

A Support Group for Siblings of Children with Autism

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## ABSTRACT

### A Support Group for Siblings of Children with Autism

Stephanie da Costa

Typically developing (TD) children who have a sibling with autism spectrum disorder (ASD) are not often given the opportunity to receive an intervention that is tailored to their complex family life situations and their unique experiences. An online support group for siblings of children with autism was implemented to provide a safe space for TD siblings to express their feelings, increase their knowledge of their sibling's disorder, learn coping strategies and problem-solving skills, and seek comfort from others in similar situations. This study consisted of a sibling support group, whereby participants attended eight weekly one-hour sessions virtually via Zoom. A mixed method approach was used in order to gather evidence for the aforementioned goals. Data gathered from the participants ( $N=5$ ) was analyzed from observations during the support group sessions and demographic questionnaires completed by parents, in addition to the *Knowledge on Autism Spectrum Disorder*, *KIDCOPE*, and the *View of Siblings Questionnaire (VSQ; pre and post)* given to participants before and after attending the support group. Qualitative results indicated that all participants improved their understanding and knowledge of their sibling's ASD, benefitted from working on their self-esteem, developed a peer network, and developed their communication skills. Furthermore, most of the participants (60%) increased their use of adaptive coping strategies, while some of the participants (40%) decreased their use of maladaptive coping strategies. Moreover, the majority of participants reported improvements in their sibling relationships in addition to satisfaction in their attendance of the sibling support group.

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## **Introduction**

Autism Spectrum Disorder (ASD) is a developmental disorder characterized by restricted and repetitive interests and difficulties in social communication (American Psychiatric Association, 2013). These symptoms can make it difficult for those with ASD to develop relationships and can pose challenges for their families. Currently, it is estimated that 1 in 66 children and youth have a diagnosis of ASD in Canada, while 1 in 160 children and youth have a diagnosis of ASD internationally (Public Health Agency of Canada, 2018; World Health Organization, 2019). These diagnoses have been increasing yearly and are continuously rising globally (World Health Organization, 2019). Though there are numerous evidence-based interventions designed and in practice for children who have autism, there is a gap in interventions aimed specifically for typically developing (TD) children who have a sibling with autism. Consequently, the TD sibling may have feelings of guilt, resentment, jealousy, or anger that they are unable to express within their families. The relationship between the TD sibling and the sibling with ASD may also be impacted, resulting in a relationship that is poorer in quality with limited interactions than that of a sibling relationship comprised of TD siblings only (Zucker et al., 2021). Hence, an intervention for TD siblings, such as a sibling support group, can provide a safe space for siblings to express their feelings, learn coping skills, and seek comfort from others in similar situations, among other benefits. The following literature review will discuss the importance of providing services for neurotypical children who have a sibling with autism. Furthermore, an analysis of various models of support groups will be provided from previous research in order to demonstrate the potential benefits of supporting the TD sibling as an important member of the family unit. Finally, a review of the efficacy of facilitating support groups using online programs will also be included.

## **Review of Literature**

### **Impact on the Family Unit**

#### ***Parental Depression and Stress***

The challenges of having a child with autism can directly impact the quality of life of parents and siblings (Benson, 2006; Janus, et al., 2007). The elevated demands that a parent of a child with autism faces in comparison to a TD child can be a risk-factor for poor mental health outcomes, such as high levels of stress and depression (Benson, 2006). A phenomenon called stress proliferation may occur, such that the high stress associated with caring for a child with ASD may spill over into other domains of the parent's life (Benson, 2006). A systematic search of peer-reviewed literature by Janus et al. (2007) showed that families of young children with disabilities as compared to families of TD children are more likely to have an income below the income cut-off, employment issues, and live in lone-parent families. These factors add significant sources of stress, further increasing overall parental stress. The parent's mental wellbeing can in turn effect their abilities to manage the behaviors displayed by their child with ASD.

Research by Benson (2006) examined the effects of stress proliferation, parental depression, and social support by administering various scales of self-administered questionnaires to parents of children with ASDs. The results indicated that 45% of parents scored above the cut-off point in the depression measure, indicating that they would be eligible for a clinical diagnosis of depression. Stress proliferation was found to significantly predict parent depression, such that an increase in stress proliferation elevated depression. However, augmented informal social support was correlated with the decrease in parent depression.

### ***Adjustment of Siblings of Children with Autism***

Siblings undoubtedly have unique relationships that are unlike any other. As a result, siblings may spend a significant amount of time with each other, providing opportunities for them to develop communication skills and/or emotional support (Tsao et al., 2012). As siblings possess a close and intimate relationship, they often construct shared meaning regarding their social interactions which has been shown to facilitate their social relationships and serve as a mechanism for learning behavior (Howe et al., 2017). However, unlike with other typical sibling relationships, having a sibling with autism can pose various challenges. Such challenges include raising the potential for adjustment difficulties, such as increased anxiety as compared to children who do not have a sibling with ASD (Shivers et al., 2013).

Research investigating the experiences of children, adolescents, and adults who have a brother or sister with ASD has revealed that participants have a mixture of both positive and negative feelings and experiences about living with their sibling (Corsano et al., 2017; Cridland et al., 2016; Dansby et al., 2018; Hinek & Milaković, 2019; Leedham et al., 2020; Petalas et al., 2009). Despite these findings, mixed feelings have been reported to eventually balance themselves out with time, as reported by adolescents (Corsano et al., 2017). Some challenges included feelings of resentment due to the impact it had on their daily lives, and feeling rejected, embarrassed, or frustrated (Corsano et al., 2017; Petalas et al., 2009).

Shivers and McGregor (2019) examined the perceptions of both parents in a sample of (N=97) adolescents who had a sibling with either ASD, intellectual and developmental disabilities (IDD), or no disabilities. The findings revealed that parents of children with ASD reported significantly less overall parental optimism and a greater perception of impact on the TD sibling as compared to the other participants. Siblings of children with ASD reported more negative feelings towards their brother or sister as well as displayed higher means of depression

and hostility on their respective scale than did the other groups. Correspondingly, the authors emphasized the importance of promoting healthy outcomes for both siblings and the entire family, such as by developing an intervention for neurotypical siblings.

The caregiving role, otherwise known as parentification, is a stressful role usually reserved for parents. However, children who have siblings with autism have been observed to take on this role (Dansby et al., 2018; Hinek & Milaković, 2019; Laghi et al., 2019). Parentification was attributed to the TD sibling committing to additional responsibilities and developing a sense of duty towards their sibling with ASD. Consequently, taking on this role was shown to be psychologically costly, as it was likely to be a predictor of anxiety and depression. Siblings developed a responsibility to protect their sibling with ASD from others and advocate for them with teachers and peers (Angell et al., 2012; Cridland et al., 2016). As such, they often educated teachers and other students about their siblings' symptoms as well as managed miscommunications. They expressed anger, frustration, and disappointment when others misunderstood their sibling, and when their sibling was not socially accepted (Angell et al., 2012; Petalas et al., 2012).

Corsano et al. (2017) examined the relationship between TD adolescents who had a brother with ASD. Their findings demonstrated that having a brother with ASD had a significant impact on their social life and relationships. A recurrent challenge for the TD sibling was feeling like they had restrictions on their own life activities as they had to be there for their brother with ASD (Corsano et al., 2017; Moss et al., 2019). Participants felt like they had to make sacrifices, such as giving up their plans, to help with their brother with autism.

Given the current worldwide pandemic, it is notable to also consider the impact of COVID-19. Recent research has investigated the impact that the COVID-19 pandemic has had on parents and siblings, specifically families who have one child with special needs such as

ASD. A study by Asbury et al. (2020) investigated the effects that the pandemic has on families, specifically of parents and their special needs child. The results showed that parents and children who have special needs are at greater risk than less vulnerable families to experience poor mental health, including feelings of loss and worry, in addition to changes in mood and behavior resulting from the pandemic. The research outlined that additional support is necessary for these families in order to navigate the additional stress that the COVID-19 pandemic has imposed on their children by the curtailed activities and interventions that usually supported their children's needs.

Furthermore, research by Toseeb (2022) explored whether sibling conflict has increased during the COVID-19 pandemic within 504 families who had a child with special education needs and disabilities, including ASD, through online questionnaires. The data revealed that sibling conflict initiated by the neurotypical sibling, such as picking on or hurting their sibling, had increased during the first lockdown in the United Kingdom. Though the frequency of sibling it is important to note that both neurotypical and special needs siblings had a high level of perpetration. This research thus implicated that a support group is valuable in mediating these adversities.

