions was the use of children's literature on disabilities including "Our Brother Had Down's Syndrome" and "I'm Telling! Kids Talk About Brothers and Sisters" (Dyson, 1998). Other activities used to increase the sibling's knowledge in a fun and interactive way included the use of puppets, human figure dolls, and arts and crafts (Lobato, 1985). Evans et al. (2001) used a slightly different approach as they had the children use puppets, flash cards, and videos to help them learn about their sibling's disability. Lastly, the use of the illusion activity and role-playing, where the TD sibling was able to act out what life is like for their sibling with a disability, was helpful in providing children with a better understanding of the disability and to elicit empathy towards their sibling's difficulties (McCullough & Simon, 2011; Dyson, 1998).

The goal of increasing sibling's knowledge was deemed successful by understanding their sibling's needs, ways in which to engage with the sibling with autism, and this in turn helped them to improve their relationship with their sibling (Dyson, 1998; McCullough & Simon, 2001). Also their knowledge helped them to appreciate the experiences and strengths of individuals with disabilities, and to be more helpful, patient, and empathic (Dyson, 1998). It also provided them with the opportunity to better understand the differences between them and their siblings with special needs (D'Arcy et al., 2005), because they were given accurate information about their sibling's disabilities (D'Arcy et al., 2005; Evans et al., 2001; Smith & Perry, 2004).

# **Self-Concept and Self-Esteem**

Siblings of children with intellectual disabilities are at risk for internalizing behaviors such as depression and externalizing behaviors such as aggression, which could have a direct impact on their self-esteem and their overall self-concept (Moyson & Roeyers, 2011). The internalizing and externalizing behaviors they may experience could be related to the limited attention they receive from their parents, or the restrictions of their social life both within and outside of the family. Their TD sibling's behaviors may also result from the concessions they feel they are expected to make for their siblings with disabilities, the feelings of guilt for being more capable than their sibling, and the embarrassment brought on by the judgment of their peer group (Barak-Levy, Goldstein, & Weinstock, 2010; Macks & Reeve, 2006; Moyson & Roeyers, 2011). According to the qualitative study conducted by Moyson and Roeyers (2011), of the 17 children interviewed, the majority felt that their well-being was dependent on the well-being of their sibling with ASD. One explanation for this may be related to the TD sibling being affected both directly and indirectly by the stress of their entire family. Levy et al.'s (2010) findings also indicated that TD siblings might show feelings of loneliness, depression, and difficultly

interacting with their peers, which could further negatively affect their self-esteem. Some children may not feel equipped with the right social tools to interact with their peers, because of the unique and limited interaction they may have with their siblings with an ID (Intellectual Disability) (Levy et al., 2010).

Despite the risk of a lower self-concept, several studies have found that siblings in fact may have a positive self-concept and positive interactions with their sibling. Older female siblings with a younger sibling with ASD, tend to develop a more positive self-concept, which is associated with better social skills when compared to younger TD siblings who had a lower self-concept (Verte et al., 2003). According to Macks and Reeve (2006), older siblings tend to have better self- concept possibly because they compare themselves to their sibling with autism. In addition, increased responsibility given to them by their parents may help to develop a higher maturity level at a younger age. Siblings also tend to adjust better if they understand and are more knowledgeable about the disability (Ross & Cuskelly, 2006).

Other factors that may impact the sibling relationship may be related to the demographics of the families who participated in the different studies, including the number of siblings in the family, birth order, gender, age, and socioeconomic status. Overall researchers have found that females, two-parent homes, older siblings, and lower socioeconomic status children tend to be at higher risk for internalizing and externalizing behaviors (Kaminsky & Dewey, 2002; Macks & Reeves, 2006; Rodrigue, Geffken, & Morgan, 1993; Verte, Roeyers, & Buysse; 2003). In addition, Kaminsky and Dewey's (2002), results indicated that families with more than two children were more likely to be well adjusted than siblings of only two children. This is because with a larger family the burden of responsibility and high expectations were not placed on only one child but spread across all the children. Despite the results of one study that found that families with more than two children had more difficulties (Pilowsky et al., 2004), according to Macks and Reeves (2006), in addition to having a sibling with a disability, having another TD sibling allowed the TD child to relate and interact with a sibling who was more similar to them from a developmental aspect.

Other studies however, have shown that younger TD siblings had more emotional adjustment problems than older TD siblings (Petalas et al., 2004). According to Rodrigue et al. (1993) no significant differences were found in relation to gender or socioeconomic status, but a birth order effect was found. They determined that older children with a sibling with autism were

more likely to exhibit high levels of internalizing and externalizing problems when compared to typical sibling dyads. Conversely, Pilowsky et al., (2004) reported no significant differences in gender, socioeconomic status, or birth order were associated with TD siblings' social and emotional adjustment. Therefore, with these discrepancies, it is difficult to draw a single conclusion about what factors to take into account when designing an educational support group for siblings. One of the possible reasons for these discrepancies could be due to the various types of methodologies used across the different studies. Parent reports and self-reports were common measures used to determine the socio-emotional adjustment of TD siblings. Indirect perceptions are those provided by parents, in particular mothers, who have either been interviewed or completed questionnaires pertaining to the adjustment level of their TD child regarding their sibling with autism. With a comparison group of typically developing siblings, it was found that parents reported siblings of children with autism had more negative outcomes with respect to socio-emotional development (Macks & Reeve, 2006) and exhibited more internalizing and externalizing problems than the control group (Verte, Roeyers, & Buysse, 2003). However, for comparison groups of children with other intellectual disabilities, there were no significant differences reported by parents (Rodrigue et al., 1993; Kaminsky & Dewey, 2002; Pilowsky et al., 2004), except for more emotional problems in siblings with autism and intellectual disabilities (ID) when compared to ID alone (Petalas et al., 2009). Nevertheless, the majority of parent reports have determined that TD children may have some negative socio-emotional outcomes. Macks and Reeve (2006) determined that a possible explanation for this could be that parents experience a high level of stress, so they assume that their children also experience the same level of stress. In addition, because parents spend significant time attending to the needs of their child with autism, they may not be completely aware of the socio- emotional adjustment of their TD child or children.

Direct measures provide a more accurate picture of the adjustment of siblings of children with autism (Verte et al., 2003). Siblings can provide a firsthand account of their relationship with their siblings. Siblings also seem to be better adjusted if they understand and are more knowledgeable about autism (Ross & Cuskelly, 2006). In addition as siblings get older they may develop more empathy towards their sibling with autism (Pilowsky et al., 2004). Siblings' perceptions of their own socio-emotional well-being have shown that they are more socially and emotionally adjusted than the reports given by their parents (Pilowsky et al., 2004). With that in

mind, there seems to be a proportion of children who are in fact at risk according to parental reports. Therefore one of the goals for children with a sibling with special needs may be to help them improve their self-concept and self-esteem.

Several studies have addressed the goal of rectifying the siblings' individual needs in order to assess the risks to their self-concept and self-esteem (D'Arcy et al., 2005; Evans et al., 2001; Lobato, 1985; Lobato & Kao, 2002, 2005; McCullough & Simon, 2011; Smith & Perry, 2004) Lobato's (1985) study examined six children, five of whom were older siblings. Through the use of arts and crafts activities and behavioral social skills training by the way of modeling, coaching, and rehearsal, Lobato (1985) addressed three goals to attempt to increase the siblings' recognition of strength in (a) themselves, (b) their sibling with special needs, and (c) other family members. The results were positive as four out of the six children not only reported a positive self-description of the support group, but also demonstrated an increase in positive self-reference statements and a decrease in negative self-reference statements (Lobato, 1985).

Socializing with other children in similar family situations with a child with ASD, allowed the TD children to create a positive atmosphere where they could open up about their own feelings and address their own needs. According to Evans et al. (2001), self-esteem was also enhanced in 10 participants who stated that they enjoyed writing positive things about their peers in the group and receiving feedback from their peers. These results were also consistent with Evans et al. (2001), who used the Culture Free Self-Esteem Test (Battle, 1981) and found an increase in children's self-esteem after six weeks of intervention. The results indicated from preto post-group intervention that the children's self-esteem in fact increased in their ability to express their feelings (Evans et al., 2001).

Another important finding of a number of studies was the siblings' ability to partake in leisure activities such as games, free play, and outdoor play with other children enabling them to continue their friendships after the completion of the support group (D'Arcy et al., 2005; Evans et al., 2001; Lobato & Kao, 2002, 2005; McCullough & Simon, 2011; Smith & Perry, 2004). These activities helped to increase their self-esteem because the TD siblings were able to focus on themselves as opposed to their sibling with special needs, who in most cases was the focus of their families (McCullough & Smith, 2011). Lobato and Kao (2005) used the Pictorial Scale of Perceived Competence and Social Acceptance for Young Children (Harter & Pike, 1983) to evaluate 43 children between 4- and 7-years-old who participated in sibling support groups over a

period of 10 sessions. It measured their perception of their own competencies, peer acceptance, and parental acceptance, which increased from pre- to post-group sessions (Lobato & Kao, 2005). The combination of leisure activities and activities about their siblings with special needs allowed the TD siblings to identify their strengths and also increased the ability to balance their own needs within their family (Lobato & Kao, 2005).

Another intervention study by D'Arcy et al. (2005), which focused on 16 children between 8 and 10-years-old, evaluated the sibling's self-esteem on the Piers- Harris Children's Self-Concept Scale (Piers & Harris, 1984). The results were consistent with other studies where siblings showed an increase in their self-esteem from pre- to post-testing (Evans et al., 2001; Lobato & Kao, 2002, 2005; McCullough & Simon, 2011; Smith & Perry, 2004). It should be noted that none of these studies used a comparison group, so the positive results cannot necessarily be considered as conclusive as other factors such as general attention from a sibling group invigilator not normally received could have contributed to the increased self-esteem and self-competence outcomes.

#### **Interaction and Communication**

Parents with a child with special needs that have a unique type of family situation tend to have different support systems that cater to their variety of needs and concerns. Unfortunately, this is not necessarily the case for siblings and as a result they can feel isolated within their own family. As stated earlier, the sibling relationship is not only complex, but also very crucial to the development of children's social, emotional, and cognitive growth. Unfortunately, when one sibling has a disability, the development of the TD sibling can be affected. According to Moyson and Roeyers' (2011) qualitative study, being able to understand each other is important for interactions amongst individuals. The sibling relationship in particular requires this understanding as a basis for developing future relationships. The 17 TD participants in Moyson and Roeyers' (2011) study expressed that it was important that the TD siblings were able to speak to their sibling with autism and the sibling could also communicate their needs to them. However, there were instances where a sibling with autism was unable to or would refuse to speak. The other difficulty that TD siblings faced was the realization that their sibling with autism was often unable to comprehend emotions and also would fixate on specific topics without regard for their TD sibling's interests (Moyson & Roeyers, 2011). During the sibling support groups, TD siblings were also beginning to detect differences between themselves and

their sibling with a disability that affected their ability to share activities. This often led to expressed anger and frustration on the part of the TD sibling. However, according to Evans et al. (2001), children were more likely to partake in an activity that was more attainable for their sibling with ASD instead of doing an activity that they enjoyed, so that they can play together. Yet, the TD sibling may have developed some resentment if they felt obligated to always play the activities that their sibling with special needs preferred (Moyson & Roeyers, 2006). Therefore, developing a bond with a sibling with a special need could become very challenging for most TD children.

Giallo and Gavidia (2006) investigated 49 participants of children with special needs using the Strengths and Difficulties Questionnaire (Goodman, 1997) for behavioral screening. Their results indicated that siblings had higher levels of problems with their peers and lower levels of prosocial behavior (Giallo & Gavidia, 2006). Kaminsky and Dewey (2001) also found that siblings of children with autism experienced lower levels of prosocial behavior, intimacy, and emotional and physical support by their sibling with autism when compared to other children with intellectual disabilities and TD children. The TD siblings may have difficulty interacting with their siblings with a special need and this may also put them at a risk for lower prosocial behavior. This may be an important element to be incorporated into the TD sibling's social development to help them to interact with their peers and develop other intimate relationships.

Despite the possibility of these risk factors, TD siblings can also develop empathy and patience when interacting with their sibling. Studies have shown that many TD siblings between the ages of 8- and 18-years-old are well adjusted and developed a better overall quality sibling relationship over time (Kaminsky & Dewey, 2002; Mack & Reeves, 2007). Taunt and Hastings (2002) also found that they were not only better adjusted, but also thrived from having a sibling with a special need because of the added responsibility and that may have helped them become role models for prosocial behavior for their sibling.

Even with the discrepancy in the literature, the majority of studies have leaned more towards the risk of low prosocial behavior in relation to this type of sibling relationship. For that reason, several support groups have attempted to address the issue that limited interactions and communications between TD siblings and their sibling with a disability may need to be the focus of future intervention. Evans et al. (2001) conducted a pilot study with 10 children between 6-and 12-years-old and two subsequent groups of nine children each between 7- and 12-years-old.

One of the objectives was to encourage positive relationships with their siblings and with their families with the hope that the TD sibling would not feel guilty for enjoying more challenging activities than their sibling with a disability (Evans et al., 2001). The pre- and post-test design was used and parents completed the Family Relation Test (Bene & Anthony, 1985) to determine if there was in fact an increase in interactions between siblings after the support group was implemented. During the group sessions, the TD siblings described and discussed their siblings' behaviors and how that impacted their relationships. The intervention group also provided the participants with tools and games that TD children could practice with each other and then play with their siblings (Evans et al., 2001). The findings of the Family Relation Test indicated an increase from pre- to post-test and resulted in a positive outcome that seemed to benefit the TD child's interactions with their sibling with ASD (Evans et al., 2001). In another study, Beyer (2009) also found that that teaching play skills (e.g., rolling a ball) to TD siblings helped to improve their sibling relationship and it entrusted the TD sibling with the role of teacher during play (Beyer, 2009). This can provide the TD sibling with a sense of responsibility, an active role in their sibling's life, and a positive role within their family.

Howe, Petrakos, and Rinaldi (1998) found the siblings who engaged in pretend play developed more shared meanings in play, conflict management skills, and a better understanding of others' emotions. To examine this issue Reagon, Higbee, and Endicott (2006) analyzed a case study of sibling interactions between a 4-year-old with autism and his older brother. The study required the children to imitate the actions and verbal statements of the video model, which showed the children how to play and to interact with each other and develop shared meanings. The results revealed a positive outcome, as the boy with autism was able to not only use the model to interact with his brother, but to also generalize this with his peers. The study showed that both the child with autism and their TD sibling could benefit from this type of intervention because they were able to develop better social skills as those in Howe et al.'s (1998) work. Both Evans et al. (2006) and Reagon et al. (2006) have shown that once TD siblings were given the supportive skills to aid in their interaction with their siblings, they were able to develop a better bond, which could possibly help to increase their prosocial behavior, and develop a better relationship with their sibling.

However, despite the success of play skills intervention to help with sibling relationships and interactions, previous research has only touched the surface when using parental support to

enhance sibling relationships. The research on current support groups has focused primarily on the TD siblings during group sessions and only referred to parents for feedback after completion of the sessions (D'Arcy et al., 2005; Dyson, 1998; Evans et al., 2001; Lobato, 1985; McCullough & Simon, 2001; McLinden, Miller, & Deprey, 1991; Smith & Perry, 2004). In their work, Lobato and Kao (2002; 2005) did however include parent group sessions to address similar issues as that covered in the sibling sessions. They also had four joint parent – TD child sessions to discuss what they had learned and experienced. The results revealed a positive outcome for the entire family as the issues were addressed together so that the parents could help to implement the changes that their TD child had learned during the support group sessions. Dallas, Stevenson, and McGurk (1993) were also one of the few researchers who investigated the impact of parental intervention. They found that maternal involvement aided the TD siblings to have a more active role in their interaction with their siblings with ASD and to use more supportive behaviors between siblings (Stevenson & McGurk, 1993). Therefore, this may be an important issue to consider when creating a sibling support group for TD siblings.

### **Coping Strategies**

Siblings of children with special needs may be bombarded with an array of emotions throughout their everyday lives. As issues arise, they can have both positive and negative experiences within their family and particularly with their sibling with a disability. The TD sibling may feel resentment or jealousy towards their brother or sister because their sibling with a special need requires a lot of attention from their parents, may be overprotected by their parents, or allowed to misbehave more because of their inability to comprehend certain things (D'Arcy et al., 2005; Evans et al., 2001; McCullough & Simon, 2011; McLinden et al., 1991; Smith & Perry, 2004). The TD child may also feel embarrassed because of the odd behaviors that their sibling exhibits and also due to the fear that others may associate their identity with that of their sibling with a disability. The behaviors that their sibling displays may be odd and unusual, but also they may be aggressive or annoying (Evans et al., 2001; Moyson & Roeyers, 2011; Smith & Elder, 2010). The TD sibling can develop feelings of guilt because they may have negative feelings towards their brother or sister. They may also feel obligated to suppress their negative feelings because it does not make them feel like a "good" sibling based on the fact that they are healthy and "normal", while their sibling is not (D'Arcy et al., 2005 Dyson, 1998). They may also feel guilty because they are capable of doing things that their sibling is unable to do, which can result

in increased levels of stress because of the need to compensate for their sibling's inabilities to fulfill their parent's expectations (McLinden et al., 1991; Smith & Perry, 2004). Stress can also stem from the constant pressure to be the good child so as not to add to their parent's stress from having a child with special needs (McCullough & Simon, 2011). According to Orfus and Howe (2008) stress can manifest in many ways including avoidance that the stress even exists, withdrawal by removing themselves from a situation, and even suppression by temporarily pushing their stress aside. Their results found that the most common coping strategies for boys who were the younger siblings was wishing the problem did not exist, while girls were more inclined to try to fix the issues at hand. Older siblings were more likely to try to suppress the issue by not discussing it. Another issue TD siblings face is how to deal with the outside world. In some cases such as autism, the disability is not so obvious to the average person, and therefore may require the TD sibling to explain their sibling's odd behaviors to others (Moyson & Roeyers, 2011; Smith & Perry, 2004). Therefore, the sibling support groups may provide a safe environment where the TD siblings can express both their positive and negative feelings, but also provide them with solutions and coping strategies to help address these feelings.

One of the major goals of the sibling support groups has been to help TD siblings improve their skills to express their emotions positively as related to the challenging situations of living with a sibling with a disability (Beyer, 2004; Evans et al., 2001; Lobato, 1985; Lobato & Kao 2002, 2005; McLinden et al., 1991). The TD siblings were also provided with an environment in which to share their experiences and the tools to problem solve their difficult situations (Beyer, 2009; D'Arcy et al., 2005; Lobato 2005, 2005; McCullough & Simon, 2011; Smith & Perry, 2004). Coping skills can be crucial to the TD siblings because in sharing their experiences and learning about others, they are able to compare information of how to handle difficult circumstances, which helps to decrease their sense of isolation that may be associated with their situation (D'Arcy et al., 2005; Evans et al., 2001; McCullough & Simon, 2011). They can learn to better understand their own unique family dynamics and in the process this may help them accept their situation and gain some perspective through learning about others' situations (McCullough & Simon, 2011; Moyson & Roeyers, 2011). Beyer (2009) found that an important aspect to include in addressing this issue is to first assess the child's cognitive understanding so that the information presented is age-appropriate and can help them to cope both intrapersonally and interpersonally. In order for the children to benefit fully from support groups they need to

understand what is being told to them so that they are able to generalize it to their everyday life.

Typically developing siblings develop their own coping mechanisms and adaptive behaviors. However, these may not always be the best ways in which to address the challenges they face. As such the support groups provide a medium to learn additional coping mechanisms and an array of solutions to choose from to solve their problems both from the instructors of the group and from the other children in the group. By sharing experiences with others, TD siblings may have experienced feelings of acceptance and they may have felt valued and therefore may have provided a more positive outcome for the group rather than focusing only on their individual support within the group (McCullough & Simon, 2011).

The support groups provided a variety of activities to the TD siblings, including the use of role-playing, relaxation techniques, feelings chart, discussion groups, and the use of Dear Aunty Blabby (D'Arcy et al., 2005; Dyson, 1998; Evans et al., 2001 Lobato, 1985; McLinden et al., 1991; Smith & Perry, 2004). Role-playing was used to reenact types of behaviors and situations that TD siblings may have experienced when interacting with their siblings and how to manage and resolve them (Evans et al., 2001). They also used relaxation techniques to help deal with any pressure to cope with high expectations of their parents and/or challenges with their siblings. Although this was deemed a positive strategy for the support group implemented by Evans et al. (2001), the children who participated in the D'Arcy et al. (2005) study were in fact not interested in the relaxation sessions as they preferred the physical activities. There was no obvious explanation for the discrepancy in these observations except for the fact that D'Arcy et al.'s study (2005) used a combination of quantitative and qualitative data collection, while Evans et al. (2001), focused more on quantitative data collection methods leading to different findings.

Another important technique used to help the TD siblings manage their feelings towards their sibling with a disability was the use of the feeling chart. The siblings were given the opportunity to write down their feelings whether positive or negative, about their siblings with ASD and then they discussed these feelings as a group (Evans et al., 2001). The exercise received positive feedback, but when they attempted to complete the exercise on their own outside of the group, the TD siblings found it more challenging perhaps because they did not have the reassurance of the group support. Smith and Perry (2004) used discussion groups to facilitate topics about feelings and attitudes towards living with a sibling with a disability. Unfortunately, there was no significant difference from pre- to post-testing for the coping/adjustment measures

for the children who participated in the group intervention, but they did learn techniques for problem-solving (Evans et al., 2001). The changes that did occur could not necessarily be attributed to the support group itself, but perhaps to the children's maturation and exposure to a new environment where they received more attention, as there was no use of a control group for comparison (Smith & Perry, 2004).

The last and most commonly used coping technique that stimulated good participation and sharing among siblings, was Dear Aunt Blabby (Meyer et al., 1985). Meyer and his associates created the advice columnist who answered letters about children's concerns similar to the siblings in the group sessions (Dyson, 1998; McLinden et al., 1991). The TD siblings would respond as experts by offering advice to others in similar situations who had written to Dear Aunt Blabby. The TD children would help Aunt Blabby respond to the letters based on how they themselves dealt with similar situations. The goal of the exercise was to provide siblings with various ways to help solve challenging situations and determine which solutions were the best for them and their interactions with their siblings with a special need. The siblings reported that this activity helped them learn ways to improve their relationship with their siblings, to decrease their behavioral issues associated with their relationship, and to cope with the unique situation in a more positive and constructive manner (Dyson, 1998; McLinden et al., 1991). This ultimately showed the success of the sibling support group in addressing the needs of these children.

### **Additional Factors Related to the Future**

Aside from the goals mentioned above, there are other factors that may be of importance to include in sibling support groups that have not yet been implemented. TD siblings of children with special needs are faced with the concerns for their sibling's future.

Another issue of concern is the lack of parental involvement within the support groups. Many interventions require parents to fill out questionnaires and feedback before and after the groups, but have no direct involvement in the groups. Lobato and Kao (2002; 2005) were among the few researchers who implemented parent sessions in addition to the sibling sessions. They also included joint sessions in which the TD children could present what they had learned from the support group. Parental involvement may result in more effective sibling support groups because the ASD diagnosis affects the entire family.