### **Implications of a Sibling Support Group**

Interventions for individuals who have a sibling with disabilities have been most actively explored within the last decade, with research pointing to the importance of understanding the needs of siblings and allowing them to be addressed (Tudor & Lerner, 2015). A qualitative study by Arnold et al. (2012) explored the support needs of adult siblings of individuals with developmental disabilities (DDs). The Supporting Siblings Survey was distributed to 139 siblings, with two open-ended questions examined within the study. The questions asked were 'what programs would you like to see targeted towards families of people with disabilities?' and

‘what programs would you like to see targeted towards siblings of people with disabilities?’. The results pointed to three major themes: receiving disability-related information, support for their caregiving role, and enhancing the formal support system to address sibling needs. Overall, the most frequent need was siblings’ desire of more sibling support services in order to share information and develop a support network. Accordingly, they desired for a more inclusive definition of family that involved siblings and not just parents. Moreover, participants desired to be educated about their sibling’s disability, future planning, system navigation, and disability awareness for the public.

Similarly, Tsao et al. (2012) reviewed literature on what sibling relationships between a TD child and a sibling who had autism resembled. Their findings showed that there was an overall lack of research on the topic of support for those who had a sibling with autism, but they emphasized the importance of informal and formal support. Finally, the authors recognized sibling support groups that could allow TD siblings to express themselves while gaining an understanding of the disability and the role of each family member within the family system. Such an intervention could aid in balancing positive and negative feelings towards their sibling.

Likewise, Corsano et al. (2017) examined the relationship of 14 TD adolescents who had a brother with ASD through semi-structured interviews conducted with the adolescents and their mothers. Contrariwise, adolescents expressed a desire to talk to experts, parents, or friends about their sibling in order to improve their relationship with them. They felt that this could help them learn how to behave around their sibling, balance the positive and negative feelings towards them, and learn more about ASDs in general. Mothers also agreed that it would be helpful to seek psychological support in order for their TD child to cope with their family situation. Although siblings were generally well adjusted, this suggested that siblings would benefit from additional support groups or programs.

In a study conducted by Cridland et al. (2016) examining perspectives of adolescents who have a sibling with autism, TD sisters expressed a desire to both distance and engage themselves with their family. Over time, they grew to be more knowledgeable of ASD and its symptoms, and developed a better understanding of their brother, growing an appreciation for them. Strategies to help them manage challenges of having a brother with ASD included seeking practical and emotional support from family and close friends. Nevertheless, some expressed a desire to seek formal support. Similar to these findings, Hinek and Milaković (2019) found that neurotypical siblings noted the support they received from family and friends, but none had received formal support, leading some to critique the experts and system. Though they understood their familial situation, participants felt that their parents often showed a double standard towards each sibling and often gave more attention, time, and other resources to the sibling with ASD. While some perceived no need for formal support, others believed that formal support would have been beneficial. They suggested that it would be useful to have someone to talk to, be part of support groups with individuals who have similar family situations or receive appropriate information regarding their sibling's symptoms. Both studies emphasized the implications in sibling support groups where siblings could discuss their experiences, express their feelings, and solve problems.

Leedham et al. (2020) analyzed data from six databases of qualitative literature investigating the experiences of participants who had a sibling with ASD, forming a sample of 18 studies. One of the themes that arose was strategies and support that they encountered. Many participants coped by spending brief periods alone, talking to peers, or exercising. Furthermore, several obtained support from parents, however many expressed the desire to access support outside of their home. If parental or other support was unavailable, participants felt isolated and felt their needs were unmet. Many felt that their needs were disregarded and were given less

attention by parents in comparison to their sibling (Dansby et al., 2018; Hinek & Milaković, 2019; Leedham et al., 2020). While participants who did seek support from professionals emphasized its value, others felt guilt was a barrier in seeking support. Participants articulated that they often felt left out of discussions with professionals.

Zucker et al. (2021) investigated the outcome that a 10-week sibling support group has on the quality of the sibling relationship and the interactions that they had. The 44 participating composed of at least one TD sibling and one sibling with ASD, were randomly assigned to an intervention group or an attention-only group. The results showed that siblings improved in the quality of their relationship and interactions, reported by both observational measures and self-reported measures. The results pointed to implications of a sibling support group and its protective factors of negative outcomes that could result from a poor sibling relationship.

### **Feasibility of Online Interventions**

An alternative to an intervention solely based on face-to-face therapy is through online mediators such as using audio and videoconferencing, telephones, or other forms of technology, which would address the numerous barriers that have been highlighted to participating in a support group. These include geographical barriers, mobility-reducing physical health issues, time constraints, distance, insufficient funds, lack of respite care if caring for someone else, and transportation (Banbury et al., 2018). To mediate these barriers, online support groups can be used asynchronously or synchronously in order to provide therapeutic benefits that may yield similar effects to face-to-face support groups. The acceptability of audio-conferencing as a means of providing support groups requires further exploration. Nonetheless, technology is increasingly being used in both developed and developing countries (Gettings et al., 2015).

Banbury et al. (2018) reviewed the feasibility, acceptability, effectiveness, and implementation of 17 studies that used videoconferencing to provide psychoeducation, support,

or both into participants' homes. Studies that used group videoconferencing for patient education or social/mental health support with adults were included within the analysis, with a total of 467 participants. Videoconferences ranged from 45 to 105 minutes and the majority met weekly. While videoconference group meetings were the only component for seven studies, the remaining studies incorporated elements such as access to information from an intervention-specific website, text-based discussion forums, and face-to-face group meetings. A range of health professionals provided group facilitation as many groups focused on support for various psychological or physical topics. In terms of feasibility, the majority used desktop computers, with some using tablets or computers connected to the participants' televisions. They found that the majority of studies demonstrated that even participants who initially experienced difficulties with the technology found it easy to use over time. Though technical problems occurred in all studies, most reported few difficulties. Most studies included good technical support, which was attributed to lowering users' anxiety. Nevertheless, participants reported a high level of satisfaction with group videoconferencing. Participants enjoyed seeing and hearing other group members, meeting people in similar situations, sharing experiences, and obtaining social support. Privacy was not reported as an issue in any of the studies. Results showed that videoconferencing groups were similar to face-to-face groups and usual care. Support groups were successful in increasing health knowledge and skills across a wide array of topics, as well as replicate group bonding, cohesiveness, and empathy that was observed in previous face-to-face research.

Correspondingly, Gettings et al. (2015) examined the efficacy of a sibling support group for six siblings, aged 8 to 13 years old, of children with neurodevelopmental disorders implemented with audio-conferencing. ASD symptoms were of high concern by all of the participants. The intervention consisted of eight 1-hour weekly face-to-face sessions, in addition to four sessions using audio-conferencing in order to overcome geographical barriers.

Interestingly, the parents who chose not to participate during the recruitment phase gave reasons that were mainly related to geographical barriers and distance. They found that after the intervention, all of the participants showed a reduction in at least one of their concerns due to reasons such as an increased understanding of their sibling's diagnosis, new coping strategies, and/or different parenting approaches. Furthermore, over half (67%) of the siblings indicated that they talked on the telephone with at least one sibling from the sibling support group outside of the sessions. Siblings also reported that they had acquired better communication with their families. Most of the siblings (67%) found the audio-conferencing was easy or very easy to use, with one sibling preferring it over meetings. Overall, siblings reported benefits to the support group such as reduced isolation, building friendships, and talking openly. Parents also reported benefits for themselves, such as increasing their own awareness of the sibling's needs. Thus, this study showed that audio-conferencing was feasible for all participants.

Finally, Giallo and Gavida-Payne (2008) conducted a six-week family-based psychoeducational intervention (Sibstars) for 21 siblings between the ages of 8 to 16 years old of children who have a disability or chronic illness. Families were randomly assigned to either an intervention or a waitlist control group. After a first face-to-face session, families read an information booklet and they completed practice activities that were provided. Sessions lasted 20 to 30 minutes and they were conducted over the telephone where support was provided to siblings and parents regarding the information booklet and its activities. The findings revealed that families reported positive aspects of the intervention. The majority of participants (parents, 94.2%; siblings, 72.3%) valued the intervention information and activities, as well as the telephone support (parents, 100%; siblings, 72.3%) in helping them use the newly learned life skills.

## **Intervention Goals**

The research literature on sibling support groups for individuals who have a sibling with disabilities has presented variations within the goals outlined by each however, they often present similar purposes. In order to promote these goals, support group sessions often include interactive activities, stories, games, handouts, or discussions, and other tools (Brouzos et al., 2017; D'Arcy et al., 2005; Dyson, 1998; Evans et al., 2001; Granat et al., 2012; Guzman, 2009; Jones et al., 2020; Kryzak et al., 2015; McCullough & Simon, 2011; Smith & Perry, 2004; Venegas, 2015). The most common goals that are implemented within sessions are facilitating open communication, increasing knowledge about their sibling's disorder, learning about coping strategies or problem-solving skills, forming peer networks, and increasing self-concept and/or self-esteem.

### ***Knowledge About Their Sibling's Disorder***

Research has found that negative experiences were linked to confusion relating to their sibling's ASD symptoms (Corsano et al., 2017; Cridland et al., 2016; Moss et al., 2019; Petalas et al., 2012). Typically developing siblings often discussed their stress related to their siblings' symptoms of unpredictable and unusual behaviors that occasionally lead to aggression (Petalas et al., 2012). At times, this made it difficult to live with their sibling, as well as generated embarrassment when these behaviors were shown in public places (Angell et al., 2012; Corsano et al., 2017). Increasing knowledge about their sibling's disability is often aimed to improve the participants' psychosocial adjustment, thus mediating internalizing and externalizing problems. Therefore, providing information about their sibling's disability and disabilities in general has been shown to be a recurrent goal within sibling support groups (Brouzos et al., 2017; D'Arcy et al., 2005; Evans et al., 2001; Gafoor, 2015; Gettings et al., 2015; Granat et al., 2012; Hansford,

2014; Jones et al., 2020; Kryzak et al., 2015; McCullough & Simon, 2011; Roberts et al., 2015; Smith & Perry, 2004; Venegas, 2015).

Studies have typically incorporated one to two sessions dedicated to psychoeducation, where participants learn about their sibling's disability or disabilities in general in order to better understand their disabled sibling (Brouzos et al., 2017; D'Arcy et al., 2005; Dyson, 1998; Evans et al., 2001; Gafoor, 2015; Gettings et al., 2015; Granat et al., 2012; Hansford, 2014; Jones et al., 2020; Kryzak et al., 2015; McCullough & Simon, 2011; Smith & Perry, 2004; Tudor & Lerner, 2015; Venegas, 2015). Generally, information about disabilities is shared through activities such as role-playing, reading books, flash cards, videos, journal entries, and so on. Studies have also included discussions about famous people who have autism in order to explain their strengths and weaknesses and to better understand the lack of homogeneity within the spectrum (Brouzos et al., 2017). Alternatively, Granat et al. (2012) examined the effectiveness of a group intervention for 54 TD siblings (aged 8 to 12 years old) of children who had a disability. Siblings watched a presentation of a guest speaker who was an older sibling of a child with a disability. The presentation was followed by discussions, questions, and games. This not only allowed children to speak to someone who had been in a similar situation, but to gain more of an understanding of what to expect when their sibling displays difficult symptoms.

Illusion activities have been described as ones that allow participants to experience a particular disorder (Dyson, 1998; Gafoor, 2015, Hansford, 2014; McCullough & Simon, 2011). These activities have incorporated hidden-picture searches during sensory challenges, which include flashing lights, or the introduction of loud banging and visual interruptions (McCullough & Simon, 2011). In Dyson's (1998) evaluation of support programs for 40 individuals (aged 7 to 12 years old) who have a sibling with disabilities, siblings reported that they learned about other disabilities in general, while some indicated that they increased their understanding about sibling

relationships. When asked about their favorite part, half of the children liked activities, such as playing outside, doing arts and crafts, and experiencing disabilities through role-playing, the most. More specifically, they favored learning about how to interact with their siblings.

Consistent with these findings, McCullough and Simon (2011), who assessed a sibling support group for three individuals (aged 7 to 10 years old) who had a sibling with DDs, found that participants preferred activities that created illusions of disability the most. That is, they enjoyed activities that allowed them to experience what it felt like to have a disability through various activities.

All studies examining the effectiveness of sibling support groups who measured the knowledge about their sibling's disorder reported a significant increase in knowledge after the intervention (Brouzos et al., 2017; D'Arcy et al., 2005; Dyson, 1998; Gafoor, 2015; Granat et al., 2012; Hanford, 2014; Kyzak et al., 2015; Roberts et al., 2015; Smith & Perry, 2004; Tudor & Lerner, 2015; Venegas, 2015). Research by Evans et al. (2001) found that there was a significant increase in involvement between siblings and an improvement in knowledge of challenging behavior, communication, and learning disabilities. Of the parents who responded to the parent questionnaire, all felt the children enjoyed the group and it helped foster open communication and a better understanding of their sibling. They also noted that their children could better relate to each other.

### ***Coping Strategies and Problem-Solving Skills***

In order to further mediate adjustment problems that participants tend to show, many support groups have incorporated the goal of increasing coping strategies and problem-solving skills (Brouzos et al., 2017; D'Arcy et al., 2005; Evans et al., 2001; Giallo & Gavidia-Payne, 2008; Granat et al., 2012; Guzman, 2009; Hansford, 2013; Jones et al., 2020; Roberts et al., 2015; Smith & Perry, 2004; Venegas, 2015). For instance, in Jones et al.'s (2020) research, the

sessions on coping and problem-solving skills allowed the siblings to discuss their frustrations and provided ways that they can cope, such as with various relaxation techniques. Similarly, Brouzos et al. (2017) and Hansford (2014), who both examined the effectiveness of a sibling support group for TD children who had a sibling with autism, dedicated a full session of their support group towards teaching the participants relaxation strategies and deep breathing. The children completed various activities that encouraged them to identify their anxiety triggers and to redirect their thoughts to something less threatening, eventually replacing their negative thoughts with more adaptive ones. Moreover, Brouzos et al. (2017) included another session dedicated to teaching participants how to build action plans and to break down their problems into steps in order to better solve them. In addition, Hansford (2014) encouraged the participants to identify a problem and find solutions using the COPE method: Clarify the Problem, Option List, Pick the Best Idea and Evaluate.

Another method used within sessions was to open discussions about learning how to handle situations that may be commonly experienced by the TD participants (D'Arcy et al., 2005; Gafoor, 2015; Giallo & Gavidia-Payne, 2008). Through discussing situations that are difficult to handle, children can learn to develop positive coping strategies from facilitators or their peer network. Furthermore, studies included activities where children could discuss their feelings through games such as a "feeling chart" or "a cube full of feelings" (Brouzos et al., 2017; Evans et al., 2001; Gafoor, 2015). In this activity, children wrote both their positive and negative feelings about their sibling, such as shame, anger, or fear, which were later discussed as a group. An alternative technique consisted of presenting activities where children could give advice to a child in a difficult situation. For instance, studies examining the effectiveness of a support group for siblings of children with autism and of children with disabilities included an activity where children offered advice to similar others who had written to Dear Aunt Blabby

(Dyson, 1998; Gafoor, 2015; Venegas, 2015). Hence, children responded to letters by helping in a way that they themselves would deal with the situations, thus working on their problem-solving skills.

All studies that measured coping/adjustment difficulties and behavioral problems observed a significant reduction after the intervention within their participants (Brouzos et al., 2017; D'Arcy et al., 2005; Evans et al., 2001; Gafoor, 2015; Giallo & Gavida-Payne, 2008; Jones et al., 2020; Kyzak et al., 2015; Roberts et al., 2015). Findings by D'Arcy et al. (2005) indicated that siblings discussed situations that were difficult to handle, and some learned new coping strategies. Many reported not being able to talk about difficulties prior to Sibshops. However, over half said that they spoke about difficult situations which they otherwise had never spoken about. Furthermore, findings by Giallo and Gavida-Payne (2008) showed that siblings had significantly lower emotional symptoms, a lower perception of daily hassles stress related to the affected child and used less distancing coping compared to the waitlist group. The intervention group engaged in more family time and routine activities, showed improvements in family problem-solving communication, and had a reduction in overall perceived family stress. Interestingly, Jones et al. (2020) found that the support group served as a buffer in externalizing behaviours for TD participants whose siblings showed more severe ASD symptomology.

### ***Self-Esteem***

Increasing self-esteem and self-concept has been a goal in numerous support groups. There is evidence that suggests that there is a heightened risk for children who have a sibling with disabilities to develop low self-esteem (Evans et al., 2001). Some possible explanations have been the lack of attention that they receive from family members, having limited opportunities for affective expression, and feeling isolated from peers in similar circumstances (D'Arcy et al., 2005; Evans et al., 2001; Gafoor, 2015; McCullough & Simon, 2011). In research

by Evans et al. (2001) and Hansford (2014), children reported that they enjoyed participating in an exercise where all support group members wrote something positive about their peers. Other activities that aimed to increase self-esteem were having talent shows and “show and tell” dedicated to celebrating qualities of each individual group member, writing about their likes or stories of themselves in a scrapbook, and playing games where the focus was on the TD sibling (Gafoor, 2015; Hansford, 2014). Through these activities, children learned that although they were in a group because they had a sibling with a disability, they are unique and special (Hansford, 2014).

Research has reported mixed findings within the evaluation of self-concept and self-esteem at post-intervention. Research by D’Arcy et al. (2005) indicated that although there were no significant differences in self-esteem, most children enjoyed Sibshops and felt that it contributed to positive outcomes such as improving the sibling relationship. In contrast, Smith and Perry (2005) found a significant increase in self-esteem at post-treatment. Furthermore, research by Gafoor (2015) who examined the effectiveness of a support group for six siblings (aged 7 to 13 years) of children with autism, found that more than half (67%) of the participants in the experimental group showed a slight improvement in self-concept and an increase in self-esteem. Finally, both Evans et al. (2001) and Roberts et al. (2015) also found an increase in global self-esteem at the end of their intervention. Thus, while findings have not shown to be consistently significant across research, self-esteem has shown to increase in some participants and yield benefits.