The use of control groups was rarely implemented and therefore it is not known if the degree to which the siblings learned during the support group can actually be attributed to the

group itself or to outside influences. For example, McLinden et al. (1991) used a control group and found no significant differences between that of the experimental and control group with respect to the Piers-Harris Children's Self-Concept Scale, which measured feelings and behaviors and the Let's Grow Together scale (Hodges, Mott, & Jenkins, 1982), which measured the effectiveness of the workshop. However, the experimental group siblings reported having higher levels of social support on the Who Helps Me scale (McLinden, 1987) compared to the control group. Thus in order to determine if the support groups are truly effective, it may be important to include a control group that partakes in recreational activities. A comparison group allows us to assess whether the intervention outcomes are successful in a more systematic way. For obvious ethical reasons, if the groups are deemed successful with respect to TD siblings' outcomes, the control group should also be provided with the same intervention after the post-test.

Previous research has found that the length of the sibling support group sessions have ranged from six to 16 weeks. Although six weeks seemed to be the general length of time for most groups (Lobato, 1985, 2002; McLinden 1991; Dyson, 1998), the feedback of siblings was that they wished the support group were longer (Smith & Perry, 2004). This is perhaps because they felt that there were more issues to discuss and they were not satisfied with the amount of information given and wished to have more time. A possible solution is also to provide siblings and parents with information packs, a DVD on transitions, and a website with additional supports, as well as follow-up sessions over a period of a few months to provide an opportunity for ongoing support and guidance (Rawson, 2009).

Various measures aside from the activities within the support group were used to obtain information about the TD sibling both before and after the group sessions. The most common measures used were questionnaires for both TD siblings and parents (D'Arcy et al., 2005; Dyson, 1998; Evans et al., 2001; Lobato & Kao, 2002, 2005; McLinden et al., 1991; Smith & Perry, 2004). In particular the most frequently used measures were the Behavior Assessment Scale for Children (BASC), which assessed a child's emotional and behavioral functioning from the perspective of the parent (Mahan & Matson, 2011; Robin et al., 2003; Wolfe-Christensen et al., 2009) and the Piers-Harris Children's Self Concept Scale, which assessed how children feel about themselves both at home and school (D'Arcy et al., 2005; McLinden et al., 1991; Smith & Perry, 2004). Both questionnaires were administered before and after the group sessions. Although, they both claimed to provide accurate information concerning the TD sibling, as stated

earlier by Verte et al. (2003), the children's self-reports also provided a more accurate depiction of how they felt as opposed to the measures based on their parents' perspectives. In the study by D'Arcy et al. (2005), who used the Piers-Harris Children's Self Concept measure, they also uncovered that two TD siblings were in fact at risk and this could provide further feedback to the family for accessing other community resources when appropriate. Separate interviews of parents and TD siblings at pre- and post-group sessions were also used (D'Arcy et al., 2005; Lobato & Kao, 2002, 2005; McLinden et al., 1991). This provided a more in-depth and open-ended assessment of the group sessions as well as the opportunity for the researchers to adjust their activities during the intervention to cater better to the needs of the TD children. Lastly, a focus group (McCullough, 2011) with only three participants, and individual observations (Lobato, 1985) with six participants, provided additional information about the behaviors and interactions exhibited by TD siblings during these activities. However, the McCullough (2011) and Lobato (1985) studies were considered to be very time consuming and could also be difficult to implement with a larger sample group. Therefore, questionnaires and interviews were deemed to be the most prevalent measures when assessing outcomes of sibling support group interventions.

### Conclusion

Overall, the findings in the review of literature have shown important implications in increasing the knowledge and education that TD children of siblings with ASD receive. In addition these children's ability to recognize their sibling's abilities and limitations can potentially help to develop a stronger and more understanding relationship with their sibling with a special need. The sibling support group may provide children with the tools and positive coping strategies that cater to the needs of TD children (D'Arcy et al., 2005; Evans et al., 2001; Lobato, 1985; Lobato & Kao, 2002; 2005; Macks & Reeve, 2006; McCullough & Simon, 2011; Ross & Cuskelly, 2006; Verte et al., 2003). Therefore their well-being may not only improve their self-esteem and self-confidence, if deemed at risk, but also may positively influence their relationship with their parents. Although some research has investigated the effectiveness of a sibling support group for TD children with a sibling with a special need, further research is warranted to understand how it is for children with a sibling with autism (D'Arcy et al., 2005; Dyson, 1998; Evans et al., 2001; Lobato 1985; Lobato & Kao, 2002; 2005; McCullough, 2011; McLinden et al., 1991). Particularly, future research of sibling support groups can provide a safe environment for the entire family to communicate their own needs and how those needs have a direct impact

on their family members. In addition to including the factors previously discussed, future research can also address the impact of whether support groups may have a lasting effect on these children's relationships. In addition, parents may be helpful informants and provide suggestions for these group sessions. Furthermore, research pertaining to support groups for typically developing children with a sibling with autism has only begun to be explored and therefore sibling support groups may provide a unique opportunity to understand the perceptions of children who have a sibling with ASD (Smith & Perry, 2004).

## **The Present Study**

Based on the methods used in previous sibling support groups, the present exploratory study proposes to systematically investigate a sibling support group with a focus on siblings of children with autism (D'Arcy et al., 2005; Dyson, 1998; Evans et al., 2001; Lobato 1985; Lobato & Kao, 2002; 2005; McCullough, 2011; McLinden et al., 1991). Previous research has shown that siblings may be at risk of developing socio-emotional difficulties and then they may be dealing with issues associated with the invisibility of autism, exacerbated abnormal social behavior, and unpredictability associated with their sibling with ASD (Beyer, 2009; Levy, 2010; Morgan 1988; Moyson & Roeyer, 2011; Pilowsky, et al., 2004; Roeyers & Myke, 1995). Therefore the current pre- post- test design was explored through the use of an experimental and a control group to determine any positive or beneficial outcomes and any changes that may have resulted from providing support to siblings of children with autism.

#### Method

### **Research Design**

Directing the current case studies of this exploratory study are the following research questions that are based on research literature.

Specifically:

- 1) a. What are the perceptions and experiences of siblings of children with ASD when they are exposed to age-appropriate knowledge about ASD?
  - b. How does being exposed to age-appropriate knowledge about ASD impact the parents' perceptions of their children's interactions?

Based on previous research, TD siblings of children with ASD have been shown to gain a better understanding of their sibling's atypical behaviors (D'Arcy et al., 2005; Dyson, 1998; Evans et al., 2001; McCullough & Simon, 2001; Ross & Cuskelly, 2006; Smith & Perry, 2004).

In turn, this may help to improve interactions their sibling with ASD.

- 2) a. How do siblings of children with ASD perceive their self-concept during the intervention?
  - b. How do the parents of siblings with ASD perceive their children's behavior and selfconcept after the group intervention?

Based on previous research, providing a safe environment to discuss feelings and coping strategies, has shown an increase in TD siblings' confidence and self-esteem (D'Arcy et al., 2005; Evans et al, 2001; Lobato, 1985; Lobato & Kao, 2002; 2005; McCullough & Simon, 2001; Smith & Perry, 2004). These outcomes will be measured using the Piers-Harris Self-Concept Questionnaire and the Behavioral Assessment System for Children (BASC).

3) What are parents' perceptions of the relationship between their children and what are parents' perceptions of their relationship with their TD child?

This is an exploratory question to understand how parents' participation in one of the group sessions may be related to their relationships with their children. Based on previous research, by providing an environment for open communication between typically developing siblings and their parents, previous research has shown improved relationship between all family members (Macks & Reeve, 2006; Petalas et al., 2009; Verte et al., 2003).

4) How do typically developing siblings perceive the sibling support intervention program topics as determined by their reflections and group discussions?

By asking a series of questions based on their drawings, poems, short stories, journal entries, and group discussions, this may provide insight into their perspectives of the group experiences (See Appendix I).

Child participants and parent interviews provided detailed qualitative data as well as completed quantitative standardized questionnaires. As both the interviewer and facilitator of the group, I was able to guide discussions and ultimately encourage families to openly discuss their experiences within their unique family situation.

### **Settings and Recruitment**

After ethical approval was obtained from both Concordia University and West Montreal Readaptation Center, the Director of the Early Intensive Behavior Intervention (EIBI) program in the Child and Family Services Department was contacted, provided with a brief description of the project, and with general information about the goals of the research project (See Appendix A).

Ethic approval was also obtained for the use of facilities at West Montreal Readaptation Center, Department of Child and Families Services in Beaconsfield, Quebec. The employees were required to distribute information letters to the parents of their clients (See Appendix B). With the challenges to obtain participants, recruitment was also obtained within the general public through distribution of a research flyer to various social organizations in the greater Montreal area (See Appendix T).

Upon receiving oral parental consent, the researcher requested to schedule an appropriate time to interview them and their child at their home. The parents read and signed the consent form before the parent and child interviews (See Appendix C). The parent completed an interview and filled out the BASC questionnaire. Each child was provided with the details of their participation in the study and oral assent was attained after each stage of the study, in order to ensure their willingness to participate (See Appendix D). Each child was then interviewed and asked to orally respond to the Piers-Harris Children's Self-Concept Scale in a separate room from their parents. Participants were then required to attend the group once a week for six consecutive weeks in a conference room at the West Montreal Readaptation Center. During week six, one parent of each participant was required to attend the group in order to attain a better understanding of what the group entailed and how it may have been beneficial to their child as well as how to further those benefits.

## **Participants**

To explore the research questions and hypotheses outlined above, a total of six typically developing children and their parents within the greater Montreal area were recruited to take part in this study. Table 1 provides detailed demographics of all participants. More specifically, three TD children participated in the Sibling Support Intervention Program (experimental group). In addition, three TD children took part in a group intervention that did not involve content related to the Sibling Support Intervention Group (control group).

As a result of the challenges in the recruitment process, the typically developing children were between 7 and 13-years-old. Half were female and half were male. Four of the siblings (66.6%) were diagnosed with Autism, while the remaining two children were diagnosed with PDD-NOS and Asperger's Syndrome, respectively. The following is a description of the families. The families' names have been changed in order to protect their anonymity.

**Table 1**Participant Demographic Information

				Gender		Number		
Family				of	Age of	of		
Name	Child	Age	Gender	Sibling	Sibling	Siblings	Diagnosis	Birth order
Williams	Sean	9	Male	Male	11	4	Autism	2 <sup>nd</sup>
Johnson	Rebecca	9	Female	Male	7	3	PDD-NOS	1 <sup>st</sup>
Smith	Roger	13	Male	Male	17	2	Autism	2 <sup>nd</sup>
Adams	Gary	9	Male	Male	10	3	Asperger's	2 <sup>nd</sup>
Brown	Candice	7	Female	Male	3	3	Autism	2 <sup>nd</sup>
Brown	Chelsea	13	Female	Male	3	3	Autism	1 <sup>st</sup>

# **Experimental Group**

**Sean Williams.** Sean is a 9-year-old boy and is the second oldest boy in his family. His oldest brother Andrew is 11-years-old and has Autism. He was diagnosed at the age of eight and is considered to be high functioning. Sean lives with his parents, Andrew, and two younger brothers.

**Rebecca Johnson.** Rebecca is a 9-year-old girl and is the eldest child. Her brother Lucas is 7-years-old and was diagnosed with Autism at the age of four and a half and is considered to be high functioning. Rebecca lives with her parents, Lucas, and her younger brother.

**Roger Smith.** Roger is a 13-year-old teenager and is the second child of his family. His brother Ryan is 17-years-old and has Autism, OCD, and ADD. He was diagnosed with Autism at the age of eight and a half and is considered to be high functioning. Roger lives with his parents and Ryan visits on weekends after he was placed in a home in May 2014.

### **Control Group**

**Gary Adams**. Gary is a 9-year-old boy and the second oldest boy in his family. His older brother John is 10-years-old and has Asperger's Syndrome. He was diagnosed at the age of seven and a half and is considered high functioning. Gary lives with his parents, John, and their

younger brother.

Cardice Brown. Candice is 7-years-old and the second child of her family. Her brother Carter is 3-years-old and has Autism. He was diagnosed with Autism in October 2014, one month prior to pre-group interviews. Carter is considered to be low functioning. Candice lives with her parents, Carter, and her older sister Chelsea. Special attention was given to Candice, the 7-year-old participant. Since there was a large age range and in order to ensure that the youngest participant receive proper attention during the group, the fun physical activities were adapt so that she would enjoy them. During the group, she interacted quite often with Gary; therefore it appeared that the activities that were adjusted accordingly encouraged her to adapt and feel comfortable during the sessions.

**Chelsea Brown.** Chelsea is a 13-year-old teenager who is the eldest child of her family. Her brother Carter is 3-years-old and has Autism. As stated above, he was recently diagnosed and is non-verbal. Chelsea lives with her parents, Carter, and Candice.

### **Procedure**

Time 1. Initial telephone calls to schedule interviews with participating families were organized. The interviews began in January 2014 and were completed in June 2014 for the experimental group. As stated previously, with the challenges associated with recruitment, the first three participants were placed in the SSIP group. As recruitment continued the last three participant interviews were completed between September and October 2014. The principal investigator completed all interviews with the children and their parents, and was present during the completion of the quantitative standardized questionnaires.

The children's interviews were audiotaped, which consisted of inquiries about their relationship with the sibling with autism as well as their knowledge of the subject (See Appendix F). All the participants completed the Piers-Harris questionnaire (See Appendix G).

The parents' interviews were related to describing their relationship with their children and the dynamics between the children in the study and their sibling with autism (See Appendix E). Parents also completed the BASC questionnaire to describe their participating children's behavioral and emotional functioning (See Appendix H).

**Sibling support intervention program (SSIP).** The intervention support group took place once a week on Saturdays from 9:00 a.m. to 11:30 a.m. for 6 sessions for the experimental group. The control group sessions took place on Sundays from 9:00 a.m. to 11:30 a.m. where the

children took part in group activities not related to the content of the sibling support group (See Appendix S). The time gap between the groups was to limit the interactions amongst the children and the parents from the two groups. The initial proposal suggested that based on previous research, groups took place on average over a six-week period, however, most of the children reported requesting longer sessions. Initially 12-week sessions were to be implemented, however with the limited number of participants and since the experimental support group sessions were conducted over the summer break, parents agreed to have their children in the group only if the number of sessions was reduced. In order to compensate for the reduced number of weeks, the duration of each session was increased from an hour and a half to two and a half hours in order to ensure that the participants received all the activities and information planned for the SSIP. In addition, a volunteer Psychology undergraduate student was hired to assist during the group and came highly recommended by a fellow Masters' student who had worked with her previously. She took field notes, helped to assist in the preparations before each session, and agreed to be my guest adult sibling to speak during the parent session regarding her experiences with her brother who has special needs.

The support group topics included: Introduction, Knowledge, Self-esteem/Self- concept, Communication with Sibling with ASD, Coping Strategies, Chosen Topic of the Children (Trouble Shooting Technique), and Parent/Child Session (See Appendix J). These topics and content of the activities were adapted from previous literature and were replicated in this study. At the end of each session, the children took part in a group discussion or were asked to write in the scrapbooks provided about their experience during the intervention sessions in the form of poems, stories, drawings, or arts and crafts (See Appendix I). The scrapbooks were used by the researcher to qualitatively analyze the children's progress. In addition, the researcher conducted individual interviews with the children and their parents three weeks prior to and subsequently following the SSIP. If time permitted at the end of a session, the children were brought to the sensory room, Snozelen and/or the gym. Snozelen is a therapy room used by individuals with special needs by providing them with various stimuli for their senses. The first session was an introduction to the group, where the children got to know each other and became more comfortable during their interactions with one another for subsequent meetings (See Appendix K). Each child completed an All About Me booklet and then presented what they wrote to the group. As the facilitator, in order to make the participants feel more comfortable, I also shared a

few examples from the All About Me booklet about myself, as did the research assistant.

Previous research suggests that siblings are sometimes provided with insufficient knowledge or insufficient information, which could affect their interactions and explanations to others as well as impact their interactions with the sibling with ASD (Moyson & Roeyers, 2011; Seligman, 1983). Therefore, session two focused on providing the TD children with ageappropriate knowledge about their siblings through a discussion about what autism entailed (See Appendix L). I asked each child in the experimental support group what he or she thought autism meant before providing him or her with accurate information. This was to determine how much each child knew before the group started. During the group session, each child share his or her ideas and it was written on a poster. I then presented the age-appropriate knowledge and provided several examples in hopes of providing a better understanding. The participants were given the opportunity to ask questions or give examples of how their siblings' displayed one or more of the characteristics on the poster boards. At the end, each child took a different colored marker and underlined which characteristics their sibling had in order to highlight how their siblings are both similar and different to other children with autism. I also invited each child to write on two different boards how they were similar and different from their sibling with autism. Both sessions one and two were completed during week one.

Session three involved the use of an illusion activity that hopefully provided the children with a glimpse of what it is like to live with autism (D'Arcy et al, 2005; McCullough & Simon, 2011; Smith & Perry, 2004) (See Appendix L). Each child was given a hidden picture search and asked to find eight things while a loud beeping noise continuously played in the background. The children were given 10 words and asked to answer various questions using only those words. The last activity required the participants to complete two problem-solving activities; the human knot and pass the hula-hoop without speaking. These illusion activities hopefully gave them a glimpse of what it is like to live with autism. Session four (See Appendix M) was comprised of a feeling chart, where the children were invited to write about their positive and negative feelings towards their siblings with autism and their parents so that they may become more aware of their feelings and how to address them (Evans et al., 2001). Each participant wrote positive and negative feelings towards their sibling and their parents on either a poster board or on index cards. Then their feelings were discussed. This session was based on research suggesting that children unable to express their feelings may be at higher risk for internalizing and externalizing behaviors. This

could impact their self-concept and self- esteem and possibly affect their emotional and socialemotional well-being (Mack & Reeves, 2006). Both sessions three and four were completed during week two.

Session five was designed to focus on the interests and talents of the children and presenting their interests to the group, as well as interacting in outdoor group games (McCullough & Smith, 2011). The objective was to maintain focus on the TD siblings with hopes of helping them to positively influence their self-concept and self-esteem (See Appendix M). The participants wrote in their scrapbooks about past happy experience and then shared with the group. They also discussed their common interests with no focus on their sibling with autism. Afterwards we went outside and played sandman at the park and took turns on the trampoline. Session six (See Appendix N) was comprised of a role-playing activity where the siblings were required to act out past experiences and provided each other with suggestions and feedback (Lobato, 1985). The participants were given art supplies to decorate two paper puppets that represented them and their sibling, respectively. Then they were invited to reenact a past recurring experience using their puppets. After each presentation everyone gave their input as to how best resolve the solution and provide better conflict resolution techniques. This session focused on the ability TD children to communicate and interact with their siblings with autism who may have delayed or impaired communication and social skills (Moyson & Roeyers, 2011). Both sessions five and six were completed during week three.

Session seven (See Appendix N) was used to provide the siblings with the tools and techniques to play various simple games that may help them to communicate better and interact with their siblings in a positive manner (Evans et al., 2001). The games were determined based on the information parents provided on the cognitive and social levels of the siblings with autism. Based on the interviews, all three siblings with autism were considered high functioning and therefore provided with the following games; Heads Up@ and Charades, and Outburst@. In addition, the participants were given science experiments to try with their siblings (fun with popsicle sticks and how to make slime). The main goal was to provide some tools and suggestions that hopefully improved their communication and interactions with their siblings in a positive manner (See Appendix N). Session eight (See Appendix O) addressed some of the negative interactions and experiences the TD children may have with their sibling with autism and how to address those issues through the use of the Dear Aunt Blabby activity. Five different

examples were presented to the participants and each child was required to provide suggestions of how to solve these negative issues or experiences. In addition, in week three, each child was invited to write down a negative issue or experience with their sibling and then present at week four for discussion. According to research, siblings of children with autism can display an array of emotions including guilt, jealousy, embarrassment, and resentment towards their sibling with ASD. Therefore, this session focused on these issues. This required the children to pretend to be experts on the subject of having a sibling with a special need and provide advice to others who have written to Aunt Blabby (Dyson, 1998; McLinden et al., 1991). Both sessions seven and eight were completed during week four.

During session nine (See Appendix O), the children also discussed their personal experiences, feelings, and questions and tried to help one another. The children were provided with relaxation techniques and coping strategy techniques (Evans et al., 2001). We practiced relaxation techniques, which included tightening and releasing of muscles and deep breathing exercises. Consequently, coping strategies to help address these issues within a safe environment were being discussed in sessions eight and nine (See Appendix O). Session 10 was allotted to the most popular topic(s) based on the issues or concerns of the children's responses during the pretest interview as well as the reoccurring topics throughout the group (See Appendix P). Previous research has yet to provide an open-ended session during their support groups; therefore it was interesting to see the new topic that arose. Each child was given individual one-on-one attention to provide suggestions related to their unique family situation. The other children worked on their posters that they presented to their parents during the last week of the group. The children were asked to respond orally to an intervention questionnaire, which provided basic information on their overall experiences and ways to improve the support group (Adapted from Dyson, 1998; See Appendix Q). Both sessions nine and 10 were completed during week five.

Sessions 11 and 12 involved participation of the parents with their TD children during the group (See Appendix R). The TD children were encouraged to communicate their concerns to their parents, as well as for parents to see what their children had learned throughout the sessions. The children decorated posters to summarize what they learned in the group to present to their parents. The most popular issues that parents disclosed during the initial interview were also discussed. In addition, an older sibling came to the group to discuss their experience growing up with a sibling with ASD and answered questions of the parents or children. As such, these

sessions were based on previous research that siblings with ASD often require more attention and support, which may impact other relationships within the family. For that reason, parental involvement within intervention may provide more supportive and interactive family dynamics. Both sessions 11 and 12 were completed during week six.

Control group. As stated in the literature review, the use of control groups was rarely implemented and as such the degree to which siblings learn compared to a control group was unknown. A control group was created to provide TD siblings with attention and the group experience with other siblings as was given to the control group, but without information on autism and about being a sibling of a child with autism. In order to compare the experiences of the children in the different groups, a similar format was followed with the exception of the content knowledge about autism. Therefore, both groups were completed over a six-week period (See Appendix S). Again sessions were combined and the duration of the group was extended.

Sessions one and two were completed during week one. During session one, each participant was given an All About Me booklet to complete. This was to help the children become more comfortable with one another as to share common interests. Each child presented their booklets to the group. In session two, we played the board game Outburst and then they wrote in their scrapbooks. Session three and four were completed during week two. In session three, the participants were asked to speak about their favorite pets and/or animals. Then during session four the children were asked to bring something for show and tell. Afterwards we went to play in the gym and a sensory room called Snozelen.