### ***Facilitating Open Communication***

Siblings have consistently reported that they were unable to communicate with parents, thus feeling distant, alone, and unseen (Dansby et al., 2018; Corsano et al., 2017; Petalas et al., 2009). It has been noted that TD siblings often have difficulty talking about their sibling with

ASD and often refrain from asking questions to parents (Corsano et al., 2017). Consequently, if they do not ask questions, their parents do not raise the issue. Effective parent-child communication has been shown to aid the TD child's adjustment and provide them with understanding of their sibling's symptoms (Petalas et al., 2009). Therefore, the central objective of sibling support groups is to facilitate open communication between participants as well as their families (Brouzos et al., 2017; Banbury et al., 2018; D'Arcy et al., 2005; Dyson, 1998; Gettings et al., 2015; Guzman, 2009; Jones et al., 2020; Kryzak et al., 2015; McCullough & Simon, 2011; Scelles et al., 2012; Tsao et al., 2012; Tudor & Lerner, 2015; Venegas, 2015). It is essential that within support group sessions, participants are able to express their feelings and to share their experiences in order to make connections with one another.

Accordingly, the first sessions typically include icebreakers that allow the participants and workshop facilitators to get to know one another. For instance, research conducted by Brouzos et al. (2017) examined the effectiveness of a sibling support group for 38 TD children between the ages of 6 to 15 years old who had a sibling with autism. Children were invited to introduce themselves in a unique and creative way in the first session. All of the children sat in a circle, and each child announced their name while stepping forward and striking a pose that reflected their personality. This was then followed by everyone jumping forward and copying these poses. Similarly, Jones et al.'s (2020) conducted a randomized controlled trial that compared a sibling support group to an attention-only control group composed of six cohorts of participants between the ages of 4 to 18. During the first session the siblings participated in discussions and activities that were designed to encourage peer networks and to form a rapport. For instance, the "sit down if..." game consisted of sitting down if the statement read applied to them as well as characteristics of their sibling. This allowed siblings to get to know each other.

Moreover, D'Arcy et al. (2005) examined the effectiveness of a support group (Sibshops) for 16 children between the ages of 8 and 10 years old who have a sibling with disabilities. The authors found that most of their participants (81.3%) did not talk about their experiences of having a sibling with special needs prior to the research. However, after attending the support group 75% of participants increased their willingness to share experiences about their siblings, and in doing so, they were able to balance their positive and negative feelings. Furthermore, the siblings were able to express specific descriptions of the negative aspects they had experienced of their siblings following the intervention, indicating that they improved in their communication skills. Likewise, Gettings et al. (2015) examined the efficacy of a sibling support group for six siblings (aged 8 to 13 years old) using audio-conferencing for siblings of children with neurodevelopmental disorders. The authors found that siblings reported that they had acquired better communication within their families after the intervention.

Many studies had noteworthy benefits regarding the facilitation of open communication within various relationships of the participant such as with their newfound peer network, as well as at their parents (D'Arcy et al., 2005; Evans et al., 2001; Gettings et al., 2015; Kyzak et al., 2015; Roberts et al., 2015). Findings by D'Arcy et al. (2005) showed that children valued meeting other siblings and attributed this factor as a positive experience. Additionally, five (31%) of the children had met the other siblings again after Sibshops ended. Approximately three quarters of the group increased their willingness to share experiences about their siblings, and in doing so were able to balance their positive and negative feelings. Furthermore, research conducted by Scelles et al. (2012) examined the reactions across 10 support groups situated throughout France of siblings, parents, and healthcare professionals that were involved in sibling support group. All participants were involved with the support group for at least two years and their ages ranged from 4 to 15 years old. Scelles et al. (2012) found that children felt relieved when their worries

and questions were acknowledged and addressed. They also felt a sense of self-esteem and satisfaction when their experiences were recognized and valued. It was satisfying for them to share their feelings and reactions.

### ***Developing a Peer Network***

Within support groups, another major goal has been for participants to meet other individuals in similar situations and to develop a lasting peer network. Along with the goal of increasing coping skills, discussions and activities focused on different ways to cope with their siblings as well as ways to utilize their support networks (Jones et al., 2020; Roberts et al., 2015; Venegas, 2015). McCullough and Simon (2011), who assessed a sibling support group for individuals who had a sibling with DDs, found that each of the siblings reported a sense of isolation or having to “go it alone”, thus group members were eager to express sentiments of shared experiences. This helped them to connect to the group and to one another, and through those dynamics the group became more cohesive. Not only did increasing peer networks demonstrate an increase in coping skills, but it had been shown to affect self-esteem as well. One participant was notably shy prior to the intervention, but by the end of the intervention had made friends (McCullough & Simon, 2011). The parents reported that this friendship had a positive effect on their child’s self-esteem.

Brouzos et al. (2017) included a session dedicated to developing friendships within the support group for TD children who had a sibling with autism. During this session, children were taught that they were not alone and had a support network that they could turn to. Children wrote the names of significant others on individual leaves, which they then attached to the “tree of support,” showing that they were surrounded by supportive and nurturing others. Other friendship activities allowed children to learn about good friendships, as well as how they would explain their sibling’s disorder to a friend. Other support groups often included outdoor play,

recreational activities, skating or swimming lessons, or a full theme park day in order to develop social networking (Dyson, 1998; Evans et al., 2001; Kryzak et al., 2015). In order to maintain peer networks, children had the opportunity to exchange telephone numbers to contact each other during the week and organize their own games during free time (Evans et al., 2001).

### **Intervention Satisfaction**

In general, research surrounding sibling support groups have reported many benefits and high satisfaction when children and parents were interviewed (Brouzos et al., 2017; D'Arcy et al., 2005; Dyson, 1998; Evans et al., 2001; Giallo & Gavida-Payne, 2008; Granat et al., 2012; Hanford, 2014; Kyzak et al., 2015; Roberts et al., 2015; Smith & Perry, 2004; Venegas, 2015). For instance, in research by D'Arcy et al. (2005), both parents and children saw benefits and wished for the group to continue. Parents highlighted that their children enjoyed Sibshops and they noticed positive implications such as an increased understanding and an awareness of the disabled sibling. Children often highly valued various activities such as role-playing, self-esteem, and emotional expression activities (Dyson, 1998; Evans et al., 2001). Scelles et al. (2012) found that healthcare professionals and parents were satisfied because the group sessions provided an opportunity to prove their interest in their sisters and brothers, and they encouraged communication within the family. Moreover, parents believed that accompanying their TD child to a support group session offered a context in which they could spend more time together. The children were pleased, and the parents felt less guilty for not finding enough time for their TD children.

### **Participant Characteristics: Age**

Middle childhood has been identified as a period where children develop an increased independence from parents and where they begin to take responsibility, exercise self-control, and develop a sense of self (Guzman, 2009). Therefore, this age group has been recognized as an

ideal time to allow children to develop their full potential by introducing supports and opportunities that may help them achieve successful outcomes into adolescence and adulthood. D'Arcy et al. (2005) stated that it was important to include participants in their middle childhood, and they labeled this period as a crucial age when peer contact is important, and when providing them with knowledge on disability, coping skills, and opportunities to share feelings was of benefit at that time in their development. Furthermore, Tudor and Lerner (2015) conducted a systematic review of 16 peer-reviewed journal articles on interventions and support groups designed for youth (aged 3 to 17 years) who have a sibling with DDs. Their results revealed that the majority of studies have chosen participants that fell within the middle childhood age, which ranged between 6 and 12 years old. In studies where the ages differed considerably, the participants were grouped based on their age (Brouzos et al., 2017; Gafoor, 2015; Guzman, 2009; Jones et al., 2020; Scelles et al., 2012; Smith & Perry, 2004). This ensured that siblings were in a group of individuals with similar needs and interests that could collectively participate in age-appropriate activities.

### **Duration**

According to a systematic review by Tudor and Lerner (2015), the majority of the 16 studies that they evaluated ran for approximately 6 to 8 weeks, where sessions ranged between 1 to 2 hours. This is consistent with other literature presenting similar research. There are also many variations with the frequency at which participants attend the support group sessions. However, the most common report has been once a week. The shortest durations observed were in D'Arcy et al.'s (2005) and Giallo and Gavida-Payne's (2008) studies. In D'Arcy et al.'s study, participants attended Sibshops, which were held monthly for 3 hours over the span of four consecutive months. Comparably, Giallo and Gavida-Payne's (2008) conducted sessions lasting

approximately 20 to 30 minutes over the telephone, where support was provided to siblings and parents regarding the information booklet and its activities.