Sessions five and six were completed during week three. In session five, the participants were required to write about a favorite past experience and share it with the group. They were then provided with art supplies to create puppets during session six. They each made a puppet show about what they liked to play with their sibling. At the end of the group, we went to the gym to play basketball and climbed on the rock-climbing wall. Session seven and eight were completed during week four. We were initially supposed to play capture the flag, however with only three participants, it was not feasible. We played hide and go seek instead and then we raced and did cartwheels in the gym. During session eight, I referred back to their All About Me booklets to determine common interests and stimulate a discussion. Before they completed their scrapbooks, each participant was required to think about an idea to practice for the talent show that they would present to their parents in week six.

Session nine and 10 were completed during week five. Each child chose a talent and practiced for the show that would be presented to their parents the following week. Session 11 and 12 were completed during week six. The participants each presented their talents to their parents.

**Time 2.** Additional telephone calls to schedule interviews with participating families were organized. The post-group interviews began in August 2014 and were completed in September 2014 for the experimental group. The post-interviews for the control group were conducted in January 2015. Once again the principal investigator completed all interviews with participants and their parents as well as invited the parents to complete the questionnaires.

The children's interviews were audiotaped which consisted of inquiries about their relationship with the sibling with autism as well as their knowledge of the subject, and their experience in the group. The children in the control group, where asked about their relationship with their sibling as well as their experience in the group. Each child was then asked questions in the Piers-Harris questionnaire.

The parents' interviews were also audiotaped, which consisted of their relationship with their children, the dynamics between the participant in the study and their sibling with autism, and if their child spoke about the group, and if they noticed any changes. Each parent then completed the BASC questionnaire that was used to gather information about the child's behavioral and emotional functioning.

**Data collection.** Upon receiving parental written consent, arrangements for individual meetings with the parents were made in their home (See Appendix C). The parents were asked to fill out individual questionnaires. Parents were also interviewed about demographic information, including information about their two children (i.e., age, birth order) and on their child with ASD's development (i.e., diagnosis and level of functioning). Each interview was approximately one hour and was audiotaped then transcribed verbatim.

Initially, during the pre-test which took take place three weeks prior to the sessions, all the children gave their oral assent (See Appendix D) and were given a questionnaire (Piers-Harris Children's Self-Concept Scale – Piers-Harris 2) (See Appendix G). They were also interviewed about their relationship with their sibling with ASD and any concerns or issues they had and wanted to discuss during the group (See Appendix F). The interviews were conducted in their homes and in a separate room from their parents to ensure they felt comfortable to answer the

questions.

The parents of the Sibling Support Intervention Program were also asked to fill out the Behavior Assessment Scale for Children questionnaire (BASC) (See Appendix H). Both the children and parents of the experimental group were invited to fill out the same questionnaires and partake in another interview three weeks after the completion of the group (See Appendix E and F). The control group and their parents were given the same questionnaires as the experimental group three weeks prior to (pre) and after (post) the intervention took place to be used for comparison during the analysis of the data. This was based on previous research that had been implemented three weeks pre-intervention and post-follow-up and showed positive intervention outcomes reported by both parents and children (Lobato & Kao, 2002; 2005). In addition, the intervention sessions for both the control and experimental group were videotaped for the researcher's educational professional development, as well as to seek clarification on responses/comments and discussions during the group in their post-interviews.

As previously mentioned, the control group took part in group activities not related to the SSIP (See Appendix S). The children and their parents were also interviewed and given the same questionnaire three weeks prior to (pre) and after the (post) group sessions. Some of the interview questions were identical to those of the experimental group; however, other questions did not pertain to the control group participants (See Appendix E and F). After the completion of the post-interview, the control group was given a debriefing letter that explained the reason for the control group and were offered a six-week session of the most significant themes from the results of the study (See Appendix U). The group will run in Summer 2015 so as to allot time for data analysis, but to also provide parents with sufficient time in between each group.

#### Measures

To examine the effects of the intervention between and within the experimental group and control group, a number of different measures were administered. The following section will provide details about the features of these assessments.

Behavior Assessment System for Children – Parent Form (BASC). The Behavior Assessment System for Children (BASC; Reynolds & Kamphaus, 1988; 2004) is a standardized test that assesses a child's (ages 2 to 25) behavioral and emotional functioning from the perspective of the child, parent, or teacher, to identify if a child manifests clinically significant problems. It is comprised of 14 components that focus on Externalizing Problems Composite

(Hyperactivity, Aggression, Conduct Problems), Internalizing Problems Composite (Anxiety, Depression, Somatization), Behavioral Symptoms Index (Atypicality, Withdrawal, Attention Problems), and Adaptive Skills Composite (Adaptability, Social Skills, Leadership, Activities of Daily Living, Functional Communication) (Reynolds & Kamphaus, 1988; 2004). The test was composed of 160 items and took approximately 10 to 20 minutes to complete. The psychometric properties showed strong test-retest reliability (0.85) and strong internal consistency (0.80 to 0.90). However, interrater reliability was fairly weak (0.46). Criterion validity was also deemed to be strong as well (Reynolds & Kamphaus, 1988; 2004).

For the purpose of this study, the parents were invited to fill out the Parent Rating Scale, which included the internalizing and externalizing subscales to assess if their TD child may be showing internalizing (i.e., depression, anxiety) and externalizing (i.e., hyperactivity, conduct problems) behavioral problems. This questionnaire was completed during the pre- and post-test periods to determine if there was a change in their child's behaviors after SSIP. In addition, post-intervention interviews were conducted to determine if there might have been changes in their child that were not evident in the questionnaire.

Piers-Harris Children's Self Concept Scale (Piers-Harris 2). The Piers-Harris Children's Self Concept Scale (Piers-Harris 2; Piers & Herzberg, 2002) also known as "The Way I Feel About Myself', is a standardized normative test that assesses children's self-concept (feelings and behavior) both at home and at school (See Appendix P). Based on the child's perspective, they are required to fill out a 60-item yes/no questionnaire about how they feel about themselves that took approximately 10 to 15 minutes to complete. The psychometric properties showed strong reliability for the overall total scale score (0.91) and moderate to high scores for each subscale. The items were divided into the following six subscales; Behavioral Adjustment (0.81), Intellectual and School Status (0.81), Physical Appearance and Attributes (0.75), Freedom from Anxiety (0.81), Popularity (0.74), and Happiness and Satisfaction (0.77) (Piers & Herzberg, 2002). There is also strong validity as results indicated positive self-concept contrary to any psychological problems that may manifest. It must be noted that although 20 items have been removed from the original scale, they have not affected the strong content validity or the original content of the Piers-Harris 2 (Piers & Herzberg, 2002).

For the purpose of this study, the questionnaire was read orally to the child during the preand post-testing period to ensure that every question was answered and to determine their perception of their self-concept. In addition the children were interviewed post-intervention to determine if there were changes not necessarily evident in the questionnaires.

#### **Qualitative Results**

# **Qualitative Data Analysis**

The purpose of the qualitative data analysis is to obtain a better understanding of the experiences of the families who have a child with autism, to capture the perspective of siblings of children with autism through both child and parent interviews, and to examine if the children experienced any benefits as a result of their participation in the Sibling Support Intervention Program. The four research questions were addressed in the in-depth analysis of the qualitative interviews, the parent and child questionnaires, and the SSIP. Interviews were audio recorded and later transcribed verbatim using Microsoft Word. In order to uncover and interpret the meaning behind the SSIP and this unique family situation, data were originally categorized using open coding in which the researcher's notes were made. This step was very open and extensive. Next, the codes were grouped into categories according to each research question. Case studies were completed for each child according to each research question.

# **Experimental Group Findings**

As aforementioned, the research questions were as follows:

- (a) What are the perceptions and experiences of siblings of children with ASD when they are exposed to age-appropriate knowledge about ASD?
- (b) How does being exposed to age-appropriate knowledge about ASD impact the parents' perceptions of their children's interactions?
- (c) How do siblings of children with ASD perceive their self-concept during the intervention?
- (d) How do the parents of siblings with ASD perceive their children's behavior and self-concept after the group intervention?
- (e) What are parents' perceptions of the relationship between their children and what are parents' perceptions of their relationship with their TD child?
- (f) How do typically developing siblings perceive the sibling support intervention program topics as determined by their reflections and group discussions?

To explore and again an in-depth understanding of the children's perceptions of their siblings with ASD and their relationship with them, the following themes emerged from the

analysis: (a) knowledge of autism and child's and parent's perspective of their interactions with siblings with ASD, (b) self-esteem and behavior, (c) parent's perceptions (d) perception of the Sibling Support Intervention Program (SSIP).

**Knowledge of autism.** One of the prominent themes that emerged from the data was how the children's perceptions and understanding of the diagnosis impacted their relationship with their sibling with autism. Overall, the participants seem to have obtained a better understanding of their siblings' diagnosis and were more patient and accepting during their interactions after they were provided with knowledge and the opportunity to discuss their perceptions.

Sean Williams. Sean's initial understanding of his brother's diagnosis was that he knew his brother had autism and "...I never really thought he was different...other than how he looked." It originally appeared as though Sean believed that autism was a physical disability and not mental. This contradicted what he stated when asked what he thought autism was between in his pregroup interview and his statements during the SSIP. He believed that autism meant that you thought differently, could not speak, could only focus on one thing, and needed to be in a place where they can get a lot of help. Sean's brother Andrew, however was verbal so it was believed that although Sean had a bit of understanding about what autism was, he still seemed to be confused when it came to relating his knowledge to his brother. According to Sean's mother, she believed that Sean did not understand anything when it came to autism and believed that since Sean appeared to idolize his older brother that he just accepted him for who he was. Mrs. Williams stated:

He's just like that's Andrew\*<sup>1</sup>. Yeah, so yeah I don't think he, he understands like when Andrew's going on and on about the same topic, to him it's just Andrew\*...Because I think an older child looking at a younger being like, look what's going on might have more questions. Whereas being the younger one, you sorta just look at him and he's always been there, he's always been the same guy.

Sean seemed to be a very quiet child and it was difficult to get him to elaborate during the pre- and post-interviews. Many of his responses were one word and as a result it was difficult to determine a true picture of his interactions with his brother. When asked what it was like growing up with his brother, he would simply state it was easy or he was happy and although I tried to get him to elaborate, he merely repeated his responses. As in any relationship, there are both positive

<sup>&</sup>lt;sup>1</sup> Name changed for anonymity

and negative aspects, yet Sean appeared to try and hide the negative, perhaps as a defense mechanism to protect his brother or to cope with any negative feelings. Yet, during the sessions, Sean made statements that appeared to be inconsistent with the happy picture that he tried to portray. For example, after completion of one of the illusion exercises in which the participants were required to find hidden pictures while a loud noise played in the background, Sean stated:

This is annoying but not hard to focus...I was taught to resist. My classroom and my brother are very loud, when you're use to loud sounds you pretend that they are not there.

These type of statements would occur ever so often throughout the group, perhaps because the other children spoke about their siblings, Sean began to feel more comfortable opening up with the other two children in the group. This was illustrated when Roger explained that when he wants to play something, his brother promised to play but then backs out at the last minute, then Sean said, "The same thing happens with my brother". In the post-interview with Sean's mother, she supported this statement when discussing Sean and Andrew's relationship. "They get along well on Andrew's\* terms".

During week five, one session was set aside to individually discuss with each participant about recurring issues and they were provided with strategies and tools to help them cope with those issues. When asked if Sean ever applied what he had learned from that session with his brother, he stated no. Perhaps he felt it would not work, or perhaps he felt that he did not want to cause any further issues with his brother, or because he idolized his brother he felt that he just had to go along with what his brother wanted. It is unclear what the reason may be. However it is possible that after the interview, because he was reminded of the strategies, that he may have applied them with Andrew. Sean's mother did state that during the group:

Every once in a while he would come out with information that you had given about autism and we would talk about it and that was really how he talked about the group, nothing much more.

Lastly, in both the pre- and post-interviews, Sean was asked to color a thermometer of how he felt to be a sibling. He colored all the way to the top for both thermometers; therefore his perspective of his relationship with his brother had remained consistent. So it appears that although Sean learned more about autism in the group it was unclear if it was beneficial and if he applied it to his relationship with his brother.

**Rebecca Johnson.** Rebecca's understanding of autism appeared to be not only based on

her experiences with her brother, but with some of her classmates who also have autism. In her initial pre-group interview she said:

To be different from other people like you're slower in things, you have a different brain like it's, like you're just not interested into what most normal kids like to do you can't- you sometimes have to work with like you can't work with other people that often like it's gonna be hard for you sometimes because you wanna stay with your own ideas.

Rebecca unlike Sean, seemed to be quite outgoing and eager to share her experiences. Her understanding of autism seemed to be quite detailed yet during the group there were still things that she did not know. In her scrapbook she wrote that she did not know that children with autism have, "difficulties understanding emotions and that they have trouble talking". Since her brother Lucas and the students in her class with autism were all verbal, Rebecca was unaware they there were some children with autism who could not speak or have very limited language. When we completed one of the illusion activities in which the participants were required to answer complex questions using only 10 words, Rebecca thought it was funny at first. She would answer the questions using only those words, but then realized that there were some questions she was unable to answer.

In addition when asked in her pre-interview if she spoke to her family or friends about her brother she said, "I don't talk to my friends about him because like they're not really part of it". Yet in her post-interview she stated:

I tell them he's autistic and I tell them what that is and they get confused...I say it's not a condition, it's just the way someone is born, they're born differently and then I give the examples cause there are other kids in my class who are like that.

It appears as though Rebecca did not feel comfortable talking about autism or her brother before the group but perhaps once given more information she felt she had a better understanding to explain to others about her brother. Her mother had a similar observation as Mrs. Johnson said before the group that she did not really feel that Rebecca had a good understanding of what autism was, nor that she really caught on that Lucas had autism, just that he was different and needed extra help. There appeared to be a change after the group as in Mrs. Johnson's post-interview, she stated:

After the class, after your sessions we talked about it a bit more, she seemed to after the – especially on the way home after the sessions she would talk about it a bit and she had

some very good things to say about it, you could tell she had a better understanding of it so I don't know if it's completely clear with her but she's definitely got a better understanding of it.

Since Lucas has high-functioning autism, Rebecca was able to verbally communicate with her brother. However, Rebecca's mother would tell her to "go easy on him...that like have to use his ideas a bit more than mine". She was aware that her brother had autism and appeared to have empathy and maybe even a little resentment towards Lucas. When asked what it was like growing up with him she said:

A bit hard because I see him do things and I see him struggling and I wanna help him but some people won't let me. They say let him do it by himself, he'll eventually learn.

After the support group sessions Rebecca said that it was a little rough sometimes but usually it was like having any other brother or sister. There was also an increase in her thermometer when asked to color how she felt to be a sibling. In the pre-group interview she colored about 75%, but after the group she colored the entire thermometer. Therefore it seems that her feeling about being a sibling improved after the group and possibly could have been attributed to her better understanding of autism and how she interacted with her brother.

Roger Smith. Roger's family situation was different from the other children in the group in that his brother Ryan not only has autism but also Obsessive Compulsive Disorder (OCD) and Attention Deficit Disorder (ADD). Roger and Ryan's relationship was difficult in that they argued and they had many physical altercations. As a result of his many behavioral issues, Ryan was put into a home and only visited his family on weekends. Ryan's initial understanding of autism seemed to be inaccurate. He said:

Like to have maybe I guess it's a disability of doing something like, like some people can run fast or bend their arms back very far but others can't.

Roger used metaphors to explain his understanding of autism, but he also seemed to be confused and unsure. As the interview continued, he said that autism is someone who has a disability in understanding things. It was believed that based on his relationship with his brother Ryan, that Roger believed that his brother's inability to do certain things or understand things was the only part of autism. Also when asked how he knew his brother had autism, Roger said that he knew because his parents told him, because they fight a lot, and Ryan takes medication. Therefore, it seems that Roger believed that in order to control his brother's anger that people

with autism need to take pills. Since Ryan had multiple diagnoses his medication was in fact for the other disorders and not for autism.

During the group sessions, Roger seemed to acquire a better understanding of what autism was through the information given on the posters as well as through the illusion activities. He said that people with autism were people who did not understand much, needed help with certain things, and needed motivation. Mrs. Smith also felt that after the group, Roger had a better understanding of autism and that the group provided him tools to better engage with his brother.

I believe he understands it a bit better, I know that he is more capable of...capable of compromising and not so quick to jump on his brother, lose patience, more patient with him definitely and able to use told to sort of say, 'Well this is how I feel if you're not – your manipulating me into playing your game, now we played your game and now your not wanting to play my game so this is how it makes me feel.' At least one time out of ten, Ryan\* will say okay then we'll play it your way but he's also able to walk away a bit more".

In addition, when Roger was asked to color on the thermometer about how he felt to be a brother, he colored 50%, but after the group sessions, he colored 75%. Although there were still areas that needed to be addressed, mainly his aggressive behaviors, there appeared to be an improvement in both Roger's understanding of autism and in his relationship with his brother.

Self-esteem and behavior. Another theme that was prominent in previous research was how siblings of children with autism were at risk of low self-esteem and internal and external behavior problems (Moyson & Roeyers, 2011). One of the goals of the group was to provide opportunities for participants to discuss their feelings in a positive and safe environment and hopefully have an effect on their self-esteem and behavior. Each child was required to complete a Piers-Harris 2 Questionnaire about how they feel about themselves and their parents completed the Behavior Assessment System for Children (BASC) questionnaire, which assessed the behavioral and emotional functioning of their child. Both questionnaires were completed before and after the group. For the Piers-Harris scores there was a Total (TOT) score and six domain scales; Behavioral Adjustment (BEH), Intellectual and School Status (INT), Physical Appearance and Attributes (PHY), Freedom From Anxiety (FRE), Popularity (POP), and Happiness and Satisfaction (HAP). Children' responses were analyzed according to each score in both their preand post-questionnaires. In addition, comparisons were made to the BASC questionnaire

completed by their parents. The BASC focused on four main scales: Externalizing Problems (hyperactivity, aggression, conduct problems), Internalizing Problems (Anxiety, Depression, Somatization), Behavioral Symptoms Index (atypicality, withdrawal, attention problems), and Adaptive Skills (adaptability, social skills. leadership, activities of daily living, functional communication).

Sean Williams. According to the Pier-Harris, the higher the TOT score, the higher the self-concept and self-esteem of the child, unfortunately, Sean's scores ranged between Average and Low range. Sean's Piers-Harris scores and the interpretive labels are shown in Table 2. Sean's TOT score made a minor decrease from Time 1 and Time 2, but remained in the Low Average interpretive label. According to the Piers-Harris, when a child has a low TOT score they are considered to have serious doubts about their own self-worth. It appears as though children in this range are less likely to view themselves as talented or competent and may be even embarrassed by their abilities. They may also give up easily as opposed to persevering in the face of adversity. According to Sean's mother, Sean was having difficulty at school and she has had difficulty trying to help him at home:

I couldn't push him at home because he was so, he took things so personally and his poor ego, so I had to just be like, all right I'm your mom not your teacher and I'll just be the mom.

The Pier-Harris score suggested that a low TOT score is correlated with difficulties associated with mood and behavior, including anxiety, depression, and general unhappiness. This was consistent with the BASC, completed by his mother, as Sean's scores for anxiety and depression were both considered to be Clinically Significant in that he has high levels of maladaptive behaviors (See Table 3 and 4). Although they remained high and are very concerning, they did decrease to At-Risk, in which treatment is not yet necessary but problems could develop and he should be monitored closely. Despite this, the researcher discussed these issues with his mother to ensure that he receives further assessment and support.

**Table 2**Sean Williams' Piers-Harris T-Scores For Time 1 and Time 2 and Their Interpretive Labels

Domain Scales	Time 1	Time 2	Interpretive Label
Behavioral Adjustment (BEH)	49	49	Average
Intellectual and School Status (INT)	46	43	Average to Low
			Average
Physical Appearance and Attributes (PHY)	32	29	Low to Low Average
Freedom from Anxiety (FRE)	51	48	Average
Popularity (POP)	39	36	Low
Happiness and Satisfaction (HAP)	40	40	Low Average
Total (TOT)	43	41	Low Average

There were six domains scales that provided a more detailed examination of Sean's selfesteem. The first was Behavioral Adjustment (BEH), which focused on the admission or denial of problematic behaviors. Sean's scores remained the same between Time 1 and Time 2. Out of the 14 items in the BEH, he only responded negatively to two of them. This was interpreted as Sean being a fairly well behaved child, but had a few issues with behavior. Consistent with the BASC, Sean's mother reported that he had improved for both externalizing and internalizing behaviors (See Table 3). Although still At-Risk for internalizing problems, his externalizing problems were now in the Average range for Time 2. For Intellectual and School Status (INT), which assesses a child's perspective of their intellectual and academic tasks and how they view their future expectations and overall satisfaction in school. Sean's scores were in the Average range in Time 1 and in the Low Average range for Time 2. According to the Piers-Harris, a score of 46 was interpreted as the child doing fairly well in school with a few difficulties. In the post-group, his T-score decreased to 43 and although remained in the Average range, it was considered to be in the lower average. So it appears as though Sean reported more difficulties than a typical child who completed the standardized questionnaire. The support group did not address academics therefore the changes in the score may be related to some of his experiences at school that were beyond the scope of this study. Physical Appearance and Attributes (PHY) was the third domain scale that measured how they viewed their physical appearance, leadership skills, and their ability to express their ideas. Sean's scores were in the Low range for Time 1 and decreased to Low

Average range in Time 2. This was deciphered as having poor self-esteem for both their physical abilities and body image. This domain may also be associated with their belief that their peers may not like them and that they feel their ideas are not valued by their peers. Sean spoke very little throughout the group and seemed to be a bit withdrawn and had to be encouraged to talk more. His PHY score supported this as he probably felt that his opinions were not as valued and decided not to express his ideas as often as others during the group, however, he elaborated more during the support group sessions with the children than during the pre- and post-interviews. During the group sessions, the children were asked to take turns writing on the poster boards about their feelings towards their parents and sibling. Sean opted to write on an index card, perhaps because he did not feel comfortable writing on the boards. In addition, in his interviews he would respond with several one-word answers and had to be persuaded to elaborate, which was not always successful. This was consistent with his BASC scores for Withdrawal, which also increased between Time 1 and Time 2 from At-Risk to Clinically Significant (See Table 4). Therefore, it appears that Sean has a tendency to withdraw in social situations.

The FRE scale focused on emotions, such as anxiety, shyness, and worry. Sean scored in the Average range for both Time 1 and Time 2. According to the scale, he reported mostly a positive emotional state with few problems. Sean falls within the Average of the standardized sample. According to the BASC, Sean's Anxiety score decreased from Time 1 to Time 2 from Clinically Significant to At-Risk. Although he decreased a little, he still seemed to have anxiety based on both questionnaires. Since Sean's PHY were Low to Low Average as it focused on his leadership skills and ability to express ideas, it was not surprising that the POP score was also low. POP scores represented a child's social functioning in relation to feeling included and ability to make friends. According to the scale, Sean may have felt that he did not have many close friends, may have felt isolated, ignored, or ridiculed by his peers. During the group sessions, when the children were asked to discuss similarities and differences between themselves and their sibling, Sean wrote that his brother does not talk a lot, stays in his room to watch videos, that his brother frustrated him because he had to repeatedly ask the same question, and that Andrew did not let him see what he is watching on the laptop. Therefore it is possible that Sean may have felt ignored occasionally by his brother. During session five, I provided strategies and tools during our one-on-one conversations to help address recurring issues that happened during interactions between siblings. When I asked Sean if he had tried any of those strategies with Andrew, he

simply said no. Sean may feel that this is the way things are and based on his low PHY score may not have felt confident enough to speak up. Yet Sean's BASC score for Functional Communication, which focused on his ability to use expressive and receptive language, had decreased from At-Risk to Clinically Significant for the Adaptability scale perhaps because his mother stated that he would talk about the group and bring up information he had learned. Therefore, although he may not have changed his interactions with his brother, he had been more open with his mother about autism. The last domain scale was Happiness and Satisfaction (HAP), which focused on his happiness and satisfaction of his life. Sean's low average T-score of 40 remained consistent between Time 1 and Time 2. According to the HAP, although Sean remained in the Average range for most individuals, Sean was in the Low Average range of that domain, meaning he had a few more negative feelings than the typical child. His level of HAP was fairly consistent with his scores in the other five domains. Unfortunately it appears as though Sean fits the criteria of a child who is at risk of behavioral issues and when asked if his mother had any concerns for him, she referred to his school and his behavioral concerns. She said in the pre group interview:

I don't know if it's a grade three thing but it's – he's always on edge. Like one little thing and he'll explode. So he seems like he's holding things together. So my concern for him is figuring out how to get them out. Or figure out what – what's triggering them all, just for like, help him deal with what's really bugging. Cause I'm still not sure.

She said that she attempts to talk to him, but sometimes he does not want to talk and she tries to be there for him when he is having a really bad moment. Although his mother was trying to help him, it seems as though he may need to be monitored closely as he may need professional help in the future. During the post-interview, her concerns seemed to shift more to his academics and not any behavioral issues even though according to both the Piers-Harris and the BASC, his self-esteem and behavioral problems have not made significant improvements. Therefore, it is possible that because of the attention that his brother with autism receives, Sean's parents may find it challenging to provide Sean with the tools he needs to express his negative feelings. In addition, it may be that he is experiencing some academic challenges that are impacting his emotional functioning.

**Table 3**Sean Williams' BASC Clinical Scale T-Scores For Time 1 and Time 2

Composite	Time 1	Clinical Scales	Time 2	Clinical Scales
Externalizing Problems	60	At-Risk	45	Average
Internalizing Problems	76	Clinically Sig.	60	At-Risk
Behavioral Symptoms Index	73	Clinically Sig.	63	At-Risk
Adaptive Skills	38	Low	40	Low

**Table 4**Sean Williams' BASC Clinical and Adaptive Scale T-Scores For Time 1 and Time 2

Scale	Time 1	Clinical Scales	Time 2	Clinical Scales
Hyperactivity	61	At-Risk	50	Average
Aggression	62	At-Risk	46	Average
Conduct Problems	54	Average	40	Low
Anxiety	82	Clinically Sig.	65	At-Risk
Depression	91	Clinically Sig.	68	At-Risk
Somatization	39	Low	42	Average
Atypicality	62	At-Risk	60	At-Risk
Withdrawal	67	At-Risk	74	Clinically Sig.
Attention Problems	64	At-Risk	61	At-Risk

Scale	Time 1	Adaptive Scale	Time 2	Adaptive Scale
Adaptability	32	At-Risk	44	Average
Social Skills	48	Average	50	Average
Leaderships	38	At-Risk	36	At-Risk
Activities of Daily Living	44	Average	49	Average
Functional	35	At-Risk	28	Clinically Sig.
Communication				

*Rebecca Johnson.* Rebecca's Piers-Harris Total (TOT) T-score were in the Average range and increased between Time 1 and Time 2 (See Table 5). Therefore, she was considered to be

within the normal range when compared to the standardized sample. According to the Piers-Harris, her scores showed a realistic self-evaluation of both her positive and negative aspects. This is consistent with her mother's behavioral report in the BASC questionnaire in which Rebecca was also within the Average range for most of the clinical and adaptive scales (See Table 6 and 7).

 Table 5

 Rebecca Johnson's Piers-Harris T-Scores For Time 1 and Time 2 and Their Interpretive Labels

Domain Scales	Time 1	Time 2	Interpretive Label
Behavioral Adjustment (BEH)	39	43	Low to Low Average
Intellectual and School Status (INT)	54	65	Average to Above
			Average
Physical Appearance and Attributes (PHY)	48	58	Average to Above
			Average
Freedom from Anxiety (FRE)	58	54	Above Average to
			Average
Popularity (POP)	68	60	Above Average
Happiness and Satisfaction (HAP)	51	51	Average
Total (TOT)	51	55	Average

The Piers-Harris focused on six domains that help to provide an accurate representation of Rebecca's self-evaluation of her self-esteem. The first domain is Behavioral Adjustment (BEH), which measures how much the child admits or denies problematic behaviors. Rebecca's T-Scores improved between Time 1 and Time 2. With a Time 1 T-Score of 39, Rebecca was considered to be on the border of the Low range and may have had significant behavioral difficulties as individuals who score in the Low range may cause trouble or have difficulty listening to authority figures, such as parents or teachers. Mrs. Johnson's initial interview said that Rebecca was sensitive to some things as there were recent marital issues. In addition, during the group when completing the feeling chart during week two, Rebecca said that she felt her parents were bossy and that she was always required to do chores that her brother was not. During the group sessions, Rebecca mimicked her parents, "Clean your room, feed the dog, Rebecca\* go do this, go do that". Perhaps Rebecca felt that her parents gave her more responsibilities than Lucas and

therefore resulted in her difficulty in listening to her parents at times. In addition, during week three, Rebecca stated that during her roleplaying scenarios she sometimes liked to scare Lucas. This may have been typical sibling rivalry, but since she scored in the Low range of the Piers-Harris, it maybe that she perceived herself as causing trouble from time to time. During Time 2, Rebecca had improved with a T-score of 43, which was in the Low Average range. Although she had increased to the Average interpretative label and was considered to have been mostly well behaved, Rebecca was in the Low Average range so she was considered to have a few more difficulties managing her behaviors. During the group sessions, the participants were given several opportunities to discuss their positive and negative feelings towards their parents and sibling with autism. Rebecca appeared to use this opportunity to share her feelings with the group and did so quite freely. Therefore, perhaps this may have contributed to her improvement in her BEH score.

The subsequent domain scales, Intellectual and School Status (INT), and Physical Appearance and Attribute (PHY) increased from Average to Above Average scores between Time 1 and Time 2. Rebecca's INT scores were consistent with her mother's statements when asked if she had any concerns about Rebecca she said, "She's super smart and everything like that, so education wise, no". In addition, during her initial interview, Rebecca made a statement that she tries to help her brother when he has difficulty, "I see him do things I see him struggling and I wanna help him". Therefore, it appears as though Rebecca feels confident enough in her academic abilities to help her brother when he has difficulty. The PHY scores, which measured her assessment of her physical appearance, leadership skills, and ability to express ideas, also increased from Average to Above Average. Accordingly, Mrs. Johnson believed that Rebecca was very confident and a leader within her group of friends. "She has a very strong personality, so she makes her presence known". This was consistent with the BASC scores for Functional Communication, which measured her expressive and receptive communication skills and her ability to seek and find out information and Leadership, which measured her ability to be creative and to work under pressure. Functional Communication increased between Time 1 and Time 2, while her Leadership abilities remained consistent (See Table 7). During the group, Rebecca would openly discuss her brother and parents; both positive and negative feelings were made, which showed her ability to express her ideas and feelings with others. In addition, she decreased in her T-score for Withdrawal in the BASC between Time 1 and Time 2, which supports that she

is open and willing to talk to others and perhaps the SSIP may have helped to improve those skills through her interactions with other children who had similar experiences.

The fourth domain, Freedom from Anxiety (FRE) decreased between Time 1 and Time 2 (See Table 5). Rebecca's FRE T-scores were in the Above Average range, which indicates that an individual is happy with their appearance and social functioning. Yet an Above Average score also signifies that an individual is denying they are bothered by any unpleasant moods like sadness or nervousness and trying to mask any real difficulties. In her initial interview, Rebecca said that her parents told her to be a little more lenient with her brother because he has autism. In addition, during the group, she would share how her brother would make weird sounds or repeat movie lines. In the post-interview she reported that he made up his own words, making it difficult to understand him. Therefore, based on all three interactions with Rebecca she did not deny any unpleasant moods, but it is possible that she is masking difficulties in relation to the marital difficulties of her parents. Her mother was concerned in her pre-group interview as she stated:

I want her to remain free-spirited, and independent and confident and all that, so it's just about that right now. So I try to build her up all the time and tell her she's doing a good job and talk to her because of the problems with, you know, the marriage and stuff like that.

There was no indication about marital issues during the post-interview so either things were either resolved or Rebecca found a better way in which to deal with those feeling. As such, her T-score for FRE decreased to an Average score, which is more indicative of the standardized sample. This was consistent with the BASC T-scores for Anxiety that also decreased between Time 1 and Time 2 (See Table 7).

Rebecca's Popularity (POP) T-scores also decreased between Time 1 and Time 2 but remained in the Above Average interpretative scale (See Table 5). Children who rate themselves in this category are considered to have successful peer relationships, feel included in activities, and are well liked by their peers. The BASC questionnaire also supported this finding, as Rebecca's Social Skills scores were in the Average range, which implies that Rebecca has sufficient social skills and no indication of any type of social difficulties. During the interviews and group interactions Rebecca appeared to be a very easygoing child with an eager willingness to participate. During the group it was her idea to underline the characteristics of autism related to each of their siblings. Her mother also stated that she was confident and very much a leader:

Well they would play games and Rebecca\* would kind of be the dominate character

all the time and others ones would go along with it.

Therefore Rebecca appears to have developed good social skills.

The last domain was Happiness and Satisfaction (HAP), which measures her overall feelings of happiness and satisfaction with life. Her score remained the same in the Average range in which her positive evaluations outnumbered the negative feelings about life in general. Rebecca was aware that there are both positive and negative aspects of interactions with her brother Lucas and that having siblings were better than being alone. She also stated, "It's not much different from a good brother/sister relationship". In addition, her overall BASC scores for externalizing and internalizing behaviors were not of concern and mostly remained in the Average range. Therefore, it appears as though Rebecca's overall self-esteem and behavioral functioning were in the typical range and a few improvements may have been attributed to SSIP, as well as the marital status of her parents (As described by her mother).

 Table 6

 Rebecca Johnson's BASC Clinical Scale T-Scores For Time 1 and Time 2

Composite	Time 1	Clinical Scales	Time 2	Clinical Scales
Externalizing Problems	49	Average	46	Average
Internalizing Problems	49	Average	38	Low
Behavioral Symptoms Index	46	Average	41	Average
Adaptive Skills	53	Average	57	Average

**Table 7**Rebecca Johnson's BASC Clinical and Adaptive Scale T-Scores For Time 1 and Time 2

Scale	Time 1	Clinical Scales	Time 2	Clinical Scales
Hyperactivity	47	Average	43	Average
Aggression	51	Average	48	Average
Conduct Problems	48	Average	48	Average
Anxiety	47	Average	40	Low
Depression	47	Average	39	Low
Somatization	53	Average	42	Average
Atypicality	44	Average	44	Average
Withdrawal	40	Low	38	Low
Attention Problems	51	Average	45	Average

Scale	Time 1	Adaptive Scale	Time 2	Adaptive Scale
Adaptability	53	Average	62	High
Social Skills	52	Average	54	Average
Leaderships	57	Average	57	Average
Activities of Daily Living	47	Average	52	Average
Functional	54	Average	57	Average
Communication				

*Roger Smith.* Roger's Piers-Harris Total (TOT) T-score increase between Time 1 and Time 2 (See Table 8). Therefore, like Rebecca, he was in the Average range when compared to the standardized sample. According to the Piers-Harris, his scores showed a realistic self-evaluation of both his positive and negative aspects. This is consistent with his mother's behavioral report in the BASC questionnaire in which Roger was also within the Average range for most of the clinical and adaptive scales (See Table 9 and 10).

 Table 8

 Roger Smith's Piers-Harris T-Scores For Time 1 and Time 2 and Their Interpretive Labels

Domain Scales	Time 1	Time 2	Interpretive Label
Behavioral Adjustment (BEH)	62	62	Above Average
Intellectual and School Status (INT)	48	48	Average
Physical Appearance and Attributes	58	58	Above Average
(PHY)			
Freedom from Anxiety (FRE)	46	48	Average
Popularity (POP)	47	47	Average
Happiness and Satisfaction (HAP)	51	59	Average to Above
			Average
Total (TOT)	51	53	Average

For the six domains of the Piers-Harris score, Roger was able to self-evaluate a representation of his self-esteem. The first domain is Behavioral Adjustment (BEH), which measures how much the child admits or denies problematic behaviors. Roger was consistent with an Above Average T-score of 62 for both Time 1 and Time 2. According to the Piers-Harris, when an individual scores in the Above Average range, this indicates that they perceive themselves as well behaved and able to comply with rules both at home and at school. If a child has a raw score of 14 (T-score of 62) this may also show that the child is in denial of behavioral problems to try to hide real difficulties. Regrettably, Roger's raw score was in fact 14 for BEH, therefore it is possible that he conceals certain emotions. His family situation was different from the other participants, in that his brother has multiple diagnoses of ASD, OCD, and ADD, and that his brother was removed from the home a few months prior to the support group because of aggressive behaviors. Therefore, it appears as though his brother requires a lot of attention from his parents. In the initial interview when I asked his mother when she first noticed a difference in Roger's brother, Ryan, Mrs. Smith proceeded to provide extreme detail from the time Ryan was born to the present. The mother appeared to be very stressed and worries constantly about Ryan and felt the need to share intimate details about her previous marriage and trauma to which Ryan and she were exposed. It seems as though Mrs. Smith worries so much about Ryan, that Roger may not receive the attention he requires. She said:

I don't worry about Roger\* as much at all. I don't worry about him, like in this instance I don't worry about him, he's a smart, smart cookie, he has a good head on his shoulders.

Therefore based on his mother's statement and that his BASC scores for externalizing and internalizing behavior remaining in the Average range, may also indicate that his mother is unaware if there are any behavioral concerns for Roger (See Table 9).

**Table 9**Roger Smith's BASC Clinical Scale T-Scores For Time 1 and Time 2

Composite	Time 1	Clinical Scales	Time 2	Clinical Scales
Externalizing Problems	52	Average	55	Average
Internalizing Problems	50	Average	46	Average
Behavioral Symptoms Index	50	Average	50	Average
Adaptive Skills	57	Average	55	Average

Roger also appears to repeat a lot of what his parents say to each other. For example, when Ryan ran away from home, Roger volunteered extremely detailed information about what happened in the events leading up to Ryan leaving. It seems as though he may be exposed to too much information about his brother and is unprepared without the proper tools to deal with that information. It is understandable that the parents would want to share information with Roger, but it is unclear if his parents are aware of the line between providing an acceptable amount of information for Roger's age and providing too much information that becomes detrimental to his well being. When asked if he talks to anyone about his brother during the pre-group interview, he said, "Not really, because I don't think it's any of their business". And when asked again during the post-group interview he made a similar statement:

I don't' really have any friends that I can talk to...I like keeping things to myself...I don't really like talking, sometimes I'll talk to my mom.

During the group session, Roger provided several examples of the difficulties and frustration he had towards his brother but did not provide any indication of possible negative feeling towards his parents. He only stated that his parents sometimes say something that he does not understand, but would not elaborate. Therefore, Roger's BEH score coincided with the fact that he may be reluctant to express certain feelings because his is aware that his parents are so overwhelmed with Ryan's behavioral issues and may not want to add to their stress level.

The next domain is Intellectual and School Status (INT), which measures his abilities pertaining to intellectual and academic tasks. Roger's T-score remained consistent at an Average range for both Time 1 and Time 2. This indicated that he has a realistic view of his academic performance and is aware that he has a few difficulties with some school tasks. His academic performance did not pertain to this study. The third domain, Physical Attributes and Performance (PHY), which measured his assessment of his physical appearance, leadership skills, and ability to express ideas, also remained consistent between Time 1 and Time 2 at an Above Average Tscore of 58. This signifies that Roger is popular with his peers and that his friends and classmates value his opinion. The BASC scores for Leadership and Functional Communication were consistent with his PHY score (See Table 10). Leadership measured his ability to be creative and work under pressure and Functional Communication measured his ability to seek information and his expressive and receptive language skills. His Leadership skills remained consistent between Time 1 and Time 2. During week three, when each child was required to share a recurring issue with their sibling through role-playing, Roger was the first to help provide suggestions to help solve conflicts with their siblings. In addition, it was Roger who was the leader during the problem solving illusion activities in week two. He was able to figure out how to resolve the human knot and pass the hula hoop activities while the other participants followed. His Functional Communication skills improved between Time 1 and Time 2 but remained in the Average range. The group provided several opportunities for Roger to express his feelings both positive and negative. In addition, during week five each child had one-on-one time to discuss strategies and tools to apply to their unique situation. Roger said that sometimes their verbal conflict would turn to physical conflict. Both Roger and his mother stated in the post-interviews that he would now walk away from his brother when he noticed that the conflicts started to escalate. "I did some things, like walk away". Roger was able to recognize that the issue would not be resolved if it continued to worsen and was able to apply strategies he learned from the group. Therefore, this may have attributed to the increase in his Functional Communication.

The fourth domain of the Piers-Harris was Freedom from Anxiety (FRE), Roger's T-scores increased from Time 1 to Time 2 but remained in the Average range (See Table 8). This implies that Roger had generally a positive emotional state but had a few mood difficulties. In his post-interview, Roger said when asked how he felt to be a sibling:

It's really tough and I'm not really happy about having a brother that acts like this but I'm

not mad that I have a brother like it. I don't know if that makes any sense like, I'm not mad that I have a brother that acts like this, I'm just upset that I don't have someone that's nicer than him cause he's really mean to me.

Roger seemed to be somewhat accepting of his family situation but wished that a few things were different between him and his brother. Also the recent run away situation may have contributed to the slight increase in his FRE score. Yet after the support group he seemed to have found better ways in which to cope with his brother's difficult behaviors. His mother said, "He is more capable of...compromising and not so quick to jump on his brother". In addition his Anxiety level score in the BASC decreased between Time 1 and Time 2, which also was inconsistent with his FRE score as both scores remained in the Average range for Time 1 and Time 2.

Popularity (POP) scores for the Piers-Harris remained the same between Time 1 and Time 2 with an Average T-score of 47. This determined that he was happy with his social functioning but admits a few difficulties with peer interactions. As stated before, Roger did not like to disclose information about Ryan to his friends. In addition, Roger had moved three times on the last five years and as such, did not have the opportunity to develop strong peer relationships. His Adaptability T-score from the BASC decreased from Time 1 to Time 2, which measured his ability to adapt and recover from situation quickly. Thus the reason may also be because of all the strenuous family issues they have, that perhaps he may not feel comfortable talking to his friends as he may feel embarrassed or that they do not understand.

The last domain of the Piers-Harris, Happiness and Satisfaction (HAP), measures individual's overall feelings of happiness and satisfaction with their life. Roger increased from 51, an Average range, to 59, an Above Average range between Time 1 and Time 2. This score was inconsistent with his BEH score. As stated early, an Above Average BEH score indicates that an individual may be trying to mask behavioral issues and further investigation into Roger's interviews and group experience indicated that he may have been doing this. Therefore, it is believed that although his HAP score had improved over time; there were still aspects of his life that he may not be content with. Therefore, overall Roger appeared to be have a positive self-esteem that had slightly improved based on the tools and strategies provided in the support group, but still seems to bear too much of the burden of his brother's behavioral issues and may even mask some of his feelings in order to alleviate some of the stress of his parents.

**Table 10**Roger Smith's BASC Clinical and Adaptive Scale T-Scores For Time 1 and Time 2

Scale	Time 1	Clinical Scales	Time 2	Clinical Scales
Hyperactivity	50	Average	52	Average
Aggression	51	Average	57	Average
Conduct Problems	54	Average	54	Average
Anxiety	52	Average	50	Average
Depression	51	Average	51	Average
Somatization	47	Average	39	Low
Atypicality	41	Average	41	Average
Withdrawal	56	Average	47	Average
Attention Problems	51	Average	51	Average

Scale	Time 1	Adaptive Scale	Time 2	Adaptive Scale
Adaptability	62	High	50	Average
Social Skills	56	Average	61	High
Leadership	55	Average	55	Average
Activities of Daily Living	55	Average	49	Average
Functional	52	Average	57	Average
Communication				

Parents' perceptions. Another important theme that was significant throughout the group was how parents perceived the relationship between siblings and their perception of their relationship with their TD child. According to previous research, this unique family dynamic results in a child with special needs requiring more attention from their parents than the typically developing child or children (Rivers & Stoneman, 2008). As a result, it may be associated with negative feelings such as resentment, anger, or frustration towards their siblings, but may also be associated with in empathy and patience (Macks & Reeve, 2007). Therefore, how much parental involvement and how much a child is able to interact with their sibling can influence how the TD child engages with their sibling and the relationship that they build with their parents (Macks &

Reeve, 2007; Rivers & Stoneman, 2008). The SSIP attempted to address these concerns by providing parents an opportunity to attend one of the SSIP sessions in order to share what the children had learned with the hopes of increasing parental involvement with their TD child and build more open relationships.

Sean Williams. During the preliminary interview, Sean was asked when he noticed that his brother was different. He said that he did not notice anything different but that he overheard his parents talking about it one day. When asked what his parents told him about autism, Sean said that his parents never sat with him and talked about it; perhaps because his parents were sensitive to his difficulty in expressing himself. Therefore, according to Sean, his parents spoke openly at home and he heard about autism while his parents were discussing it. Mrs. Williams said that Sean knew his brother was different but that she did not feel he had a good understanding of autism. This was consistent with Mrs. Williams' perception as she stated that:

I find that he has difficulty talking about his feelings sometimes like, like it's hard for him to open up, he likes to keep things to himself.

Based on Mrs. Williams' responses to the BASC questionnaires, it is not surprising that Sean was very withdrawn and had difficulty opening up to others. Before the group, Mrs. Williams said that Sean would play with Andrew but it was always on Andrew's terms.

I think Sean\* has had to adapt to Andrew's\* style, all of Sean's\* life he's sort of had to adapt to that. Like if they were playing games, it was Andrew's\* game. If it was a game that they were making up together, it was always by Andrew's\* rules, cause he's so rigid. So Sean\* has just for of adapted to that.