### **The Current Study**

Previous research has shown that a support group for children who have a sibling with autism may provide opportunities for children to learn about their sibling's disability, to develop communication skills and a peer network, and to establish needed coping and problem-solving skills. The support group may mediate externalizing and internalizing problems, as well as increase their self-esteem. Finally, it may also improve the relationships between siblings and parents given newly learned strategies and skills. In-person support groups have shown their efficacy; however, the implementation of technology-based intervention has been shown to be promising. The purpose of this study was to explore the outcomes of a support group for typically developing children who have a sibling with autism. Due to the restrictions for in-person interventions placed by COVID-19, this support group, unlike any other of this topic, was conducted over Zoom. Thus, the efficacy of using technology to address the above issues was also examined.

The questions of this study were as follows: (1) will children's knowledge of ASD increase once they are exposed to age-appropriate knowledge about ASD? (2) will children perceive an increase in their coping strategies, problem-solving skills, and self-esteem after they attend a sibling support group? (3) will children's relationships improve with their sibling after attending a sibling support group? (4) will children express an increase in open communication with their parents and/or peers after they attend a sibling support group? (5) how will typically developing siblings perceive the sibling support intervention?

## **Method**

### **Settings and Recruitment**

Upon obtaining ethical approval from Concordia University, recruitment was obtained within the general public through distribution of a research flyer to various social organizations in the greater Montreal area (See Appendix C). In addition, the families were recruited from online forums offering support to parents who have a child with ASD, centers providing services to these families, special needs schools, a pediatric clinic “Ago: Children’s Health and Wellness Center”, advertisement in the “Family” newspaper, Facebook, and word of mouth.

Parents expressed their interest via email to the researcher, where additional information about the support group was exchanged. Once the researcher received consent from both the parents and the children, the participants received pre-test questionnaires, which they completed and sent via email. Both the parents and children read and signed the consent form before the sibling support group (See Appendix A and B). Once all the pre-test questionnaires were completed by the participants, the researcher requested to schedule an appropriate time for all the participants to meet weekly for eight weeks. Participants were then required to attend the group once a week for eight consecutive weeks virtually via Zoom.

### **Participants**

To explore the research questions and hypotheses outlined above, a total of five typically developing children and their parents were recruited to take part in this study. Table 1 provides detailed demographics of all participants. The children included in the study were typically developing and had at least one sibling with a DSM-V diagnosis of Autism Spectrum Disorder (ASD). The typically developing children were between eleven and twelve years old. Three were female and two were male. The following is a description of the families. The participants’ names have been changed in order to protect their anonymity.

**Table 1***Participant Demographic Information*

Child	Age	Gender	Gender of Sibling with ASD	Age of Sibling with ASD	Number of Siblings	Parent's Marital Status	Birth Order
Participant 1	12	Non- binary	Male	9	2	Married	1 <sup>st</sup>
Participant 2	11	Female	Male	8	1	Married	1 <sup>st</sup>
Participant 3	11	Male	Female	16	1	Married	2 <sup>nd</sup>
Participant 4	11	Female	Female	12	1	Married	2 <sup>nd</sup>
Participant 5	11	Female	Male	14	1	Divorced	2 <sup>nd</sup>

*Participant 1*

Participant 1 was 12 years old and identifies as non-binary. Both Participant 1 and their parents identified preferred pronouns as “they” and “them”, which was used to refer to them. Participant 1 was the oldest in their family and had two younger siblings: a 9-year-old brother, and a 3-year-old sister. Their younger brother was diagnosed at the age of eight and was considered to have high functioning autism. Participant 1 lived with their parents, their brother,

and their sister. Participant 1 was attending school with their brother but was planning on changing schools in the following year.

### ***Participant 2***

Participant 2 was an 11-year-old girl and the eldest child in her family. Her brother was 8 years old and was diagnosed with autism at the age of two and a half years old. Her brother was non-verbal and was identified as having difficulty communicating and difficulty with emotional regulation. Participant 2 lived with her parents and younger brother. She attended a different school than her brother.

### ***Participant 3***

Participant 3 was an 11-year-old boy and was the youngest child in his family. His sister was 16 years old and was diagnosed with autism at the age of fifteen years old. His sister was identified as having difficulty with anxiety, having social stress, obsessions, and compulsions. Participant 3 lived with his mother, stepfather, and older sister. He had immigrated to Canada within the last five years. He attended a different school than his sister.

### ***Participant 4***

Participant 4 was an 11-year-old girl and was the youngest child. Her sister was 12 years old and was diagnosed with autism at the age of six years old. Her sister was considered to have high functioning autism. Participant 4 lived with her parents and older sister. She had recently immigrated to Canada. She attended the same school as her sister.

### ***Participant 5***

Participant 5 was an 11-year-old girl and was the youngest child. She had a 14-year-old brother who was diagnosed with autism at the age of three years old. Her brother was identified as having difficulty with anxiety, verbal stimming, and physical aggression. Participant 5's parents were divorced; thus, she partially lived with her mother's, her father's, her grandparents',

and her uncle's houses. Her brother was always with her in the same household. She attended a different school than her brother.

## **Measures**

### ***Demographic Questionnaire for Parents***

After the parents gave consent for their child's participation, they completed a demographic questionnaire that was related to their home and family environment (see Appendix F). Additional questions were listed to gather information about their child who had autism in addition to the child participating in the study. Such questions included the birth order, gender, the relationship of the siblings of interest, and other pertinent information that was relevant for this study such whether their child had ever participated in a support group and what their understanding was of their sibling's diagnosis. Finally, concerns from the parent's perspective of their child participating were answered.

### ***Knowledge Questionnaire About Autism for Siblings***

As knowledge of autism is important to understanding what one's siblings are going through, a questionnaire for siblings was created based on the *Knowledge on Autism Spectrum Disorder* created by Ilg et al. in 2012, and the *Autism Knowledge Measure for Young Children* created by Perry in 1989 (see Appendix G). The questions were selected based on the literature review and the current known information about ASD. This measure was administered to children prior to the intervention and immediately after the intervention in order to detect improvements in these skills. The questions contained simple language that is made suitable for children. The questionnaire had 13 items that children responded to by circling "true", "false", or "not sure" on the items. Knowledge of ASD was evaluated with true or false questions such as "People with autism have difficulty communicating". Correct items were summed to produce a total score. Thus, high scores represented a greater knowledge of autism.

### ***KIDCOPE***

The KIDCOPE was administered to the participant before and after the intervention in order to measure cognitive and behavioral coping (Spirito et al., 1988) (see Appendix H). This was a self-report measure that was designed for children and adolescents aged 7-12 years old. The 15-item checklist asked children to rate the frequency and efficacy of various coping strategies. Four of the strategies asked were about approach-oriented coping skills and were thus considered to be positive or adaptive. The approach-oriented strategies included problem-solving, positive emotion regulation, cognitive restructuring, and social support. Conversely, seven were escape-oriented and thus considered negative or maladaptive. The escape-oriented strategies included distraction, negative emotion regulation, social withdrawal, self-criticism, blaming others, emotional expression, wishful thinking, and resignation. For instance, items included “I just tried to forget” and “I stayed by myself”. The child was asked to recall a recent event, that happened within the last month, concerning their sibling with autism and to indicate by circling yes or no if any of the 15 coping strategies were used. The efficacy of the coping strategy was then assessed by asking the child to rate how helpful the strategy was on a 3-point scale: “not at all”, “a little”, or “a lot”. According to Spirito et al. (1988), the KIDCOPE had moderate to fairly high test-retest reliability over a short duration. Furthermore, it had a report of correlations with other coping measures, including the Coping Strategies Inventory (CSI).

### ***View of Siblings Questionnaire***

The *View of Siblings Questionnaire* was administered to participants before and at the end of their participation of the support group (see Appendix I and J respectfully). This measure was based on questions derived from *The Network of Relationships—Relationship Quality Version* created by Buhrmester and Furman (2008), *Having a Brother or Sister with Autism* questionnaire created by Venegas (2015), and the *Sibling’s Views Questionnaire* created by

Gettings et al. (2015). The items selected from these questionnaires were based on the literature review and the current known information about ASD. It was intended to assess the relationship that participants had with their sibling with autism before the intervention, whether their relationship improved after the completion of the intervention, and their satisfaction with the intervention. Furthermore, it included questions that assessed the level of support that the participant had before and after the support group. These questions were not included in the analysis as the participants were not able to answer them due to the complexity of the questions.

### **Procedure**

The recruitment took place as soon as ethical approval was granted by Concordia University. Families that were interested in participating contacted me via e-mail and were presented with an online brief description of the study and its overall purpose and procedure. This also informed parents that if they wished to participate, that they had to have a functional computer with video and audio capacities. They were also informed that their child needed to have a quiet room where they could participate autonomously in the weekly one-hour group sessions, and that that the support group sessions would be recorded via Zoom. The parents who agreed to participate received a letter via e-mail that explained the intent of the study as well as a consent form and a questionnaire. They were also asked to reply with their child's availabilities to attend the weekly one-hour support group sessions based on a few choices (i.e.: Saturday morning, Sunday morning, weekly evenings). A poll was created through "Doodle", where each participant indicated their availabilities. The parent consent form gave permission for their child to participate in the sibling support group as well as to complete additional questionnaires and interviews. The parents were asked to electronically sign the consent form and sent it back via e-mail. The parent's demographic questionnaire asked the parents to fill out information about their children's' ages, school, grade level, the DSM-V diagnosis of their child with ASD,

intensity of the sibling's autism, as well as additional information about relationship between both of their children who are relevant to the study (see Appendix F).