It seems as though Sean would accept things the way they were perhaps because he found it challenging to engage with Andrew. During the support group, Sean was provided with relaxation techniques in which he could use during stressful situations either pertaining to his brother or to school. He was also provided with various games to play with Andrew, including a Popsicle stick game, charades, and a few science experiments. In addition, during week two, Sean was given opportunities to discuss his feelings and was provided with trouble shooting techniques during the one-on-one portion of week five. The trouble-shooting techniques were based on recurring problems between the child and their sibling. Sean continually stated that his brother would isolate himself and only wanted to play video games. He also said that Andrew would ignore him when called on and would bother him when his friends came over. In order to

help Sean he was told to use his parents as a resource by asking for their help before the situation escalated. Also with parental supervision, Sean was given the suggestion to research new games and ideas on the Internet that he could do with his brother in order to engage more with him. Lastly, in week six, Sean was able to review a poster he had decorated with all of the information he had learned from the support group with his mother so she could see what he had learned. After the group sessions, his mother said:

He's actually been a little better since the group. He doesn't seem as stressed and more willing to me to help him with his homework. I think the fact that he has a new teacher. He's asked me a little about Andrew\*, like ways to help Andrew\* engage with him more. He still talks more with Andrew\* than with me but I'm okay with that. So ya.

So according to Mrs. Williams, based on his use of the techniques that were suggested during the support group, both Sean's relationship with Andrew and her relationship with Sean had somewhat improved after the group.

Rebecca Johnson. In the pre-group interview, Rebecca was asked when she noticed a difference in her brother. She said that she just knew for a long time but was unsure when exactly, but noticed around the age of six and that he was not very excited about school. When asked what her parents had told her about autism, she said, "That I have to take it easy on him... That like I have to use his ideas a bit more than mine". For that reason, is it believed that her parents told her that he was different is some ways and she did more of what he wanted which could have created a bit of resentment. Yet, she also seemed to have empathy towards her brother as she said that she saw him struggling at times and wanted to help him. Her mother made a similar statement:

They get along so well, 90% of the time she is just, I don't want to say like smothering, she doesn't like smother him, but she's a mother hen. She looks out for him....she wants to help him. She's super good with him. She's super good with both of her brothers. I sometimes though like, these two play so well together, that sometimes she tries to play with them and then she's the third wheel and that doesn't always work. But she tries, she wants to play with them.

Perhaps being the eldest child of the family, Rebecca may have felt an obligation to take care of her younger brothers and to be a role model for them. In addition, although Rebecca appeared to take on a positive big sister role, there were times when she may have felt that

because she is the oldest, her parents expected more from her. During the group, when asked about any positive or negative feelings she had towards her parents, she said that she felt her parents were very bossy and that she was required to do chores and her brother did not. It seems as though she had mixed feelings about the big sister role and may felt that her parents might have a few unrealistic expectations. She also was reluctant to share this with her parents and her mother made no indication of her negative feelings during the pre- and post-interviews.

During the trouble shooting activity in week five of the SSIP, some of the recurring issues that Rebecca had shared throughout the group included being embarrassed by noises and loud sounds her brother made, and the fact that he was not required to do chores. In addition, he bothered her when her friends are over, he only liked to play games that he would not lose, and that he did not give her privacy by continually going into her room. Her mother's perspective however, was that Rebecca was very protective of him, and that she was not embarrassed or ashamed by him. So it seems as though her mother believed that the relationship between Rebecca and her brother is mostly positive and that he did not embarrass her, a sentiment that was not shared by Rebecca. Aside from the noises and the games, the issues that Rebecca had with her brother appeared to be that of a typical brother/sister relationship. The following strategies were given to Rebecca; to try and explain to her friends about her brother and maybe include him in at least one game while her friends were over so that he would not bother them, ask her parents if he could help her with the chores such help cleaning up the toys or help her feed the dog. In addition, when her brother made weird noises that she did not like, she could walk away and ignore the noises so that maybe the frequency of them would decrease. After the support group sessions, it appeared as though Rebecca used some of these techniques, as she had a better understanding of autism and was able to explain to her friends about her brother. Her mother also noticed a difference and said that she noticed that Rebecca included him a lot more.

In terms of the relationship between Rebecca and her mother, Mrs. Johnson said that she believed that she was pretty close to Rebecca, that they have an open relationship, and even attempted to make a day for just the two of them every once in a while. This was consistent with her post-interview as Mrs. Johnson felt that in being proactive and having little talks, that Rebecca was very receptive. In addition, the BASC questionnaire supported her statements as her Functional Communication increased between Time 1 and Time 2 in that her ability to seek and find out new information had improved (See Table 7). As such, there was no change in the

relationship between Rebecca and her mother.

Roger Smith. In the initial interview, when asked when he noticed a difference in his brother, he said that he was four-years-old and he was playing with a toy and his brother claimed that it was his but it was not. His mother also stated, "I wanna say the first time he cognitively realized that there was a difference was probably around four-years-old". Therefore his belief that this was his first memory quite possibly could have been what his parents told him. When asked what his parents told him about autism, Roger said that it was a disability in understanding things.

According to Roger's mother, the relationship between Roger and his brother Ryan was very complex. The fighting between them got more intense once Roger grew older and his mental age surpassed Ryan's. Their mother said:

Physically it was getting disgusting because Ry-Roger\* had no patience for his brother after a while which I don't blame him but there's no sense in hitting but then again his brother hit first by you know, so there was always a back and forth thing.

Roger shared quite a few experiences about the arguments and physical altercations he had with his brother throughout the group. During week five, we discussed the most recurring issues during the trouble shooting session. Roger stated that his brother only wanted to do what he wanted and there was no reciprocation, that Ryan would ignore his questions, and that Ryan used violence to resolve issues with his brother. Roger was provided with the following strategies in order to overcome those recurring issues with his brother; try to develop a level of mutual respect by attempting to refrain from name calling and hitting, to focus on the reasons why he was upset and not focus on his brother, to walk away from a verbal argument before it escalated into a physical altercation, and attempted to use the relaxation techniques given during week five. Furthermore, during the last session, Roger was able to share his poster board with his mother that contained his experience in the group.

After the group sessions, Roger said that when he fought with his brother, he would use a strategy he learned in the group by walking away from his brother. His mother also noticed a difference as she stated:

He's not on edge, he's not constantly mad at his brother. He has a way of, you know, being more relaxed around him and he'll simply walk away. The last visit we had he was upset with him because he wouldn't stop whistling or something like that or something silly. It

was something simple as that but in reality he will just sort of saying, 'Fine you're making me angry, I'm not dealing with you anymore' and he'll walk off. Whereas before the group he was a little more agitated with him and everything he did.

For that reason, although there were still issues between the two boys, it is believed that the group appeared to have helped improve the relationship between Roger and his brother. As for the relationship between Roger and his mother, Mrs. Smith perceived their relationship as very close and caring. She also felt that their relationship was very open. She made the following statement:

Roger\* and I are very close, we have a really open relationship. I talk to him a lot about his brother. He's really smart and very mature, he's more mature that Ryan\*, you know, like he understands things better. Not to say that he doesn't need guidance here and there but he's good, a good kid.

In the mother's perceptive, she believed that they were very close, and it appeared as though she talked a lot about her concerns for Ryan with Roger. As mentioned earlier, Roger seemed to know too many details about the events leading up to Ryan running away from home and she also seemed to tell Roger about all of Ryan's behavioral issues that occurred at his home and with his caregivers. Although this information might have been too much for a 13-year-old boy to handle, she shared all of this with him because she considered him to be mature. It is reasonable to believe that she would want to share information with him however, she might not realized the implications that this could have on Roger's overall well-being. She said:

I don't really see as much concern cause he is a wonderful ma-, little boy is gonna be an awesome man and he's so caring and loving and he has a bit of anxiety, he has a bit of worry, but it's not in my opinion, I think it's just sort of a learning curve a maturity.

Consequently, she does not feel that she should worry about Roger especially in comparison to Ryan's needs. This was consistent with his Above Average BEH score in the Piers-Harris, which indicated that he was trying to conceal feelings since his parents had so much to deal with on a daily basis. Roger may also have felt the need to be a responsible role model child because Ryan caused so much stress on the family. Overall, it is unclear if there was a change in the relationship between Ryan and his mother.

**Perception of the sibling support intervention program (SSIP).** Throughout the SSIP each child was asked to write in their weekly scrapbooks about their experiences and what they

enjoyed about the activities. The participants were also asked to fill out a SSIP evaluation questionnaire at the end of week five to determine which activities were most popular and any suggestions for future groups (See Appendix O). In addition both the participants and their parents were asked to provide suggestions about the group during their post-interviews.

Sean Williams. Throughout the group, Sean's scrapbook did not contain a lot of information about the support group. It seemed as though he enjoyed the activities not related to the autism topics. During week one, he wrote, "Today I didn't learn much" and he drew a picture about a comic book, which was not related to anything we had done in the group. However, when asked directly what he had learned he said that he did not know that some children with autism did not talk, that their brain was different, and that they could learn through visual aids. It appears as though Sean had difficulty writing or expressing his feelings and that resulted in the focus of the scrapbook was on non-related topics that he could write about. He also appeared to be a little withdrawn near the end of the session, which was consistent with his ratings on the BASC questionnaire. During week two, he traced the scissors and drew the ball pit from the sensory room, snozelen. Yet, when asked directly what he had enjoyed he replied that he liked the talking activity (10 words) and said "It would be frustrating for me" (See Table 11). He seemed to understand that having limited ability to express himself in language would make it difficult to communicate with others. He also said that he did not like the annoying sound and hidden picture, perhaps because it reminded him of when his brother was loud.

In week three, for the first session we focused the attention on the TD child and not on their sibling and then for the second part we did a role-playing activity with puppets. Sean wrote that he enjoyed going to the park, but did not like that we were not able to go on the trampoline. In week four, the participants learned different games to play with their siblings, relaxation techniques, and science experiments. Sean wrote that he enjoyed playing charades and that he enjoyed acting more than guessing. In week five, everyone drew and decorated posters to summarize what they had learned in the last four weeks. Each child was also taken aside to review trouble-shooting techniques related specifically to their sibling relationship. They also completed the SSIP evaluation questionnaire. Sean helped to decorate the posters and wrote that he learned it was hard to make friends, that he liked the 10 words activity, and that he liked playing sandman and charades. Therefore, it seems that Sean did in fact learn about autism, enjoyed some social activities, and may have gained some strategies that may be useful in dealing

with issues of autism, as well as the fun activities he could play with other children.

After Sean completed the SSIP Evaluation Questionnaire, he wrote that he mostly enjoyed charades and snozelen and that he learned "that it is very hard to have autism". In addition he enjoyed the group discussions, the illusion activities, Dear Aunt Blabby, and the scrapbooks (See Table 11). Lastly, in the post-interview Sean was asked what he liked about the group and he said the trampoline, the park, and snozelen. He also said that he enjoyed learning about autism. In addition, his mother was asked if he spoke about the support group and she said every once in a while he would talk about information about autism that he learned from the group but not much else. In general, it appears as though Sean did in fact learn new things about autism and that he enjoyed some of the activities related to autism, but preferred the leisure activities.

**Rebecca Johnson.** During the group, Rebecca's scrapbook had information related to the group; what she had learned as well as what she enjoyed. Rebecca seemed to have an artistic talent and made her scrapbook very colorful. According to Rebecca's mother, she is a very confident and outgoing child and her scrapbook seemed to match her personality. During week one, she wrote that she learned that children with autism have some difficulties including understanding emotions and that they can have trouble talking. She also learned in week two that people with autism can only say some words and she enjoyed the 10-word activity. During week three, the participants were asked to reenact a recurring conflict that they had with their sibling using puppets they made. Rebecca said that she learned how kids with autism react when they are mad and how to help them. She also enjoyed making the puppets and snozelen. During week four, the participants learned different games and activities to do with their sibling and Rebecca said that she enjoyed charades the most. In week five of the group, she decorated the posters and wrote, "I learned that autism can affect with talking, actions, and looks". She also wrote that she had learned games to play with her sibling, played charades, went to the park, and learned what it was like to have autism. Overall, from Rebecca's perspective it appears that she learned quite a bit of information throughout the group and had fun at the same time. In the SSIP evaluation questionnaire, Rebecca wrote that she enjoyed going outside, snozelen, playing charades, and that she learned about autism. She also enjoyed arts and crafts, learning about brothers and sisters, learning how to get along with their sibling, Dear Aunt Blabby, and the scrapbook (See Table 11).

Lastly, during the post-group interviews when asked what her experience was like in the

group, she said that she liked learning about autism, the 10 words, Dear Aunt Blabby, the scrapbooks, and the final posters. This was consistent with what she had said she enjoyed during the support group sessions. Her mother reported that Rebecca had talked about the group on their way home and she learned a lot of new things that she did not know and that Mrs. Johnson felt that she had a better understanding than before. So it appears as though Rebecca enjoyed the group and learned new knowledge about autism.

Roger Smith. Roger wrote about the activities that were done each week, but did not always write what he liked or disliked. He also did not decorate his scrapbook with any of the material provided which seemed to give the impression that he preferred to write. During week one, Roger wrote that we had talked about autism and the similarities about our siblings, but did not write what he had learned. During week two, he wrote what we had done: 10 words, the hidden picture, and went to the gym. He also wrote that he had fun and enjoyed the ball pit and hammock in the sensory room. In week three, he wrote that we played sandman and played with puppets and during week four he wrote that he liked charades. For week five, he wrote on the posters that he had learned that "autism is someone that has a disability, it's hard to do different things". He also wrote that he frequently fought with his brother a lot and that his brother always makes his own rules. It seems as though even though he learned different games to play with his brother he may have be reluctant to play because his brother makes his own rules and they fight a lot. Lastly, he wrote that he liked Dear Aunt Blabby perhaps because the hypothetical scenarios gave him an opportunity to give advice, listen to each other's advice, and felt that others had similar challenges as him.

The SSIP evaluation questionnaire was completed after the posters and he wrote that he liked Sean and Rebecca, that he enjoyed playing outside, and that he liked sandman. When asked what he learned in the SSIP, he reported that he would use different ways to deal with his brother. In Roger's and his mother's post-interviews, they also confirmed that he had applied some of what he had learned in the group to help him with his brother. Therefore, although he did not always write what he enjoyed in his scrapbook, based on the chart in the questionnaire, Roger stated that he enjoyed the group discussions, learning about autism, illusion activity, feeling chart, learning about brothers and sisters, Dear Aunty Blabby, relaxation techniques, and the scrapbook (See Table 11). In his post-interview, Roger stated that he learned about autism and different things he could do with Ryan. He said that he tried different things with Ryan even

though it did not always work. He liked being with Sean and Rebecca and that he got to learn how their brothers were different from his. Roger also said that he would attend another group. His mother also said that he told her he enjoyed the group and the activities that we did. She stated that she was sure he would do another group and that she was happy to see that he liked the group as much as he did. As such, Roger seemed to have benefitted from the group as he not only learned about autism, but he also reported that he had learned strategies and tools to help him with his brother.

**Table 11**Types and Frequency of Activities Enjoyed Most by Participants

Type of Activity	Sean	Rebecca	Roger	Total
Arts& Crafts				1
Group Discussions				2
Learning about Autism				1
Illusion Activity (what it feels like to have				2
autism)				
Feeling Chart				1
Learning about brothers and sisters				2
Learning how to get along with my sibling				1
Dear Aunt Blabby				2
Relaxation Techniques				1
Scrapbook				3

In general, based on Table 11, the most enjoyed activity was the scrapbook. They also seemed to enjoy group discussions, illusion activities, learning about brothers and sisters, and Dear Aunt Blabby. These activities seemed to have given the participants a better understanding of autism and their sibling.

### **Control Group Findings**

The purpose of the control group intervention was to have a neutral group to compare to the experimental sibling support group in order to analyze whether providing direct sibling support was beneficial to siblings of children with autism or if providing group activities that provide children with attention was as helpful and beneficial in promoting social and behavioral well-

being. For comparison purposes, the results of the control group were also analyzed to answer the first three research questions and examined if there were any changes between their pre- and post-interviews and their questionnaires. The following themes were used to interpret the data after open coding was applied: (a) knowledge of autism and child's and parent's perspective of interactions with siblings with ASD, (b) self-esteem and behavior, and (c) parents' perceptions.

**Knowledge of autism.** As previous research has shown, a child's knowledge of their sibling's diagnosis can have an influence on their interactions with their sibling with autism. During the control group sessions, the participants were not exposed to any knowledge and they participated in various activities not related to autism (See Appendix S).

Gary Adams. Gary's initial understanding of autism was that it was someone who was different and worries. This did not change in the post-interview as he again stated that an individual with autism is someone who is different and with whom you cannot really get along. Therefore, between his pre- and post-interview, Gary's knowledge of autism essentially did not change. During Gary's interviews, he described his relationship with his brother to be somewhat difficult as his older brother, John would change rules in the middle of a game and Gary would be mad that he changed the rules. He also said that his brother preferred to play on his iPod and isolate himself than play with him and that he usually takes Gary's things without asking. When asked if he spoke to his brother about what bothers him, he replied that he did and John would listen for a while, but then reverted back to his old ways. The problems that Gary had with John were brought up in both the pre- and post-interviews. So it seems as though Gary's strategies for interacting with his brother in difficult situations were not effective and did not seem to improve over the course of the sessions.

When asked to color on a thermometer about how he felt to be a sibling, Gary colored to 50% in his pre-interview and when asked what he would change to increase the thermometer, he said, "Him not to have specials needs, like not to have that problem". During the time of his pre-interview, Gary had recently found out that his brother had Asperger's and perhaps was trying to cope with the news by wishing his brother did not have Asperger's Syndrome. After the control group sessions, when asked the same question, Gary colored the thermometer to 70%, and said, "I would, I would make things just easier with him and me. Like get along with each other more". So it appears that from Gary's perspective, they still have the same difficulties. However, their relationship had slightly improved but it is unclear as to how things have changed other than

perhaps the new diagnosis contributed to him having more empathy for his brother as he may have felt it was his responsibility to make things easier for him.

Candice Brown. Candice's expressed her knowledge of autism during her initial interview by stating that when you have autism it is difficult to learn and that it takes time to learn things. She also said, "It's like my brother". Her mother said that she believed that Candice did not know anything about autism and that she had told her that it is something that Carter has that prevents him from doing things at a regular pace. Candice reiterated in her interview what her mother had told her. In her post-interview, she said that it is someone who is different, that they need more help, and that they have difficulty with transitions. It seems as though Candice's understanding of autism had somewhat changed between the pre- and post-interviews, as she seemed to understand it a little better, which could have resulted from her observing her brother more after attending the controlgroup sessions. During the pre-group interview, Candice described her relationship with her brother to be positive and enjoyable. However during her post-group interview, she not only described her relationship to be positive but she was also more open to sharing negative experiences with her brother. She said that he did not like to share the iPad with her and he would scream, kick, and push her away. She also said "He gets upset for no reason 'cause like he plays this game and if he loses he starts to scream". Before the control group sessions began, Candice, like Gary, recently found out that her brother had autism. As a result, it seems that by the time of the post-interview, she had become more comfortable discussing all aspects of her relationship with her brother. It could also be that the control group sessions with a focus on enjoying herself and getting individual attention, gave her the opportunity to discuss this issue more openly during the interview.

When asked to color on the thermometer about how she felt as a sibling, Candice colored 100% at both the pre- and post-interviews. When asked if she would change anything both times she said she wished he could talk, but that they had their own way of communicating because he would bring her to things that he wanted. Therefore based on Candice's point of view of her relationship with her brother, it had remained mostly consistent but she was more open to mentioning the negative aspects of her relationship.

*Chelsea Brown.* Chelsea seemed to have had a pretty good understanding about autism. In her pre-interview, Chelsea said that it was someone with a disability and that the brain did not communicate the way that it should. She also said that a person with autism was different but not

in a terrible way. Her mother also believed that she had a good understanding of autism because they had spoken about it in her presence. In her post-interview, Chelsea again said that it was a disability and their brain function was different. She also said that a person had a missing piece that was supposed to be there. Overall, it seems as though Chelsea had a fairly good understanding about autism. In addition when asked what it was like to be a sister in her pregroup interview, she said:

I like everything about it. I'd rather have brothers and sisters than be an only child because when I grow up Candice\* can be my maid of honor and Carter\* is gonna be my husband's best man.

In addition during her post-interview, Chelsea said:

Carter\* is going to talk for sure, I hope so. So I'll have these video of him and they'll be super cute cause Carter\* didn't talk then. Then he's going to be like 'oh my god I can't believe I didn't talk for 3 years 'cause I wanted to say so much.

Since Carter is currently non-verbal, there is no guarantee that he will speak in the future nor if social situations like being a best man will be easy for him. Chelsea seemed to be very hopeful that her brother will be capable of these things, which may show that she has a positive outlook for the future. Even if the harsh reality of the future does not allow him to do these things, she believed that her brother may be different than others with autism and that his only issue is that he cannot talk and that this may change with development.

Throughout both interviews, she continually stated that the only problem her brother has is that he cannot talk and she even seemed to be protective at times. She explained how everyone has a problem but each person's problem is different and her brother's only problem was that he could not speak. When asked to color the thermometer about how she felt as a sibling, she colored 100% at both her pre- and post-interview. When asked what she wanted to change in the pre-group interview she said nothing and that she enjoyed her relationship with her brother. However, in her post-interview she added:

Maybe I'd just change that he would like talk because it's not that it bother's me, it's just that sometimes when we really don't know what he wants. We can't ask him what he wants. So we kind of have to show him different things to help kinda guess what he wants.

It appears as though over time, Chelsea slowly started to realize that his inability to speak could impact other areas. Therefore, it appears that Chelsea accepted her brother's language

difficulties and has learned to accommodate his needs. She was protective and expressed that her knowledge of autism had no negative impact on her relationship with her brother, but made her realize that she had to create different ways to help Carter communicate his needs.

**Self-esteem and behavior.** Unlike the experimental group sessions, the control group did not discuss or participate in any activities related to self-esteem or feelings towards their sibling with autism. The focus of the control group was to participate in fun activities, such as a puppet show, show and tell, and recreational games. As such, any changes in their Piers-Harris questionnaire or the BASC questionnaire completed by their parents could be attributed merely to the extra attention and relationship with the group members, or other reasons and not to any type of sibling support intervention or knowledge about ASD.

Gary Adams. Gary's Total (TOT) score increased between Time 1 and Time 2 from an Average range to a High adaptability range. His average score meant that he was considered to be within the normal range for the standardized sample. When Gary's score increased to a High adaptability range score in his post questionnaire, this meant that he was typically confident across many domains. Table 12 indicates that Gary's T-scores in almost all domains had increased between Time 1 and Time 2 with the exception of his Happiness and Satisfaction scale, which remained the same. In both Gary's pre- and post-interviews, his statements about the issues and concerns he had with his brother had not changed nor did the positive aspects of their relationship.

**Table 12**Gary Adams' Piers-Harris T-Scores For Time 1 and Time 2 and Their Interpretive Labels

Domain Scales	Time 1	Time 2	Interpretive Label
Behavioral Adjustment (BEH)	49	54	Average
Intellectual and School Status (INT)	42	59	Low Average to
			Average
Physical Appearance and Attributes	42	58	Low Average to
(PHY)			Average
Freedom from Anxiety (FRE)	51	54	Average
Popularity (POP)	50	54	Average
Happiness and Satisfaction (HAP)	51	51	Average
Total (TOT)	49	60	Average to High

There were also improvements in the behavioral BASC questionnaire that Gary's mother completed between Time 1 and Time 2 (See Table 13 and 14). However, there were two areas of concern during the pre-group session interviews, Hyperactivity and Anxiety (See Table 14). In the pre-group session questionnaire, Gary's hyperactive score was in the At-Risk range, which indicated that he had a moderately high level for impulsive, disruptive, and uncontrolled behaviors. His mother did not report this in her interview. However during the group, Gary seemed to be overly eager at times to complete the tasks (i.e., the puppets for the puppet show) in order to move on to the next activity. In addition, the interview was completed at the end of summer where there was lacking school structure. Consequently during his post-questionnaire, his T-score decreased to the Average range and it was no longer necessary to complete a follow up. He had been in school for about 5 month so he had the structure that he probably needed to help with his over-active behavior that was reported by his mother.

Gary's Anxiety T-score was also in the At-Risk range, which suggested that he had a more than average level of worry and nervousness. His mother's pre-group session interview was consistent with his Anxiety T-score as she stated:

I find he is a high achiever and sometimes he takes things a little bit too seriously and I think he worries a lot about things, like for example he's going into grade 3 and he's worried about starting grade 3 so he's had a bit of anxiety about that. So I don't know if his worrying has much to do with John\* or that his own personality but he is a worrier and he takes things quite seriously.

Gary's mother said that she tried to address his anxiety by helping him practice his reading skills and provided him with opportunities to talk about his concerns. In the post-control group sessions, based on the BASC questionnaire, his Anxiety T-score had decreased to an Average range so it appears as though he had adjusted well to grade three. In general, it seems that although most of his T-scores had changed between Time 1 and Time 2, they remained in the Average range. Therefore, there is no clear indication that the control group sessions had any impact on his self-esteem and behavior.

Table 13

Gary Adams' BASC Clinical Scale T-Scores For Time 1 and Time 2

Composite	Time 1	Clinical Scales	Time 2	Clinical Scales
Externalizing Problems	57	Average	51	Average
Internalizing Problems	53	Average	51	Average
Behavioral Symptoms Index	50	Average	48	Average
Adaptive Skills	58	Average	55	Average

**Table 14**Gary Adams' BASC Clinical and Adaptive Scale T-Scores For Time 1 and Time 2

Scale	Time 1	Clinical Scales	Time 2	Clinical Scales
Hyperactivity	63	At-Risk	58	Average
Aggression	51	Average	48	Average
Conduct Problems	56	Average	48	Average
Anxiety	60	At-Risk	55	Average
Depression	53	Average	53	Average
Somatization	44	Average	44	Average
Atypicality	44	Average	41	Average
Withdrawal	40	Low	40	Low
Attention Problems	51	Average	51	Average

Scale	Time 1	Adaptive Scale	Time 2	Adaptive Scale
Adaptability	57	High	55	Average
Social Skills	54	Average	52	Average
Leadership	64	High	59	Average
Activities of Daily Living	52	Average	52	Average
Functional	57	Average	52	Average
Communication				

*Candice Brown.* For the Piers-Harris scale, Candice's TOT T-score remained in the High adaptability range between Time 1 and Time 2 (See Table 15). This indicated that she was

considered to have a good self-concept and self-esteem. Her scores for PHY and POP had increased between Time 1 and Time 2, while her T-scores for BEH and INT remained consistent. Her score for BEH was concerning as a child with an Above Average T-score may reveal that the child is in fact in denial about certain behavioral problems in order to conceal difficulties. This coincided with her T-score for FRE as her anxiety level had increased between Time 1 and Time 2. According to the Piers-Harris, a low FRE score indicates that she may feel anxious about school or general aspects of her life. Although she seemed to have fun in the group, her knowledge of autism had not change nor did she develop any new strategies for interacting with her brother. Therefore she remained protective and it is possible that she might have developed some anxiety in her relationship to her brother Carter. In addition, her level of HAP had also decreased between Time 1 and Time 2, which possibly revealed that her anxiety and denial of behavioral issues were beginning to affect her level of happiness. In addition in her interviews, Candice was reluctant to reveal negative feelings about her brother as she only indicated that she did not like the fact that he did not talk. Yet in her post-interview she not only disclosed that she wished he talked, but also that he would scream at her if he did not get his way, and would sometimes be aggressive towards her (i.e., kicking and pushing). This is consistent with the decrease in her HAP T-score and her increase in her anxiety level with a low FRE T-score in Time 2. Consequently there did not seem to be positive changes based on her experience in the group.

**Table 15**Candice Brown's Piers-Harris T-Scores For Time 1 and Time 2 and Their Interpretive Labels

Domain Scales	Time 1	Time 2	Interpretive Label
Behavioral Adjustment (BEH)	62	62	Above Average
Intellectual and School Status (INT)	65	65	Above Average
Physical Appearance and Attributes	48	58	Average to Above
(PHY)			Average
Freedom from Anxiety (FRE)	51	38	Average to Low
Popularity (POP)	54	60	Average to Above
			Average
Happiness and Satisfaction (HAP)	59	51	Above Average to
			Average
Total (TOT)	60	63	High

Mrs. Brown's BASC questionnaires also revealed that Candice was At-Risk for externalizing problems, especially Conduct Problems and Aggression (See Table 17). According to her pre-group questionnaire, Candice's Aggression T-score was Clinically Significant in Time 1, which indicated that she had a higher than average level of aggressive behaviors, and can be argumentative, defiant, and possibly threatening to others. During her pre-interview, Mrs. Brown said that Candice had a tendency to bully some children at school, that she is not so friendly, and that she had been acting out. This was consistent with her BEH score of her Piers-Harris, as she seemed to have tried to mask the behaviors that her mother had revealed. Her mother was aware of her issues and talked to her about the effects and causes of bullying. Her Time 2 T-score for Aggression had decreased to At-Risk, which indicated that she no longer required formal intervention, but that Mrs. Brown should carefully monitor her, as there is potential for problems to develop. This also included Conduct Problems as this remained in the At-risk clinical scale, which indicated that she might occasionally engage in rule-breaking behavior such as deception or cheating. There was also an incident of possible deception in week 3 when Candice claimed to have lost her headband when it was time to leave. We went to search for it in Snozelen and then the gym. When she went to snozelen she proceeded to play and had to be reminded to look for her headband. At first when we looked in the gym, we could not find it but when we returned a

second time, she found it on top of the hockey net. It is unclear if she actually lost her headband or if she claimed she did so that she could play in snozelen again. However, based on her Conduct Problem T-score it is possible that she purposely left it so she could play, indicating that she is in need of more positive attention. Again Mrs. Brown should also carefully monitor for an increase to any potential problems.

There were some positive aspects on the results of her BASC, as Candice had low internalizing behaviors, excellent Leadership skills, and Functional Communication skills that were evident during the group. For example she would initiate racing in the gym and was very articulate during show and tell activities. Overall, Candice did not have internalizing behaviors, but was clearly At-risk for externalizing behaviors. It is unclear whether these behaviors were directly related to her brother and whether they would improve as her knowledge about autism and the needs of her brother increased.

Table 16

Candice Brown's BASC Clinical Scale T-Scores For Time 1 and Time 2

Composite	Time 1	Clinical Scales	Time 2	Clinical Scales
Externalizing Problems	62	At-Risk	65	At-Risk
Internalizing Problems	39	Low	38	Low
Behavioral Symptoms Index	51	Average	49	Average
Adaptive Skills	58	Average	61	High

**Table 17**Candice Brown's BASC Clinical and Adaptive Scale T-Scores For Time 1 and Time 2

Scale	Time 1	Clinical Scales	Time 2	Clinical Scales
Hyperactivity	49	Average	58	Average
Aggression	71	Clinically Sig.	68	At-Risk
Conduct Problems	62	At-Risk	65	At-Risk
Anxiety	34	Low	36	Low
Depression	53	Average	49	Average
Somatization	36	Low	36	Low
Atypicality	55	Average	46	Average
Withdrawal	37	Low	37	Low
Attention Problems	39	Low	39	Low

Scale	Time 1	Adaptive Scale	Time 2	Adaptive Scale
Adaptability	46	Average	46	Average
Social Skills	50	Average	59	Average
Leadership	68	High	66	High
Activities of Daily Living	57	Average	57	Average
Functional	64	High	68	High
Communication				

Chelsea Brown. Chelsea's initial TOT T-score was 72; this suggests that she had a very strong self-esteem but that she may have also exaggerated it in the positive direction. This was consistent with all her domain scores as they were all in the Above range (See Table 18). According to the Piers-Harris manual, an Above average BEH score suggests that the individual is trying to hide certain behavioral difficulties and according to her BASC, Chelsea is At-Risk for externalizing behaviors including hyperactivity, aggression, and conduct problems (See Table 19). In addition, an above average FRE score implies that Chelsea was in denial that she was bothered by certain unpleasant moods such as sadness and worry. This score was consistent between Time 1 and Time 2. During her pre-group session interview, when asked questions about her brother, Chelsea seemed to become a bit protective and seemed to try to hide negative

feelings she had towards her brother or the fact that he has autism. For example, when asked what it was like living with her brother she said:

I like living with him. I like everything about him its just that he doesn't talk and I want him to say my name, but no I'm perfectly fine.

Typically when asked this question, previous participants would describe both positive and negative things about living with their sibling, as would typical developing sibling dyads. Yet, Chelsea immediately said that she liked everything and that she was perfectly fine. Perhaps since she was in the control group sessions, Chelsea was not given the opportunity to discuss her feelings and as a result her T-score in Time 2 remained the same.

 Table 18

 Chelsea Brown's Piers-Harris T-Scores For Time 1 and Time 2 and Their Interpretive Labels

Domain Scales	Time 1	Time 2	Interpretive Label
Behavioral Adjustment (BEH)	62	54	Above Average to
			Average
Intellectual and School Status (INT)	65	65	Above Average
Physical Appearance and Attributes	58	58	Above Average
(PHY)			
Freedom from Anxiety (FRE)	65	65	Above Average
Popularity (POP)	68	60	Above Average
Happiness and Satisfaction (HAP)	59	59	Above Average
Total (TOT)	72	66	Very High to High

There was another discrepancy between Chelsea's INT T-score and her mother's BASC T-score for Attention Problems and Hyperactivity. According to Chelsea, her Above Average INT T-score indicated that she was confident in her intellectual abilities. It also suggested that she was well behaved and was able to pay attention in class. Chelsea may have felt that she was able to complete academic tasks, however according to Mrs. Brown, Chelsea's T-score for Attention Problems during Time 1 was considered to be Clinically Significant which suggested a high level of maladjustment and in Time 2 was in the At-Risk clinical scale. Her Hyperactivity T-score remained in the At-Risk clinical scale; therefore Chelsea appears to have attention difficulties that need to be monitored. According to Mrs. Brown's interview, she said the Chelsea does not

always pay attention, was easily distracted, and wanted her to learn to focus more in school as she was having difficulty. In addition, she hired a tutor to help Chelsea with her homework and that her main issue was that it was difficult for her to concentrate and focus. Therefore Chelsea's INT T-score was inconsistent with her mother's perception of her attention and academic abilities. Mrs. Brown had tried to address her attention issues by providing the tutor and removed some of the extra curricular activities that were distracting her from her schoolwork. During the control group sessions, Chelsea seemed to focus for the most part, but she sometimes doodled on her scrapbook while someone else was talking. Her mother also said that Chelsea did not always listen to instructions when she would tell Chelsea to let her brother to do tasks independently in order to build his autonomy. Chelsea would ignore her mother's request and helped her brother, which had she been in the experimental group sessions, she would have had the opportunity to discuss strategies and learn the tools to differentiate between helping her brother and impeding his autonomy. In general, since there was no significant improvement in the Piers-Harris or BASC, it seems as though her external behaviors are a cause for concern and if not addressed perhaps could lead to other issues. In addition, Chelsea seemed to need a safe environment where she could to express any negative feelings, as she tends to conceal them at this time.

**Table 19**Chelsea Brown's BASC Clinical Scale T-Scores For Time 1 and Time 2

Composite	Time 1	Clinical Scales	Time 2	Clinical Scales
Externalizing Problems	64	At-Risk	61	At-Risk
Internalizing Problems	39	Low	33	Low
Behavioral Symptoms Index	54	Average	53	Average
Adaptive Skills	57	Average	59	Average

 Table 20

 Chelsea Brown's BASC Clinical and Adaptive Scale T-Scores For Time 1 and Time 2

Scale	Time 1	Clinical Scales	Time 2	Clinical Scales
Hyperactivity	67	At-Risk	61	At-Risk
Aggression	55	Average	60	At-Risk
Conduct Problems	65	At-Risk	59	Average
Anxiety	45	Average	37	Low
Depression	43	Average	37	Low
Somatization	36	Low	36	Low
Atypicality	46	Average	54	Average
Withdrawal	35	Low	35	Low
Attention Problems	74	Clinically Sig.	67	At-Risk

Scale	Time 1	Adaptive Scale	Time 2	Adaptive Scale
Adaptability	62	High	62	High
Social Skills	56	Average	65	High
Leadership	57	Average	55	Average
Activities of Daily Living	55	Average	62	High
Functional	49	Average	45	Average
Communication				

Parents' perceptions. An important theme of the experimental support group sessions was how the parents perceived the relationship between siblings and their perception of their relationship with their child. The level of parental involvement was shown to influence how the TD children engaged with their siblings and the relationship between the TD child and his or her parents. For the control group sessions, the purpose of the parental involvement was the attention that they gave their children on the last day of the group. On the last day, the parents were invited to attend the group to watch their children perform a talent show, but none of the weekly topics nor conversations about their sibling with autism were discussed.

*Gary Adams.* According to Mrs. Adams, Gary and his brother John have a lot in common, including climbing, making up plays, and hip hop dance routines. They also enjoy a lot of rough

play and are both physically strong, as such, they engage with each other quite often. They are also very competitive, but Mrs. Adams believes this leads to them fighting a lot. John could tolerate a little competition but was unable to realize when to stop, while Gary would stop and wanted to move on, but John would try to push him to continue. Another issue arose when Gary would have a friend over and he got frustrated if John acted inappropriately in the game they were playing. Therefore, it appears as though Gary and John have a good relationship, but that when they fought or Gary became frustrated with John, Gary did not seem to have the appropriate tools to express his feelings to his brother.

During the post-interview, Mrs. Adams reiterated what she had said in her initial interview that Gary and John got along, but they sometimes fought, especially because Gary did not always give into John demands. There was also no change in Gary's pre- and post-interviews as he said his brother would still use his things without permission and that John would frequently isolate himself. According to both Mrs. Adams' and Gary's interviews, there had been no change to the relationship between Gary and John and as such, this may imply that the parental involvement in the group did not change anything about their relationship. In addition, Gary's mother also did not express any changes to their relationship after the control group sessions. She stated that she felt close to Gary and would engage in conversations with him about any issues he had, including his anxiety about starting grade 3. It also appears that the control group sessions did not change between the relationship between Gary and his mother.

Candice Brown. Mrs. Brown felt that she had a very open relationship with all of her children and that no subject is off limits. During Candice's interview, she continually said that the only thing she would change was her desire that her brother would talk. Mrs. Brown also said the same thing in her interview so it appears that Candice internalized her mother's explanation and she repeated what her mother told her about her brother. Therefore, it seems as though this may have contributed to her At-Risk externalizing behaviors, as Candice may not have been expressing her true feelings. During the post-group interview, Mrs. Brown changed her perception of their relationship as she stated that she was not very close to Candice and their relationship had been strained and there was more tension since the birth of Carter. She also stated that Candice was close to her father and that their relationship is more "business" than a mother-daughter relationship. Therefore, it seems as though her mother expressed that her relationship with her daughter was more strained since the initial interview.

In addition, there appears to be little change in the relationship between Candice and Carter. In her initial interview, Mrs. Brown said that they enjoyed a lot of rough and tumble play, such as wrestling. She also said that Candice is starting to understand his needs and that Carter would attempt to engage with Candice; for example when he would take her hand to get a glass of milk. In the post-group interview, she said that Candice was a bit bossy with Carter and as a result they tended to be frequently at odds with each other. However as in the pre-interview, she was slowly starting to respect his boundaries and she helped him. Therefore, it seems the group sessions had not given her new strategies to use with Carter.

Chelsea Brown. As with the other 2 participants of the control group sessions, Chelsea's relationship with her mother and her brother Carter had not changed between Time 1 and Time 2. According to Mrs. Brown, she viewed the relationship between Chelsea and Carter as more of a mother/son relationship than a sister/brother relationship and that she tended to take care of him often, which was consistent with her protective statements towards her brother. Since there is a 10-year age gap between them, it seems as though this contributed to the dynamics of their relationship to be more of a caregiver/son relationship. In addition, Mrs. Brown also said that Chelsea tends to do too much for Carter and does not give him opportunities to do things independently. This did not change significantly after the control group sessions although Chelsea seemed to be aware of it.

As for the relationship between Chelsea and her mother, Mrs. Brown stated that Chelsea tended to listen to her more than her father and that they have an open honest relationship. This also did not change between Time 1 and Time 2; therefore the control group sessions did not focus on developing strategies to improve her relationship with her mother.

### Discussion

In general, the purpose of this study was to explore how children experienced a sibling support group for siblings of children with autism and how this group promotes their understanding and responding to their sibling with autism. More specifically, this study attempted to provide TD siblings with an opportunity to voice their perspectives and needs. Lastly, these sessions were designed to empower TD siblings by giving them concrete knowledge about autism in order to recognize their sibling's abilities and limitations and possibly, to help them develop stronger and more understanding relationships within their family.

# **Relationship Between Siblings**

In order to gain an understanding of the relationship between TD children and their sibling with autism, this study elicited the perceptions and experiences of TD children and one of their parents. In general, TD children from the experimental group showed that after acquiring knowledge about autism, learning ways in which to engage with their sibling, and an open environment in which to discuss their feelings, that there appeared to be improvements in the relationship between siblings. Parents also felt that after the SSIP, their children would openly speak about what they had learned in the sessions and most parents' perceptions were that there was an improvement in the interactions between their children.

According to Seligman (1983) TD siblings who received a limited amount of information or who are not aware of the diagnosis of their sibling tended to have difficulty interacting with this sibling and understanding their needs. In the pre-group interview and during the group, the TD children expressed their difficulties engaging with their sibling with autism especially when their sibling would ignore them or would expect the TD child to only do the activities that they wanted to do.

Previous research has shown that the use of the illusion activity and role-playing were helpful in providing children with a better understand of the disability and to elicit empathy towards their sibling's difficulties (McCullough & Simon, 2011; Dyson, 1998). Therefore in providing the TD children with an opportunity to discuss their understanding of autism and to engage in role-playing, illusion activities, feeling charts, and trouble shooting techniques throughout the SSIP, it was perceived by participants to improve the interaction between siblings. In particular, Rebecca Johnson had stated after the support group sessions, that she was able to explain to her friends about her brother's diagnosis. It seems that TD siblings also tended to adjust better if they were more knowledgeable and understood the disability (Ross & Cuskelly; 2006). Kaminsky and Dewey (2011) stated that children tend to feel uncomfortable discussing the disability with their parents and may refrain from seeking information from parents. This was consistent with parent perceptions in the pre-group session interviews where all the parents stated that they felt their TD child did not have a good understanding of the diagnosis and that the diagnosis was not discussed often. However, after the group the parents perceived that their child would approach them to discuss the topic and that their TD child had attained a better understanding of autism.

The SSIP also provided an environment for TD siblings to develop better ways in which to communicate their needs and wants to their sibling with autism. Moyson and Roeyers' (2011) qualitative study showed the importance of communication and understanding had on the interactions between siblings. Children with autism have the tendency to fixate on specific topics and have difficulty comprehending emotions; in addition, TD siblings have a tendency to develop some resentment if they were obligated to always play the activities of their sibling with autism (Moyson & Roeyers, 2006). This was a recurring issue that was discussed in the SSIP and during the trouble shooting techniques. As a result, each TD child was provided with strategies to help engage their sibling with autism when such events occurred and they were also taught different games to play with their sibling. The TD children were also taught a relaxation technique to use as a coping strategy during stressful family situations (Evans et al., 2001). During his post-interview, Roger openly expressed the use of techniques with his brother during his post-group sessions interview. His mother also noticed a difference in their interactions, as Roger had become more patient with his brother and would remove himself from situations that had the tendency to escalate.

The qualitative analysis that focused on children's self-esteem and self-concept (Piers-Harris 2; Piers & Herzberg, 2002) of the TD children showed that two out of the three children of the experimental group who had an average self-concept showed a slight improvement between Time 1 and Time 2. This measure was intended to assess children's perceptions of their selfconcept based on six domains, including Behavioral Adjustment, Freedom from Anxiety, and Happiness and Satisfaction. Levy et al. (2010) found that TD siblings might show feelings of depression, loneliness, and difficulty interacting with peers, which could further affect their selfesteem. Unfortunately, this was the case for Sean Williams whose Piers-Harris score was in the low range. His ratings of his self-concept showed improvements after the group but still remained low, which indicated that with such a low score for self-esteem, he was At-Risk for internalizing and externalizing behaviors. This was consistent with the BASC completed by his mother in which he was in fact at risk for both internalizing and externalizing behaviors. In addition, Petalas et al. (2004) had shown that younger TD siblings have more emotional adjustment problems than older siblings. Both Sean and Roger were younger siblings while Rebecca was an older sibling. Sean showed obvious emotional adjustment problems while Roger's difficulties were not that obvious. Roger's above average Behavioral Adjustment (BEH) score indicated that he may have

been hiding or unaware of his negative feelings. According to Evans et al. (2001) socializing with other children in similar family situations with a child with ASD, allowed the TD children to create a positive atmosphere to discuss their own feelings and address their own needs. As in previous studies, leisure activities such as games and free play also seemed to have helped children focus on themselves through interactions with other children as opposed to focusing on their sibling with autism (D'Arcy et al., 2005; Evans et al., 2001; Lobato & Kao, 2002, 2005; McCullough & Simon, 2011; Smith & Perry, 2004). The SSIP had attempted to create such environment for the TD children where they were able to openly discuss their feelings, which might have contributed to areas of improvement based on the Piers-Harris scores. Previous studies that evaluated sibling's self-esteem with the use of the Piers-Harris also showed an increase in their self-esteem from pre- to post-testing based on their interactions with other siblings and the attention that they received (Lobato & Kao, 2002, 2005; McLinden et al., 1991; Smith & Perry, 2004).

Self-reports and parent reports were a common measure used to determine the socio-emotional adjustment of TD siblings. The Behavioral Assessment Scale for Children (BASC; Reynolds & Kamphaus, 1988, 2004) was used to assess parents' perceptions of their TD children's emotional and behavioral functioning. In this study, the self-esteem of the children also seemed to be related to the emotional and behavioral assessment completed by the TD children's parents. However, previous research showed discrepancies between parent and child reports of the children's socio-emotional adjustments and those parents reported more negative outcomes (Macks & Reeve, 2006). This was not the case with the participants of the SSIP as the parents overall reports tended to be consistent with their TD children's Piers-Harris reports.