After receiving parental consent and the completed demographic questionnaire, parents were given an option for their child to either conduct a pre-test meeting via Zoom with each participant individually, or for them to aid with completing the pre-test questionnaires for the participants. All participants opted to complete the questionnaires autonomously. One participant, Participant 3, chose to meet for a few minutes during this process. This meeting, via Zoom, was organized per Participant 3's and his parent's request in order to familiarize himself with the researcher and ask any questions pertaining to the research. The meeting went well, and he said that he was looking forward to the start of the support group.

The pre-test measures were the *Knowledge on Autism Spectrum Disorder*, *KIDCOPE*, and the pre-test version *View of Siblings Questionnaire (VSQ-pre)* (see Appendix G-I). Once the pre-test measures were completed, an e-mail was sent to the parents containing some of the activities that would be used during the sessions. Parents printed the activities and ensured that their child had access to a pencil and paper during the sessions. During the Zoom sessions, parents also ensured that their child was in a quiet room and had set up the computers if they needed help. Once the eight weekly support group sessions ended, the participants completed post-test questionnaires, which was the same *Knowledge Questionnaire About Autism for Siblings*, *KIDCOPE*, and the post-test version of the *View of Siblings Questionnaire (VSQ-post)* (see Appendix G, H, I). The researcher sent a thank you email along with a thank you letter containing resources and a completion certification to their provided addresses (Appendix K-L).

### **Sibling Support Group**

Participants, who were between the ages of eleven and twelve, participated in the support group that was exclusively designed for children who have a sibling with autism spectrum

disorder. The support group included eight sessions with the ultimate goal of increasing the child's knowledge of autism, increasing their problem-solving and coping skills, increasing their peer network, and improving their relationships with their siblings and parents. The support group was conducted over Zoom and lasted approximately one-hour for a period of eight weeks. Each session targeted the goals that were previously mentioned, and children worked on developing these skills. The sessions included various activities that assisted in developing these skills. Based on the participants ages, which were between eleven and twelve, the support group sessions were tailored in accordance with their age in order to provide age-appropriate activities and topics. Furthermore, based on the demographic questionnaires and pre-test questionnaires, the activities were also tailored based on the relevant challenges that the participants encountered in their daily lives regarding the subject. The overview of the intervention sessions and the activities are included in Appendix D and Appendix E respectfully.

## **Results**

### **Data Analysis**

As previously mentioned, the research questions were the following:

- (1) Will children's knowledge of ASD increase once they are exposed to age-appropriate knowledge about ASD?
- (2) Will children perceive an increase in their coping strategies, problem-solving skills, and self-esteem after they attend a sibling support group?
- (3) Will children's relationships improve with their sibling after attending a sibling support group?
- (4) Will children express an increase in open communication with their parents and/or peers after they attend a sibling support group?
- (5) How will typically developing siblings perceive the sibling support intervention?

In order to explore children's understanding of their sibling's disability, their communication skills and peer network, coping and problem-solving skills and strategies, self-esteem, and relationships with their brother or sister with autism, the following themes were developed for the analysis:

- a) Knowledge About Their Sibling's ASD
- b) Coping Strategies and Problem-Solving Skills
- c) Self-Esteem
- d) Sibling Relationship
- e) Facilitating Open Communication, Developing a Peer Network, and Intervention Satisfaction

The data was collected from information provided by the questionnaires from both parents and participants, along with observations that were gathered from the participants during the support group sessions. The observations included non-verbal behavior, as well as quotes from participants. As such, the topics were discussed throughout multiple sessions regardless of the theme of the session and differed for each participant.

***Research Question #1: Will children's knowledge of ASD increase once they are exposed to age-appropriate knowledge about ASD?***

In order to evaluate whether participating in the intervention increased the participant's knowledge of ASD, knowledge about their sibling's ASD was identified using the *Knowledge Questionnaire About Autism for Siblings* and qualitative data that was collected during the recorded weekly Zoom sessions during the sibling support group (see Appendix G). More specifically, the qualitative data was mainly collected from observations during the first, second, and third sibling support group sessions titled "Introduction" (session one), and "Let's Learn About Autism" (session two and three, see Appendix D and E), in addition to information

gathered from the demographic questionnaire completed by parents. Nevertheless, it should be noted that the understanding of autism seemed to increase throughout the sessions as various facets of the disorder and its effect on the participants were addressed. The results of the *Knowledge Questionnaire About Autism for Siblings* administered before and after the sibling support group for each participant can be found in Table 2.

**Table 2**

*Questionnaire About Autism for Siblings Scores for Time 1 and Time 2 and Their Percentage of Change*

Participant	Time 1 (%)	Time 2 (%)	Change (%)
Participant 1	85	100	+ 15
Participant 2	92	100	+ 8
Participant 3	61	92	+ 31
Participant 4	69	100	+ 31
Participant 5	77	92	+ 15

**Participant 1.** Their mother expressed that Participant 1’s understanding of ASD seemed good. When asked whether they talked openly about ASD and whether the word “autism” was used, she stated “We discuss it openly and do use the word Autism”. When asked about Participant 1’s awareness of their brother’s diagnosis, their mother indicated that they had talked openly with them since their brother’s diagnosis. Though Participant 1 had been aware of their brother’s diagnosis, their parents also stated that Participant 1 had difficulty “of separating what was simply a ‘difficult child/sibling’ temperament from what might fall under ASD”. The mother also stated, “they wouldn’t have had a reference point to know what extreme behaviour was”. Though these statements seemed to contradict themselves, as Participant 1’s mother had pointed

out that autism was discussed at home, it suggested that perhaps Participant 1 had difficulty understanding their brother in terms of the particular ASD characteristics that were present despite having some knowledge of autism in general.

Within the first session, which was an introductory session, Participant 1 was asked about their sibling's diagnosis. They seemed to laugh nervously while making this statement: "My brother has type one autism...I don't really know what that means, my parents just told me it was type one and I don't know". Thus, although it seemed that Participant 1 had access to information about autism and the opportunity to openly discuss it at home, they did not entirely understand what autism was in relation to their brother.

During session three, it seemed like Participant 1 was gaining an understanding of ASD and learning to empathize with people who had autism. They were engaging and seemed excited to participate. When shown a video from the perspective of people with autism who explained that they would not change their disorder, Participant 1 stated: "I felt the same way because so many of our inventions have been made by autistic people – it's really cool. So, I don't think I would change that either".

After watching the illusion video, which revealed the perspective of what a child with autism could sound, feel, and look like, the researcher asked how Participant 1 felt about what their sibling could perhaps experience on a daily basis. Participant 1 answered, "I have thought of it but it's kind of hard to imagine it". These statements seemed to demonstrate the progress of Participant 1's thinking regarding their understanding about ASD and its application to their brother. When asked to write everything they knew about autism in pairs, Participant 1 responded that it was difficult for their brother to understand social etiquette and emotions within others at times. For instance, they stated:

My brother doesn't know when to say something and when not to. The other day, my dad was feeling sad because it was Father's Day and my grandfather died over Christmas. My brother said as a joke: why don't you make a Father's Day card and mail it to him.

Subsequently, when addressing questions that the siblings had about ASD, Participant 1 asked the following: "Is there a rough estimate of how many people have autism in the world; How many types of autism are there; and Is it genetic?". Their questions were answered, and they seemed to have a better understanding within the session. By asking these questions, Participant 1 seemed to demonstrate their interest in gaining knowledge about autism and being able to apply it to their own sibling. As Participant 1 was unsure what type of autism their brother had at the start of the support group, they now understood which type of autism he had and its explanation. Finally, during the final Jeopardy activity that tested the newly taught knowledge of autism, Participant 1's knowledge gained through the session seemed to be retained as they answered each question correctly and seemed enthusiastic to participate.

According to scores derived from the *Questionnaire About Autism for Siblings*, Participant 1 showed an increase of 15% in their scores after the support group session. To elaborate, Participant 1 received a perfect score after attending the sibling support group. This suggested that Participant 1 increased their understanding of autism spectrum disorder in general, and perhaps their understanding of their sibling's diagnosis.

**Participant 2.** Participant 2's parents expressed that Participant 2's understanding of autism had evolved since she had discovered that her brother had autism. Her parents stated: "At first she didn't seem to understand, but as she was more exposed to it, she understands". Her parents also indicated that the word "autism" is used at home. When asked about Participant 2's awareness of the disorder, her parents indicated that she felt bad at first, but seemed okay with it.

They also stated that “she started to notice a difference when he was not able to communicate with her”. As previously mentioned, Participant 2’s brother was nonverbal.