# **Experimental and Control Group Comparisons**

The majority of previous research did not implement control groups, therefore it was unclear as to whether the degree to what the children learned in the support groups could actually be attributed to the group itself or to outside influences (D'Arcy et al., 2005; Dyson, 1998; Evans et al., 2001; Lobato, 1985; Lobato & Kao, 2002, 2005; McCullough & Simon, 2011; Smith & Perry, 2004). Implementing a comparison group in this exploratory study, afforded the opportunity to describe changes that occurred in the experimental sessions that provided the children with social support and knowledge about ASD. The present study was comprised of both an experimental and control group, which explored and described the outcomes of the SSIP. Both

groups had three participants, therefore, with such a small sample statistical comparisons could not be carried out systematically. The experimental group consisted of two males, (aged 9 and 13) and one female (aged 9). Both males were the younger of two siblings, while the female was the eldest of three siblings. The control group consisted of two females (aged 7 and 13) and one male (aged 9). The 13-year-old female was the eldest of three while the other two children were the second oldest of three children.

The results of the study seemed to indicate that there were some improvements in the relationships of two out of the three participants of the experimental group. Both Rebecca and Roger had expressed improvements in their relationships with their sibling, as demonstrated by the increase in their thermometers activity. Rebecca was able to communicate with her peers about her brother and this was indicated in her post-interview group, while Roger described the strategies he used that he learned from the group to help during conflicts with his brother. Sean had appeared to suppress his negative feelings about his brother as a coping strategy and appeared to be very withdrawn during individual interview sessions. For that reason, it was unclear if there were any changes in his relationship with his brother. Yet, according to his mother's follow up interview, Sean was beginning to openly talk to her about his brother's diagnosis.

Based on a descriptive analysis of the control group data, there did not appear to be any apparent change in the relationships between the TD children and their sibling with autism. Gary continued to have the same difficulties and an inability to express his feelings effectively to his brother. Gary also stated in both his pre- and post-interviews that he wished his brother did not have a problem. This was consistent with previous literature; for example, Orfus and Howe (2008) confirmed that wishing that their sibling did not have a problem was the most common coping strategy amongst younger male siblings of a TD child who had a sibling with special needs. Candice and Chelsea continued to constantly reiterate how happy they were in their interactions with their brother and they expressed that they wanted their brother to communicate one day like everyone else. Orfus and Howe (2008) also found that trying to fix a problem was a common coping strategy amongst girls. It appears that in the absence of receiving the SSIP, the control group participants who were girls, seemed to have developed common coping strategies as an alternative to dealing with their difficulties interacting with their sibling with autism.

Based on the results of self-esteem questionnaires used in previous intervention studies, TD

children showed an increase in self-esteem from pre- to post-testing (D'Arcy et al., 2002; Evans et al., 2001; Lobato & Kao, 2002, 2005; McCullough & Simon, 2011; Smith & Perry, 2004). In particular, the Piers-Harris revealed children who maybe at risk of low self-concept in three sibling studies, including McLinden et al. (1991), which used a comparison group (D'Arcy et al., 2005; Smith & Perry, 2004). The present study also used the Piers-Harris to measure the selfconcept of the TD siblings in both the experimental and control groups. Roger and Rebecca in the experimental group had an increased overall self-concept score from Time 1 to Time 2, while Sean's score slightly decreased. This could be related to Roger's and Rebecca's perceived improvements in their relationship with their siblings, while Sean's relationship with his brother remained the same. The experimental group's BASC scores for internalizing and externalizing behaviors (BASC) all decreased between Time 1 and Time 2. It is interesting to note that despite Sean's scores decreasing, they still showed concerning results for behavioral problems, including withdrawal, which could explain his lack of willingness to openly discuss his relationship with his brother. Therefore, one of the positive outcomes of the SSIP may be that it exposed children who are at risk of behavioral issues to content that may contribute to providing additional emotional support for longer periods of time after the completion of the SSIP.

The control group also completed the Piers-Harris questionnaire. Both Gary and Candice's TOT scores increased from Time 1 to Time 2. Chelsea's had the highest TOT score of all the participants from both groups and although she slightly decreased from Time 1 to Time 2 she still had the highest self-concept TOT score. Gary's self-concept perceptions were also consistent with his mother's ratings of emotional and behavioral functioning showing a decrease in internalizing and externalizing behaviors between Time 1 and Time 2. Candice and Chelsea's Piers-Harris scores were inconsistent with their mother's BASC as both girls were deemed At-Risk for externalizing behaviors, which was consistent with the parent interviews. The internalizing and externalizing behaviors decreased for both Gary and Chelsea, but Candice's externalizing behaviors increased between Time 1 and Time 2. Consequently, there appears to be more consistent improvements between the participants' self-esteem and behaviors for the experimental group than for the control group. Since there was a small sample size, the overall results of the study cannot be interpreted statistically and are not generalizable, but are relevant for showing descriptive changes over time within each group.

### **Limitations and Future Directions**

Although this study has shown some benefits to sibling support groups and added to the paucity of research on support groups for siblings of children with autism and their experiences, certain methodological limitations need to be addressed.

The small sample size is one of the limitations of this study. Given that there were only six participants, three in the experimental group and three in the control group that were investigated, more sophisticated quantitative analysis could not be implemented, therefore, conclusions from this study cannot be generalized. Despite the fact that the results cannot be generalized to the public, this exploratory study did allow a thorough qualitative analysis of each of the participants. For the participant case studies, future investigations can focus on issues related to this unique family dynamics and particular areas of the SSIP that showed promising benefits to participants. Future sibling support groups can focus on a quantitative investigation model that can provide a clearer understanding of the interactions between TD children and their sibling with autism. This study revealed the following themes that were relevant to understanding the impact this sibling support group intervention had on TD children: knowledge of autism and its influence on sibling interactions, discussion of feelings and the impact on the TD children's self-esteem and behaviors, and parent's perceptions of their interactions with their TD children.

According to the study by Rawson (2009), once TD siblings have reached adulthood, their concerns for their siblings also begin to change. The TD siblings are no longer concerned about how to interact or cope with the outside world, but are now worried about where their sibling with a disability will live, how they will function once their parents have died, and their financial needs (Moyson & Roeyers, 2011; Rawson, 2009). Unfortunately TD children are limited in the support and resources they receive. Since their concerns and needs change as they get older, an aspect that may be deemed important to include is a follow-up to sibling support groups once the children have entered adolescence and then again when they are adults. Currently, the research focuses on support groups for children from 3- to 12-years-old. To date, either no follow up has been done or, only a maximum of a 3-month follow-up has been conducted for TD children (Lobato & Kao, 2002, 2005). More specifically, future investigations can attempt to investigate if long term periodic follow up support for TD siblings during adolescence and again in early adulthood could help TD children and what intervention tools are the most effective for different concerns, for what durations, and the procedures available once the concerns of TD siblings have

changed (D'Arcy et al., 2005). It will also be important to study the comparative experiences of TD children with siblings with autism who are non-verbal and those who are verbal in a more systematic way to uncover differences in the sibling interaction and the impact of the TD children's experiences within their families.

Another issue, which preceded the Sibling Support Intervention Program, was the number of weekly sessions. According to previous research, the general length of most groups was between six and eight weeks (Lobato, 1985, 2002; McLinden 1991; Dyson, 1998). The initial study was designed to be 12 weeks. However with the challenges of recruitment, a limited number of willing participants, and the group sessions being implemented during the summer, this resulted in the SSIP being reduced to six weeks. In addition, the time limitations of the SSIP did not allow for a further in-depth follow up of participants who were considered to be at risk for behavioral issues. Future investigations could attempt to increase the number of weekly sessions and in addition provide siblings and parents with information packs, a DVD on transitions, and a website with additional supports as well as follow-up sessions over a period of a few months to provide an opportunity for ongoing support and guidance (Rawson, 2009). Additionally, observations of sibling interactions before and after the SSIP may provide future investigators with an in-depth understanding of this type of dyad and longitudinal research could also provide more insight into the sibling experience.

The children in this study ages ranged from 7-years-old to 13-years-old. As a result of the challenges with recruitment, the age range of required participants was broadened in order to increase the likelihood of willing participants. Previous research suggested that the most difficult time of development is between middle and late childhood (i.e., 8 to 12-years-old), especially if the TD child is younger than their sibling with special needs (Orfus & Howe, 2008). For the present study, two of the three children in the experimental group were younger siblings (9 and 13, respectively) and one child from the control group was also a younger sibling (9 years old). According to Piaget's Cognitive Development theory, children in the SSIP were either in the concrete operations period (seven to 11) or formal operations period (11 to 15) (Piaget, 1971). Since majority of the children (4/6) were in the concrete operations stage, the TD children were more likely to be sensitive to issues about differential treatment and family rules. Therefore perhaps, the way in which they interpreted and understood information may have had an influence on their level of understanding of the information they received in the SSIP. Beyer

(2009) explained that there is a difference in the developmental stages of children and this may have obscured the effect of the sibling group for participants. In addition, one of the participants, Candice, is 7-years-old and the youngest child in the study. As such this posed additional limitations, as her level of social cognitive understanding and interaction with older siblings may have impacted her experience in the group. Since Candice has an older sibling (Chelsea) and participated in more leisure activities in the control group, her age did not appear to be a major issue. She engaged quite appropriately with Gary (9-years-old) as well as her sister. It is important to note that had Candice been considered for the experimental group, she would not have been included because of her age, the age of the other participants, and her limited ability to understand activities and information given in the SSIP.

## **Implications and Practical Applications**

Despite its limitations, this study has contributed to the growing research on sibling support groups for siblings of children with autism. Currently, there are limited research studies investigating support groups solely for siblings of children with autism (e.g., Smith & Perry, 2004). The majority of studies have investigated sibling support groups for children with a wide variety of developmental disabilities including autism, Down's syndrome, physical handicaps, and cerebral palsy (D'Arcy et al., 2005; Dyson, 1998; Evans et al., 2001; Lobato, 1985; Lobato & Kao, 2002, 2005; McCullough & Simon, 2011; McLinden et al., 1991). Therefore, this study represents one of the first to study sibling support groups for siblings of children with autism.

Meyer (1990) created the original intervention program for sibling support groups, and the results of this study corroborated with Meyer's Sibshop goals. To reiterate, this model emphasized the importance of providing information for siblings, as well as their family members, and increased peer support. The experiences of the children in this study demonstrated the importance of age-appropriate information about autism, opportunities to express and discuss positive and negative feelings, and parental involvement and perception of their family dynamics as significant aspects of the SSIP. Therefore these descriptive findings can be used to further respond to the needs of siblings with autism. Future research can investigate if the SSIP or at least the concept of providing knowledge and support to siblings can be used by general family support services to enhance sibling relationships and interactions.

In addition, this study highlights the challenges of this unique family type. Since autism is a spectrum of disorders, even in creating a sibling support group specifically for TD children with a

sibling with autism, the differences and challenges of each family are still quite distinctive. According to Beyer (2009) the effects of autism on sibling relationships can either be positive or negative and are determined by a variety of variables (the number of siblings in the family, birth order, gender, age, and socioeconomic status) related to their family environment. According to Bronfenbrenner's Ecological Theory, a child develops within a complex system of relationships affected by multiple levels of the surrounding environment (Bronfenbrenner, 2005). As such, various professionals, including social workers, psychologists, and clinicians who work with families with ASD need to understand and recognize this unique sibling relationship and provide support when necessary. In addition, based on Minuchin's (1985) family system's theory, the success of a family is based on the support that the entire family receives including the needs of the TD siblings.

Overall, this study illuminates the societal implications of an effective intervention and how it can help TD children understand the nature of their sibling's diagnosis, reflect on their family relationships, and develop strategies to develop and proactively participate within their family.

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Appendix A Supervisor Information Letter



To all EIBI supervisors,

As a current Master's student in the Department of Education at Concordia University, the final requirement of my degree is to complete a research thesis. I have chosen to conduct a **sibling support group for siblings of children with autism** under the direction of my faculty supervisor Dr. Harriet Petrakos (telephone; 514-848-2424, ext. 2013; email: <a href="https://hpetrakos@education.concordia.ca">hpetrakos@education.concordia.ca</a>).

In order to conduct my support group I would appreciate your assistance in the recruitment process. I am searching for typically developing siblings who would be willing to partake in a 6-week sibling support intervention program. The program will address various issues, concerns, as well as techniques and strategies to help these children in their interactions with their sibling with ASD. In this project, the typically developing siblings are required to be between the ages of **7 and 13 years** old.

Your help and guidance in finding families that would be willing to take part in this project would be greatly appreciated.

I have attached the parent information letter and parent consent form that will provide you with additional information about the research project. If you have any questions or concerns, please do not hesitate to contact me.

Thank you in advance,

Keisha Gafoor, M.A. Thesis Candidate (Child Studies) Department of Education Concordia University Email: keishagafoor85@gmail.com Telephone: (514) 946-7105 Appendix B
Parent Information Letter



Dear Parent(s)/Guardian(s),

I am a thesis candidate from the Department of Education at Concordia University. I am interested in developing a sibling support intervention program for siblings of children with Autism Spectrum Disorder (ASD). We are trying to understand the impact of children's behaviors and interactions with their parents and sibling with autism.

The research project will study siblings of children with autism in a 6-week intervention program that focuses on various topics pertaining to growing up with a sibling with ASD and provide opportunities to address various issues, concerns, as well as techniques and strategies. Each week on Saturdays for an hour and a half the children will partake in various activities that may help them develop a better understanding of their sibling and themselves.

When you consent to participate in this study, we will give you a questionnaire to answer questions about your child and complete an interview that will take approximately 1 hour. We will also have your child complete one questionnaire about themselves and complete an interview that will take approximately 20 to 30 minutes. The interviews will be audiotaped. Three weeks later your child will participate in the 6-week sibling support group that will be videotaped solely for the purpose of data collection at the West Montreal Readaptation Center at the Child and Family Services office in Beaconsfield, Quebec. There will be two groups of three children. Your child will be randomly placed in either the control group or experimental group. This is to provide the researcher with comparison data to see how effective the support group was. The control group will partake in various activities but none of which will include discussions about siblings or autism. After the completion of the two groups and the collection of data, the researcher will provide the control group with the most beneficial information obtained from the support group in Summer 2015. You will also be required to participate in the last two sessions of the group with your child. The interviews and questionnaire will be repeated three weeks after the sibling group.

All information in this study will remain confidential and your child's name will not be identified in any results that are summarized at the end of the study.

A benefit of this study may be that it will provide information on the perceptions and interactions between siblings and their parents. We cannot and do not guarantee or promise that you will receive benefits from this study. Our goal is to further enhance the understanding and relationships between a typically developing child with a sibling with autism.

We require that your typically developing child be between the **ages of 7 and 13 years old** and that your child with autism spectrum disorder. If your children meets this criteria and you are interested in participating in this study please read the attached consent form, sign, and return to your EIBI supervisor.

Thank you for your consideration. If you have any questions or concerns please feel free to contact me, Keisha Gafoor at <a href="keisha.gafoor@mail.mcgill.ca">keisha.gafoor@mail.mcgill.ca</a> or my thesis advisor Dr. Hariclia Petrakos (telephone: 848-2424, ext. 2013; email: hpetrakos@education.concordia.ca).

Sincerely,

Keisha Gafoor, M.A. Thesis Candidate (Child Study) Department of Education Concordia University

# Appendix C Parent Consent Form



# **CONSENT FORM TO PARTICIPATE IN RESEARCH**Siblings of Children with Autism: Sibling Support Intervention Program

This is to state that I agree to participate in a program of research being conducted by Keisha Gafoor (telephone: (514) 946-7105; email: keishagafoor85@gmail.com) of the Department of Education at Concordia University for a Master's degree under the direction of Dr. Harriet (Hariclia) Petrakos (telephone: (514) 848-2424, ext. 2013; email: hpetrakos@education.concordia.ca).

### A. PURPOSE

I have been informed that the goal of this research is to develop a sibling support group for siblings of children with autism. This information will add to the research of special needs. The goal is also to understand how children interact with their parents and siblings with autism.

### **B. PROCEDURES**

## I have been informed that the procedure is the following:

- I understand that my child and I will be asked to partake in the study from Summer 2014 to Fall 2014.
- I understand that after I sign the consent form, my child will be asked for his/her verbal assent.
- I understand that once we consent, we will have a meeting at my home with the researcher.
- I understand that at the meeting we will be asked to fill out questionnaires and participate in interviews.
- I understand that I will be asked questions about my child in the study and my child with autism. This meeting will take about 1 hour.
- I understand that my child will asked be about how they feel about themself and their sibling. The questionnaire and interview will take about 20 to 30 minutes.

I understand that both interviews will be audiotaped and that only the researcher and her teacher will listen to the interviews.

- \_ I understand that my child will be asked to participate in a sibling support group. I understand that the group will meet for two hours and a half for 6weeks. The group will meet at the West Montreal Readaptation Center at the Child and Family Services office in Beaconsfield, Quebec.
- I understand that a flip of a coin will be used and my child will be put in the control group or the experimental group. I understand that I will not know which group my child is in. The experimental group will participate in activities related to siblings and autism. The control group will participate in activities that are not about siblings or autism. I understand that if my child is

in the control group, that I will be contacted in Spring 2015. I will have the choice to have my child participate in a sibling support group in Summer 2015.

- I understand that the group meetings will be videotaped. Only the researcher and her teacher will watch the videotapes.
- I understand that after the group, my child and I will be asked to fill out a questionnaire and participate an interview.
- I understand that the interviews will be audiotaped again. I understand that the audiotapes, videotapes, and paper copies will be safely locked at Concordia University for 5 years and then destroyed after the end of the research.

### C. RISKS AND BENEFITS

- I understand that the researcher does not promise that my child or I will benefit from the study. A benefit may be to understand the child's point of view and how they interact with their siblings.
- I understand that my participation in the research will require a significant amount of my time, although every effort will be made to make it convenient for me.

### D. CONDITIONS OF PARTICIPATION

- I understand that I am free to withdraw my consent and discontinue my participation at anytime without negative consequences.
- I understand that my participation in this study is CONFIDENTIAL (i.e., the researcher will know, but will not disclose my identity). We will only share information with the parent if we suspect the child needs attention.
- I understand that the data from this study may be published, but only group findings will be reported. No identifying information will be included in publications.

I HAVE CAREFULLY STUDIED THE ABOVE AND UNDERSTAND THIS AGREEN FREELY CONSENT AND VOLUNTARILY AGREE TO PARTICIPATE IN THIS STU	
NAME (please print)	-
SIGNATURE	-
CHILD'S NAME	
HOME TELEPHONE NUMBER	
OTHER TELEPHONE NUMBER	

If at any time you have questions about your rights as a research participant, please contact: Adela Reid, Research Ethics and Compliance Officer, Concordia University, at (514) 848-2424 ext. 7481 or by email at <a href="mailto:AdelaReid@Concordia.ca">AdelaReid@Concordia.ca</a>.

Karoline Girard, Ethics Research Committee of the WMRC at 819-376-3984, ext. 347 or by email at: karoline girard csdi@ssss.gouv.qc.ca.

Stuart Rechnitzer, Ombudsman for West Montreal Readaptation Centre (WMRC), at 514 363-3025, ext. 2203 or by email at srechnitzer.crom@ssss.gouv.qc.ca.

# Appendix D Child's Verbal Assent Form (seven to 13-years-old)

THE CHILD WILL BE ASKED FOR VERBAL ASSENT AT THE BEGINNING OF EACH SESSION AND THE RESEARCHER WILL DOCUMENT THE DAY AND TIME OF THE CONSENT.

Hi (child's name). My name is Keisha Gafoor. Your mom or dad told me it was okay for you to do some activities with me. At first, I will ask you some questions. If you get tired you can take a break. You may decide to stop at any time. You do not have to answer any questions that you do

not want to. Everything that you say will be kept private. I will have to tell an adult if I think you are not safe though.

Every Saturday/Sunday, your mom or dad will drop you off to meet with me and five other children. We will do different activities. If you do not like any of the activities you can tell me you want to stop. No one will be mad, we will just be happy that you came to the group.

Today we will be
(Explain activity, i.e. Board Games, Show and Tell, Activities in a Scrapbook, All About Me Activity).
Is that ok with you?
DATE: TIME:

# Appendix E Parent Interview Questions (Pre and Post)

- 1. (Control & Experimental) How old are your children?
- 2. (Control & Experimental) When did you first notice a difference in your child (with ASD)?
- 3. (Control & Experimental) Can you tell me a little about your child (with ASD)? When was he/she diagnosed?

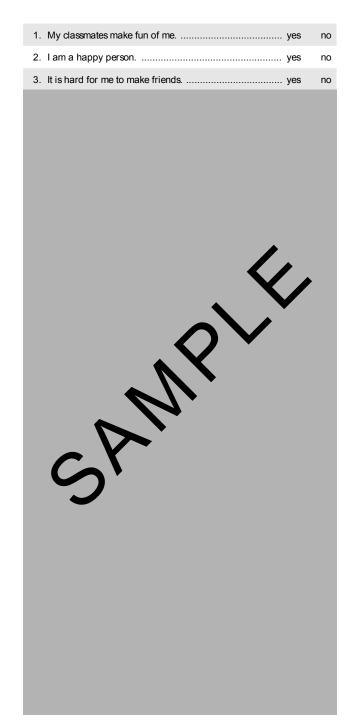
- 4. (Experimental) How did your other child/children react to the diagnosis? When do you think they noticed there was a difference?
- 5. (Experimental) How does your child understand the diagnosis? How is it discussed at home? Is the word "Autism" mentioned?
- 6. (Control & Experimental) Can you tell me a little about your relationship with your other child/children?
- 7. (Control & Experimental) Can you tell me about the relationship between your two children? How do they get along?
- 8. (Experimental) Do you have any concerns or issues about your child with ASD? Your other child? How do you handle these concerns or issues?
- 9. (PRE-TEST only) (Experimental) What are some concern or issues that you would like to be addressed during the group?
- 10. (Experimental) Has your child even participated in another sibling group?
- 11. (POST-TEST only) (Control & Experimental) Did your child talk about the group?

# Appendix F Child Interview Questions (Pre and Post)

- 1. (Control & Experimental) What do you think it means to have autism? (Faye, 2008)
- 2. (Experimental) Does your sibling have autism? (if yes) How do you know? (Faye, 2008)
- 3. (Control & Experimental) Can you tell me when you first realized/felt/saw that your brother/sister was different? (Moyson & Roeyers, 2011) How did it make you feel?