During the first session, Participant 2 seemed to express confusion about her brother’s diagnosis. She was asked what her sibling’s diagnosis was, and replied: “I don’t really know, but all I know is that he’s non-verbal, that’s really all I know”. Evidently, though her parents had reported that autism is openly discussed at home, it was clear that Participant 2 had still not come to completely understand autism and how it applied to her brother. When asked about what three wishes she would want, she wished that her brother could talk. Based on the observations and findings from her parent’s demographic questionnaire, it seemed that Participant 2 had not yet fully grasped an understanding of her brother’s diagnosis of autism and how to interact with him, but that it seemed to be evolving.

When addressing famous people with autism, she asked: “aren’t there different types of autism? I forget what it’s called but isn’t there’s a type of autistic where you’re smarter?”. These questions showed that Participant 2 still had not understood the features of autism and was focusing on intelligence rather than the correct key features within ASD. When asked what her sibling had difficulty with, she responded:

My brother has difficulty with speech and it’s hard for him to focus, if you’re talking to him, he gets distracted and looks away. And I think he has difficulty understanding what we’re trying to say to him sometimes.

These instances indicate that she was lacking some information about her sibling’s diagnosis, however, she asked questions and was openly ready to learn new information.

During session three, it seemed as though Participant 2 was starting to gain a better understanding of ASD and learning to empathize with people who have autism. During the Jeopardy game, she answered each question about autism correctly, and seemed motivated to

participate. She seemed to start to gain an understanding of autism in general, and the key features and difficulties that her brother had been facing regarding his autism.

Finally, based on Participant 2's scores derived from the *Questionnaire About Autism for Siblings*, she showed an increase of 8% in her scores after the support group session. There appeared to be an improvement of Participant 2's understanding of autism spectrum disorder in general, and perhaps her understanding of her sibling's diagnosis, as shown with evidence from her score and evidence throughout the support group sessions.

**Participant 3.** Participant 3's parents indicated that they talked openly about autism, and that his understanding of his sister's behaviors seemed to increase after she had received a diagnosis. However, when asked in the first session what his sibling's diagnosis was, he stated: "I don't really know because my mom told me 2 years ago and I forgot". Thus, contrary to his parent's report, it seemed that his knowledge was limited about ASD in general and when referring to his sister.

Though he was unable to attend the second session, he asked questions about autism within the third session. His questions were answered, and he was also given the challenge of communicating some of his questions with his parents, which he agreed to. He also seemed to gain a better understanding of what his sister may have been experiencing. When shown the illusion video, which demonstrated what someone with autism could experience, he stated: "My sister always tells me she cannot be next to a lot of people, it makes her upset – noises bother her". These comments alluded to evidence that he was beginning to gain empathy and an understanding of autism in general and of his sister.

When asked to share what he knew about autism, Participant 3 said: "I find my sister doesn't really get humor and she can't tell when it's the wrong time to say something". He combined ideas with another participant, Participant 5, and listed some things about autism that

he knew. This included: “Whenever I say something sarcastic, she gets serious”. Participant 3 seemed to realize that there were some commonalities between his sister’s features of autism, and the features that other participants’ siblings had as well. During the Jeopardy game, he, like the previous participants, answered each question correctly. He seemed to have retained the information about autism that he had been taught. During the fourth session, he reported that he had completed the homework in explaining autism to his parents. He said, “they were happy that I knew more about autism, and I feel more confident about it”.

Finally, according to scores derived from the *Questionnaire About Autism for Siblings*, Participant 3 showed an increase of 31% in his score after attending the support group. This near perfect score suggested that Participant 3 increased his understanding of autism spectrum disorder in general, and perhaps his understanding of his sister’s diagnosis.

**Participant 4.** Participant 4’s parents indicated that she was completely understanding of her sister’s diagnosis. They indicated that they used the words “autism” and “Asperger’s” at home. During the first session, she indicated that her sister had autism and Asperger’s syndrome, which was the previous diagnosis in the DSM-IV but is now considered as high functioning autism.

During the second session, Participant 4 indicated that her sister had mild echolalia, showing that she understood one of her sister’s symptoms. She was able to list many qualities of autism that her sister had and accompanied it with some of the strategies that her sister used. For instance, she said that her sister struggled with finding what to say but had cards that sometimes helped her. Nevertheless, even though she seemed to demonstrate some knowledge of autism, it seemed to be mainly focused on her sister’s features, and not that of others. When she watched the video of people with autism who said that they would not want to cure their own autism, she responded:

I thought the videos were pretty good, I thought they made interesting points. I liked that they said they wouldn't change even if they could. I never really heard it from their point of view before. I think my sibling would feel the same because she likes it. Whenever we ask her why she does something she says it's because I'm autistic and it's a special talent.

This indicated that she had started to gain an understanding of autism during the session while thinking of her sister and those in general who have ASD. Moreover, during the Jeopardy game, she answered each question about autism correctly, and seemed interested to participate.

Her scores within the *Questionnaire About Autism for Siblings* reflected that she improved in the knowledge that she had of autism in general after attending the sibling support group. As such, her scores increased by 31% and she received a perfect score. Her scores perhaps reflected that she may have had a fair understanding of her sister's autism, as it was high functioning, but not of autism in general. These findings suggest that Participant 4 gained a better understanding of autism after attending the support group sessions.

**Participant 5.** Participant 5's parents indicated that she seemed to notice her sibling had autism around the age of 7-years-old. They indicated in the demographic questionnaire that her understanding of autism was good and that she questioned her mother a lot about autism.

During the first session, when asked about her sibling's diagnosis she simply stated: "my brother has autism". She also stated that one of her wishes, if she could have three wishes, would be: "I wish that my brother didn't have autism and that he could be like me". This indicated that she understood that her brother was different than her, but perhaps did not grasp why. In response to another participant, she stated: "I feel like kids with autism are smarter than regular kids because they can remember everything". She seemed to focus on her brother's diagnosis, but perhaps mistakenly internalized myths for symptoms for the disorder. When asked about how she felt during the illusion activity, she stated, "It's kind of difficult because whenever we hear

one thing that's not that loud, it's like a million times louder to him than it is to us". This statement showed that she was making progress in understanding autism and another person's point of view, perhaps her brother's.

During the third session, she seemed to list many symptoms of autism that were correct. For instance, she said, "I know that most autistic people have trouble communicating, expressing themselves, or socializing". Additionally, during the Jeopardy game, she answered each question about autism correctly, and seemed involved in the game.

Consistent with the improvements of the other participants, Participant 5 also showed progress of her knowledge of autism in her *Questionnaire About Autism for Siblings* score. She showed an increase of 15% in her scores after her attendance of the sibling support group. This score, along with evidence throughout the support group sessions, suggested that Participant 5 increased her understanding of autism spectrum disorder in general, and perhaps better understood her brother's diagnosis as well.

***Research Question #2: Will children perceive an increase in their coping strategies, problem-solving skills, and self-esteem after they attend a sibling support group?***

**Coping strategies and problem-solving skills.** Another significant theme shown in past research was that of providing typically developing siblings with needed coping strategies and problem-solving skills in order to mediate adjustment problems (Brouzos et al., 2017; D'Arcy et al., 2005; Evans et al., 2001; Giallo & Gavidia-Payne, 2008; Granat et al., 2012; Guzman, 2009; Hansford, 2013; Jones et al., 2020; Roberts et al., 2015; Smith & Perry, 2004; Venegas, 2015). Within sessions four, six, and seven, the participants learned various coping strategies, how to regulate their emotions, problem-solving strategies, and elements of restructuring cognitions (see Appendix D). For instance, the children were exposed to various situations that were commonly experienced by TD siblings and were encouraged to identify the possible anxiety triggers (see

Appendix E). This allowed them to redirect their thoughts to something less threatening, eventually replacing their negative thoughts with more adaptive ones. Furthermore, the participants were taught how to build an action plan to break down their problems into steps that were more easily solvable. Another activity that encouraged problem-solving was the ‘Dear Rose’ advice letters, by which participants were given situations by a child similar to them in a difficult situation and were asked to offer advice or a solution. They were also exposed to elements of mindfulness and deep breathing exercises. In order to further evaluate the efficacy that the support group had on the participants’ coping strategies, the participants completed the *KIDCOPE* both before and after the sibling support group (see Appendix H). The results of the *KIDCOPE* administered before the sibling support group for each participant can be found in Table 3, while the results of the *KIDCOPE* administered after the sibling support group for each participant can be found in Table 4.