- 4. (Experimental) What have your parents told you about autism? (Faye, 2008)
- 5. (Experimental & Control) Can you tell me about what it is like to live with your sibling?
- 6. (Control & Experimental) Do you still get to partake in the same activities that you did before you found out that your sibling was different? (if no) How does that make you feel?
- 7. (Control & Experimental) Can you draw a thermometer measuring how you feel as a sibling? If you had a magic wand, what would you change so that the thermometer would rise? (Moyson & Roeyers, 2011)
- 8. (Control & Experimental) What is it like growing up with your sibling (with ASD) (Adapted from Orfus, 2005)?
- 9. (Control & Experimental) What do you like to do with your sibling (with ASD)? (Adapted from Orfus, 2005)
- 10. (Control & Experiemental) What do you dislike about your sibling (with ASD)? (Adapted from Ofus, 2005)
- 11. (Experimental) Do you talk to your friends, parents, and others about your sibling's differences? Why or why not? (Adapted from Faye, 2008)
- 12. (Control & Experimental) What would you say if someone asked you how it feels to be a sibling? (Moyson & Roeyers, 2011)
- 13. (PRE-TEST only) (Experimental) What would you like to talk about during the future group meetings?
- 14. (POST-TEST only) (Control & Experimental) What was your experience like in the group?

Appendix G Sample of Piers-Harris Questionnaire



# The Way I Feel About Myself PIERS-HARRIS 2

AutoScore<sup>™</sup> Form

by Ellen V Flers, Ph.D., Dale B Harris, Ph.D., & David S Herzberg Ph.D

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Client's Name (or ID #):						
Today's Date:					Age:	
loday 5 Date.					. 7.80	 
Gender: (circle or	ie)	Female		Male	Grade:	 
School:						 
Teacher's Name	(opti	onal):				
Race/Ethnicity:		Asian		Hispanic		White
		Black		Native Am	erican	Other

#### **Directions**

Here are some sentences that tell how some people feel about themselves. Read each sentence and decide whether it tells the way you feel about yourself. If it is *true* or *mostly true* for you, circle the word *yes* next to the statement. If it is *false* or *mostly false* for you, circle the word *no*. Answer every question, even if some are hard to decide. Do not circle both *yes* and *no* for the same sentence. If you want to change your answer, cross it out with an X and circle your new answer.

Remember that there are no right or wrong answers. Only you can tell us how you feel about yourself, so we hope you will mark each sentence the way you really feel inside.

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2345678

# Sample Questions

1.	My classmates make fun of me	yes no
2.	I am a happy person	yes no
3.	It is hard for me to make friends	yes no
4.	I am often sad	yes no
5.	I am smart	
6.	I am shy	yes no
7.	I get nervous when the teacher calls on me	
8.	My looks bother me	
9.	I am a leader in games and sports	yes no
10.	I get worried when we have tests in school	yes no
11.	. I am popular	yes no
12.	. I am well behaved in school	yes no
13.	It is usually my fault when something goes wrong	yes no
14.	I cause trouble for my family	yes no
15.	. I am strong	yes no
16.	. I am an important member of my family	yes no
17.	I give up easily	yes no
18.	. I am good in my schoolwork	yes no
	I do many bad things	
	I behave badly at home	

Appendix H
Sample of Behavioral Assessment System for Children
(www.pearsonassessments.com/NR/.../0/basc2assistplusigindivrpt.pdf)

# Parent Rating Scales Report Behavior Assessment System for Children, Second Edition

Cecil R. Reynolds Randy W. Kamphaus

#### Child Information

ID: 123-45-6789 Name: SAMPLE, TIMMY Sex: MALE

Birth Date: 03/01/1996 Child Age: 8:7 Child Grade: 3

School: SAMPLE SCHOOL

Other Data:

#### Test Information

Test Date: 10/30/2004 Rater: MR SAMPLE Sex: MALE Relationship: FATHER

Norm Group 1: General - Combined Sex

Results contained herein are confidential, and should only be viewed by those with proper authorization.

The Behavior Assessment System for Children, Second Edition (BASC-2) is an integrated system designed to facilitate the differential diagnosis and classification of a variety of emotional and behavioral disorders of children and to aid in the design of treatment plans. This computer-generated report should not be the sole basis for making important diagnostic or treatment decisions.

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Report printed for: AGS INTERNAL USERS

Report Date: 03/25/2005 Page 1 of 18

SAMPLE, TIMMY Test Date: 10/30/2004

## Items by Scale

Withdrawal		Adaptability	
Item	Response	Item	Response
16. Makes friends easily.		Shares toys or possessions with other	Sometimes
21. Refuses to join group activities.	Never		
25. Will change direction to avoid having to greet someone.	Sometimes	<ul><li>14. Recovers quickly after a setback.</li><li>33. Is easily soothed when angry.</li></ul>	Sometimes Sometimes
48. Avoids competing with other children.	Sometimes	46. Adjusts well to changes in routine.	Often
53. Is chosen last by other children for games.	Never	65. Adjusts well to new teachers.	Often
57. Is shy with other children.	Sometimes	78. Adjusts well to changes in family plans.	Often
80. Quickly joins group activities.	Sometimes	110. Is a 'good sport.'	Almost always
89. Shows fear of strangers.	Sometimes	142. Is stubborn.	Sometimes
112. Avoids other children.	Never	Functional Communication	
121. Has trouble making new friends.	Never		Response
144. Prefers to be alone.	Sometimes	34. Provides own telephone number when	Almost always
153. Is shy with adults.	Often	asked.	
Adaptive Scales		66. Speaks in short phrases that are hard to understand.	Sometimes
Activities of Daily Living		76. Answers telephone properly.	Often
Item	Response	81. Is unclear when presenting ideas.	Never
3. Has trouble following regular routines.	Sometimes	98. Has difficulty explaining rules of games to	Never
35. Acts in a safe manner.	Often	others.	
39. Organizes chores or other tasks well.	Almost always	108. Is able to describe feelings accurately.	Sometimes
67. Sets realistic goals.	Often	113. Tracks down information when needed.	Often
71. Volunteers to help clean up around the house.	Sometimes	122. Responds appropriately when asked a question.	Almost always
99. Attends to issues of personal safety.	Almost always	130. Is clear when telling about personal experiences.	Almost always
103. Has trouble fastening buttons on clothing.	Never	140. Accurately takes down messages.	Sometimes
131. Needs to be reminded to brush teeth.	Sometimes	145. Has trouble getting information when needed.	Sometimes

SAMPLE, TIMMY Test Date: 10/30/2004

#### Items by Scale

154. Communicates clearly.

Often Content Scales

Leadership		Anger Control	
Item	Response	Item	Response
Gives good suggestions for solving problems.	Never	1. Shares toys or possessions with other children.	Sometimes
19. Joins clubs or social groups.	Sometimes	6. Cannot wait to take turn.	Almost always
36. Is a 'self-starter.'	Often	9. Has a short attention span.	Sometimes
51. Is good at getting people to work together.	Almost always	26. Hits other children.	Never
68. Is creative.	Sometimes	56. Argues when denied own way.	Often
83. Is usually chosen as a leader.	Almost always	58. Threatens to hurt others.	Never
100. Will speak up if the situation calls for it.	Sometimes	65. Adjusts well to new teachers.	Often
132. Makes decisions easily.	Often	92. Says, 'I want to die' or 'I wish I were dead.'	Sometimes
Social Skills		142. Is stubborn.	Sometimes
Item	Response		
31. Congratulates others when good things happen to them.	Often		
63. Encourages others to do their best.	Often		
85. Offers help to other children.	Sometimes		
95. Compliments others.	Often		

Sometimes

Sometimes Often

Sometimes

117. Tries to bring out the best in other

127. Volunteers to help with things.

149. Shows interest in others' ideas.159. Says, 'please' and 'thank you.'

people.

Appendix I Questions for Scrapbook

- 1. Can you draw a picture about today's session? (Take notes on what the child says about their drawing)
- 2. Can you tell me about your picture/poem/short story? (What should I write on your picture)
- 3. Why did you decide to write/draw this?

Appendix J Experiment Group Activities

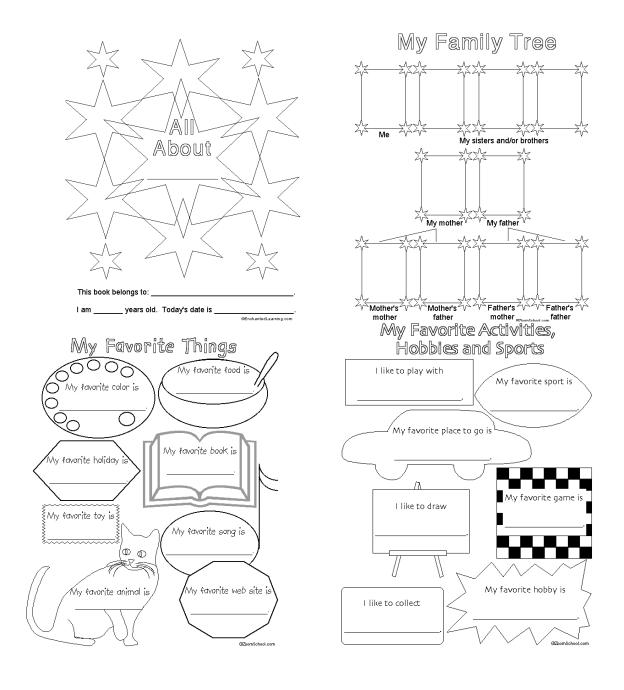
Week	Session	Topic/Content	Data Collection (Child)	Data Collection (Parent)
N/A	Pre-test	N/A	<ul><li>Interview (Appendix F)</li><li>Piers-Harris Children's Self Concept Scale</li></ul>	<ul> <li>Interview (Appendix E)</li> <li>Behavioural Assessment         Scale for Children –         Parent Form (BASC)     </li> </ul>
1	1	Introduction – learn about each other	<ul><li>Completion of All About Me Booklet</li><li>Presentation of Booklet</li></ul>	N/A
1	2	Knowledge	<ul><li> What is Autism?</li><li> Group discussion</li><li> Journal entry in scrapbooks</li></ul>	N/A
2	3	Knowledge	<ul><li>Review of previous week</li><li>Illusion Activity</li><li>Group Discussion</li><li>Journal entry in scrapbook</li></ul>	N/A
2	4	Self-esteem/self- concept	<ul><li>Feeling Chart</li><li>Discussion of Chart &amp; drawing</li><li>Show and Tell</li></ul>	N/A
3	5	Self-esteem/ self- concept	<ul><li>Write story/poem in scrapbook</li><li>Present story/poem</li><li>Outdoor group games</li></ul>	N/A
3	6	Communication with Sibling with ASD	<ul> <li>Arts &amp;Crafts (hand puppets)</li> <li>Role-playing with puppets</li> <li>Discussion/suggestions about role-playing</li> </ul>	N/A
4	7	Communication with Sibling with ASD	<ul><li> Games to play with Sibling</li><li> Journal entry in scrapbook</li></ul>	N/A
4	8	Coping Strategies	<ul> <li>Discussions of concerns/difficulties with sibling</li> </ul>	N/A

			<ul> <li>Write down difficult situation (for session nine)</li> </ul>	
5	9	Coping Strategies	<ul> <li>Dear Aunt Blabby (topics from session eight)</li> <li>Relaxation technique</li> <li>Prepare poem/short story/drawing for session 11</li> </ul>	N/A
5	10	Trouble Shooting Techniques	<ul> <li>Provided with individualized trouble shooting techniques</li> <li>Completion of evaluation questionnaire (Appendix Q)</li> </ul>	N/A
6	11	Parent/Child Session	<ul> <li>Presentation from an adult sibling and question period</li> </ul>	• Issues from the interviews with the parents and how to address
6	12	Parent/Child Session	<ul> <li>Presentation of poems/short stories from scrapbook presented to parents</li> <li>Graduation ceremony</li> </ul>	N/A
	Post-test	N/A	<ul><li>Interview (Appendix F)</li><li>Piers-Harris Children's Self Concept Scale</li></ul>	<ul> <li>Interview (Appendix E)</li> <li>Behavioural Assessment Scale for Children – Parent Form (BASC)</li> </ul>

Appendix K Session one: Introduction <u>Objective</u>: To help the TD siblings to learn about each other and become comfortable with each other during subsequent interactions.

9 a.m. to 9:30 a.m. – Each child completed an All About Me booklet, which is a combination of worksheets for the children to fill out about their favorite things, their family, and friends. (<a href="https://www.enchantedlearning.com/crafts/books/allaboutme">www.enchantedlearning.com/crafts/books/allaboutme</a>, 2010).

#### 9:30 a.m. – 10 a.m. Presentation of All About Me booklets to the group



Appendix L Session two and three: Knowledge <u>Objective</u>: To provide TD siblings with age-appropriate knowledge that will help them to better understand their siblings with ASD and be able to explain to others about the siblings disorder.

Session Two:

10: a.m. – 10:20 a.m. – Snack

10:20 a.m. – 11:15 a.m. – What is Autism? and group discussion – The children will be asked what they think autism is and answers will be written on a large piece of paper. Afterwards information explaining the three main components of autism and how they relate to some of the answers the children gave. Examples and metaphors explaining the challenges that children with autism face will also be given. The children will be asked to give their input in how they are different from their sibling with ASD at school, home, play, and the future (D'Arcy et al., 2005; Smith & Perry, 2004).

11:15 a.m. – 11:30 a.m. – Children asked to write in their scrapbooks about what they learned today that they never knew before about autism

#### Session Three:

9:00 a.m.-10 a.m.— Illusion Activity - Give the siblings the illusion that they have
Autism so they can get a glimpse of what their siblings experiences
and hopefully adjust their reactions and expectations based on a better
understanding of their sibling. Some of the activities include the
following; (a) hidden-picture searchers during sensory challenging
scenarios including flashing light or loud banging noises, (b) a list of
10 words that require the child to answer complex questions using
only these words, (c) problem solving and team work without using
expressive language (McCullough & Simon, 2011).

10 a.m. – 10:20 a.m. – Group Discussion about Illusion activity

Appendix M Session four and five: Self-esteem/Self concept

<u>Objective</u>: To maintain focus on the TD siblings with hopes of helping to positively influence their self-concept and self-esteem.

Session four:

10:20 a.m. – 10:50 a.m. – Feeling Chart – Write about the positive and negative feelings they have towards their sibling and parents. (Before any negative feelings arise, the children will be told that it is okay if they will not be judged and that it is okay to discuss what they do not like. The children are also be given the option to choose to provide information anonymously, however if heinous information is found the appropriate authorities will be contacted) (Evans et al., 2001)

10:50 a.m. – 11:15 a.m. – Discussion of Feelings Chart and scrapbook

11:15 a.m. – 11:30 a.m. – Show and Tell about their best talents

Session five:

9 a.m. – 9:15 a.m. - Free Play

9:15 a.m. – 9:30 a.m. – Write a story or poem about himself or herself or about things they like in their scrapbook

9:30 a.m. – 9:45 a.m. – Presentation of story or poem to group

9:45 a.m. – 10:15 a.m. - Outdoors group games – tag, hide and go seek (maintain focus on the TD children and not their siblings – to help increase their self-esteem) (McCullough & Smith, 2011)

Appendix N
Session six and seven: Communication with Sibling with ASD

<u>Objective</u>: The main goal is to provide some tools and suggestions/techniques that will hopefully improve their communication and interactions with their siblings in a positive manner.

#### Session six:

10:15 a.m. – 10:30 a.m. – Art and Craft – hand puppets of themselves and their sibling (Lobato, 1985)

10:30 a.m. – 11 a.m. - Role-playing activity with hand puppets (pick a past experience to act out)

11 a.m. – 11:30 a.m. – Discussion of role-playing and suggestions from others about alternative ways in which to solve the issues at hand

#### Session seven:

9 a.m. – 9:15 a.m. – Free Play

9:15 a.m. – 10 a.m. – Learn games they could play with their siblings (This will depend of the level of functioning of the children with ASD as determined in the interview with the parents) (Evans et al., 2001)

Appendix O Session eight and nine: Coping Strategies <u>Objective</u>: To provide the TD siblings with way in which to deal with their siblings challenging behaviors as well as relaxation techniques to help them to adjust better to their family dynamics.

## Session eight:

- 10:00 a.m. 11:00 a.m. Discussion of concerns and/or difficulties they may have with their siblings (discussion of feelings and attitudes related to living with their sibling)
- 11:00 a.m. 11:15 a.m. Activity write down a difficult situation they have had or continue to have with their sibling or parents (will be exchanged in Session nine so a peer may provide a solution)
- 11:15 a.m. -11: 30 a.m. Write in their scrapbooks

#### Session nine:

9 a.m. – 9:15 a.m. – Free Play

- 9:15 a.m. 9:45 a.m. Dear Aunt Blabby was created by Meyer and Vadasy (1985) in which the children will be required to answer letters written by other siblings by offering advice to Aunt Blabby and how she could help these children. The siblings will be required to provide solutions to peers' difficult situations from session eight (Dyson, 1998; McLinden et al., 1991).
- 9:45 a.m. 10:15 a.m. Coping strategy technique the children will learn a relaxation breathing exercise to help them relax and also be able to show their sibling with ASD the technique (Evans et al., 2001).
- 10:15 a.m. 11:30 a.m. Prepare a poem, short story, drawing etc. on posters of what they would like to share with their parents during Session 11 about what they have learned and what they want their parents to know about what may bother them.

Appendix P Session 10: Trouble Shooting Techniques <u>Objective:</u> To provide the TD siblings with an opportunity to discuss topics and issues they may have with the siblings with autism that had either not been brought up throughout the intervention or were discussed during their pre-group interviews.

#### Session 10:

10:15 a.m. – 11:30 a.m. – Each child has a one-on-one discussion about their relationship with their sibling with autism and were provided with strategies to help them to overcome those obstacles. At the end, each child completed the Intervention Evaluation questionnaire (Dyson, 1998). (See Appendix Q)

Appendix Q SSIP Evaluation Questionnaire (Adapted from Dyson, 1998)

1		$\sim$		1 1		
	Dear	( )	hı	М	ren	•

We have come to the end of our Sibling Support Intervention Program. We would like to know how you feel about the Sibling Group so that we can make it better in the future. Please answer the following questions.

	uld like the Sibling Support Intervention Program to meet: (please put an "Xment)
0	nce a week nce every two weeks
	ther times
The S	Sibling Support Intervention Program should meet (please put an "X")
In	the morning
In	the afternoon
O	n Saturday
O	ther times (when)
The t	type of activities I liked the best are: (please put an "X")
	Arts & Crafts
	Group Discussions
	Learning about Autism
	Learning what it feels like to have Autism
	Feeling Chart
f.	Learning about brothers and sisters
g.	Learning how to get along with my brother or sister
h.	Dear Aunt Blabby
i.	Relaxation techniques
j.	Presentation from an adult sibling
k.	Parents' day
1.	Writing in my scrapbook

7.	What else would you like to learn from the Sibling Support Intervention Program?
	<u> </u>
8.	Would you like to add anything else? (Comments)

Appendix R Session 11 and 12: Parent/Child Sessions <u>Objective</u>: To provide TD siblings with the tools able to communicate their concerns to their parents as well as for parents to see what their children have learned throughout the sessions

#### Session 11:

- 9 a.m. -9:30 a.m. Issues that parents provide during their initial interview and how to address those issues.
- 9:30 a.m. 10:30 a.m. Presentation from an TD adult sibling about their experiences growing up with their sibling with autism and question period (According to reports by siblings from a previous support group, they requested to learn from someone who had grown up with a sibling with a disability (Dyson, 1998)).

#### Session 12:

- 10:30 a.m. 11:15 a.m. Presentation of a selection of their poems/short story etc. and other activities from their scrapbook about what they had learned throughout the group
- 11:15 a.m. 11:30 a.m. Graduation ceremony (Each child presented with a certificate of completion)

Appendix S Control Group and Experimental Group Weekly Activity Schedule

Week	Control Group	Experimental Group
1	Introduction: All About Me Booklet	Introduction: All About Me Booklet
	Board Games	What is Autism?
2	Group Discussion – pets/animals	Illusion Activity
	Show and Tell	Feeling Chart
3	Creative Writing	Creative writing and Outdoor games
	Art & Crafts: puppet show	Role Playing with puppets
4	Outdoor games	Learn games to play with sibling
	Drama – create a talent show	Discussion of difficulties or
		concerns with sibling
5	Practice Talent Show	Dear Aunt Blabby
		Coping Strategies
		Trouble Shooting Techniques
6	Present talent show to parents	Parent Discussion of Issues
	Presentation of Scrapbooks	Adult Sibling Presentation
		Presentation of Scrapbooks

Appendix T Recruitment Flyer



# Siblings of Children with Autism: Sibling Support Intervention Program

Primary Investigator: Keisha Gafoor (telephone: (514) 946-7105;

Email: keishagafoor85@gmail.com)

Thesis Advisor: Dr. Harriet (Hariclia) Petrakos (telephone: (514) 848-2424, ext. 2013;

Email: hpetrakos@education.concordia.ca)

#### VOLUNTEERS NEEDED

For a research study on a sibling support group for siblings of children with autism to better understand their interactions within their family.

# Participants must be

- Between the ages of 7 and 13-years-old
- Have one sibling with Autism Spectrum Disorder (ASD)

# Participants will be:

- Required participate in a 6-week sibling support group
- Required to partake in an interview and complete a questionnaire before and after the group
- One parent/ guardian is required to fill out a questionnaire and partake in an interview before and after the group

# For further details please contact:

Keisha Gafoor M.A. Thesis Candidate (Child Studies)

Department of Education Concordia University **Telephone:** (514) 946-7105

E-mail: keishagafoor85@gmail.com

Appendix U Post Control Group Debriefing Letter Debriefing Form: Siblings of Children with Autism: Sibling Support Intervention Program

Dear Parent(s)/ Guardian(s),

Thank you for agreeing to participate in this study! We truly appreciate your collaboration!

The general purpose of this research was to better understand the relationship between a typically developing sibling and a sibling with autism. One of the goals of the study was to provide different tools and support to the typically developing siblings. Another goal was to try to understand how children behave and interact with their parents and sibling with autism.

We invited people who had a least one child between the ages of 7 and 13-years-old to participate. In this study, you were asked to fill out a questionnaire and partake in an interview with the researcher. Your child was also asked to fill out a questionnaire and partake in an interview. This was done before and after the support group to see if the group was in fact helpful. In order to see if the sibling support group was actually helpfully, there were two groups. One group received support and different tools to help them better interact with their sibling with autism. The other group participated in different activities, but they did not discuss their siblings or autism. Since everyone within a family may be affected in some way by autism (directly or indirectly), the results from the study will hopefully provide the researcher with information about the best ways in which to help and support siblings of children with autism.

Your child was in the group that only discussed different activities and did not discuss their relationship with their siblings or autism. If you feel especially concerned that your child was not in the sibling support group, know that a sibling support group will be offered to your child in Summer 2015. A letter will be sent out in May of 2015 with the option for your child to participate in the group. If you have any questions or concerns before then, please contact the graduate student Keisha Gafoor (514-946-7105) or her thesis advisor Dr. Harriet Petrakos (514-848-2424 ext. 2013).

Thank you

Keisha Gafoor, M.A. Thesis Candidate (Child Studies) Department of Education Concordia University Email: keishagafoor85@gmail.com