**Table 3**

*KIDCOPE Scores for Time 1*

Participant	Positive Coping Strategies		Negative/Maladaptive Coping Strategies	
	Frequency (%)	Efficacy (%)	Frequency (%)	Efficacy (%)
Participant 1	40	30	70	50
Participant 2	20	0	80	5
Participant 3	60	60	40	25
Participant 4	80	60	70	40
Participant 5	60	40	70	45

**Table 4***KIDCOPE Scores for Time 2*

Participant	Positive Coping Strategies		Negative/Maladaptive Coping Strategies	
	Frequency (%)	Efficacy (%)	Frequency (%)	Efficacy (%)
Participant 1	80	40	40	5
Participant 2	100	70	70	35
Participant 3	100	90	50	10
Participant 4	80	60	70	20
Participant 5	60	40	90	40

**Participant 1.** As demonstrated within Participant 1's results within the *KIDCOPE* measure, Participant 1's use of positive or adaptive coping strategies doubled after the support group. In other words, before the support group, they were using 40% of the positive coping strategies indicated within the measure, while after attending the support group, they were using 80% of the positive coping strategies. Furthermore, they were more likely to endorse these positive coping strategies. This increase demonstrated that after attending the support group, Participant 1 increased their adaptive coping strategies and were more likely to endorse them.

Equally, Participant 1 used 70% of the negative or maladaptive coping strategies indicated in the *KIDCOPE* measure, while they only used 40% of the negative or maladaptive coping strategies after attending the support group. Moreover, they were 10 times less likely to endorse the negative coping strategies that they had used after attending the support group, indicating the efficacy of the negative coping strategy from being 50% effective, to being 5% effective when used. These results showed that after attending the support group, Participant 1

decreased their negative coping strategies and were less likely to endorse them. In addition, Participant 1 displayed an interesting revelation within their results. Within five of the strategies, which were identified by *KIDCOPE* as being a negative or maladaptive coping strategy, Participant 1 indicated that they had not done the strategy, however they also indicated that it helped them to not do it. For instance, in strategies such as “I did something like watch TV or played a game to forget it”, “I stayed by myself”, “I kept quiet about the problem”, “I blamed myself for causing the problem”, and “I yelled, screamed, or got mad”, Participant 1 indicated that they did not engage in this strategy, however indicated that it helped “a little” to not do it. This not only showed that Participant 1 had learned that using negative or maladaptive coping strategies were ineffective, but that avoiding engaging in them would be effective.

During the fourth session in which we discussed coping skills and emotions, Participant 1 participated well in activities that focused on identifying emotions. When asked to identify both negative and positive feelings they had regarding their sibling, Participant 1 was able to identify both. In this activity, Participant 1 learned that it is important to balance both negative and positive emotions. Furthermore, when asked what coping strategies they used, Participant 1 indicated that when they felt sad, they “swallow it” and “usually talk to no one”. In this session, Participant 1 reflected on the positive coping strategies that they could use, as well as began to identify support systems.

Within the sixth session, Participant 1 continued to identify positive coping strategies. They identified “taking a deep breath or counting to 10” and “walking away and coming back when I’ve cooled down to talk about it” as their preferred coping strategies. Participant 1 also identified a difficult situation that had recently happened and was able to identify solutions along with the other group members.

Finally, during session seven, Participant 1 learned about mindfulness and elements of cognitive restructuring. Both Participant 1 and their parents had reported using these elements at home with both Participant 1 and their brother. They reported their satisfaction and success when used in the home.

Thus, according to Participant 1 and their parent's report, both Participant 1 and their sibling with ASD had seemed to benefit from the mindfulness and relaxation techniques learned from the support group. This paralleled evidence from the *KIDCOPE*, indicating an increase in positive or adaptive coping strategies, and a decrease in negative or maladaptive strategies.

**Participant 2.** According to the results derived from the *KIDCOPE* measure, Participant 2's use of positive or adaptive coping strategies increased by five times after the support group. In other words, before the support group, she was using 20% of the positive coping strategies indicated within the measure, whereas she was using 100%, or all the positive coping strategies indicated within *KIDCOPE*, after attending the support group. Furthermore, she was much more likely to endorse these positive coping strategies. Before the support group, she did not endorse any of the positive coping strategies that she was using. However, after the support group, she showed an endorsement of 70% within the positive or adaptive coping strategies that she was using. This increase demonstrated that after attending the support group, Participant 2 not only increased her adaptive or positive coping strategies but was also more likely to endorse them.

Accordingly, Participant 2 used 80% of the negative or maladaptive coping strategies indicated in the *KIDCOPE* measure, while she used 70% of the negative or maladaptive coping strategies after attending the support group. Conversely, she was more likely to endorse the negative coping strategies she was using after attending the support group than before attending the support group. Though these results may have seemed contradictory, it appeared that she also learned that it was helpful to avoid engaging in negative coping strategies. For instance, though

she indicated that she did not engage in the strategy, “I stayed by myself”, she indicated that it helped “a little” to not do it. This showed that Participant 2 had started to learn that some negative or maladaptive coping strategies were ineffective and that avoiding engaging in them would be effective.

During the fourth session in which we discussed coping skills and emotions, Participant 2 participated well in activities that focused on identifying emotions. When asked to identify both negative and positive feelings she had regarding her sibling, she was able to identify both. In this activity, Participant 2 seemed to learn that it was important to balance both negative and positive emotions. Furthermore, when asked what coping strategies she used, Participant 2 indicated that when she felt lonely or upset, she “sits there until it’s all over” and “I don’t talk to anyone when I have negative emotions”. In this session, Participant 2 reflected on the positive coping strategies that she could use, as well as began to identify support systems.

Within the sixth session, Participant 2 continued to work on identifying positive coping strategies that she could use. For instance, she said that she “could start talking about it” with friends or family members, or “listen to music to calm down” before talking about the situation. When presented with scenarios that could be experienced by her, she participated in thinking of solutions that she could do. Subsequently, during the seventh session, Participant 2 participated in learning about cognitive restructuring and mindfulness. The observations from the support group sessions thus reflected the results from the *KIDCOPE*, indicating an increase in Participant 2’s use of positive or adaptive coping strategies, and a decrease in her use of negative or maladaptive strategies after attending the support group.

**Participant 3.** Based on the findings from the *KIDCOPE* measure, Participant 3’s use of positive or adaptive coping strategies increased by six times after the support group. In other words, before the support group, he was using 60% of the positive coping strategies indicated

within the measure, whereas he was using 100%, or all the positive coping strategies indicated within *KIDCOPE* after attending the support group. Additionally, he was more likely to endorse these positive coping strategies. Before the support group, he endorsed 60% of the positive coping strategies that he was using. However, after the support group, he showed an endorsement of 90% within the positive or adaptive coping strategies that he was using. This increase demonstrated that after attending the support group, Participant 3 not only increased his adaptive or positive coping strategies but was also more likely to endorse them.

Alternatively, Participant 3 used 40% of the negative or maladaptive coping strategies indicated in the *KIDCOPE* measure, while he used 50% of the negative or maladaptive coping strategies after attending the support group. While this displayed an increase in his use of negative or maladaptive coping strategies, he indicated that he was less likely to endorse them or consider them effective. As such, his endorsement of the negative strategies used was 25%, whereas after attending the support group, they decreased to 10%. Furthermore, Participant 3 displayed similar patterns to the other participants. It appeared that he also learned that it was helpful to avoid engaging in negative coping strategies. For instance, though he indicated that he did not engage in the strategies such as, “I just tried to forget it”, “I blamed someone else for causing the problem”, “I wished I could make things different”, and “I didn’t do anything because the problem couldn’t be fixed”, he indicated that it helped “a little” to not do it. In addition, for the maladaptive strategy, “I yelled, screamed, or got mad”, he indicated that he did not do this, and that it helped “a lot” to not to do. This showed that Participant 3 had successfully gained an understanding that negative or maladaptive coping strategies were ineffective and that avoiding engaging in them would be effective.

During the fourth session, in which we discussed coping skills and emotions, Participant 3 participated well in activities that focused on identifying emotions. When asked to identify

both negative and positive feelings he had regarding his sibling, he was able to identify both. In this activity, Participant 3 learned that it is important to balance both negative and positive emotions. Furthermore, when asked what coping strategies he used, Participant 3 indicated that when he felt lonely or upset, “I just sit in my bed. I don’t really know what to do”. In this session, Participant 3 reflected on the positive coping strategies that he could use, as well as began to identify support systems.

Though Participant 3 was absent during the sixth session, an email was sent to his parents that contained useful positive coping strategies. In the beginning of the seventh session, we discussed the strategies and ones that he could use. Afterwards, Participant 3 joined in learning about cognitive restructuring and mindfulness. The evidence taken from the support group sessions seemed to be consistent with the results from the *KIDCOPE*, indicating an increase in Participant 3’s use of positive or adaptive coping strategies. Perhaps his negative or maladaptive strategies did not increase after attending the support group because he was not present for one of the sessions that was focused on problem-solving skills and coping strategies. Nevertheless, it seemed that he still learned that negative or maladaptive coping strategies were ineffective.

**Participant 4.** According to the results derived from the *KIDCOPE* measure, Participant 4’s use of positive or adaptive coping strategies remained the same before and after attending the support group. However, she indicated that she used over half of the positive coping strategies identified by *KIDCOPE*, and that she was over half as likely to endorse them.

Consistently, Participant 4 showed no change in her use of negative or maladaptive coping strategies before and after attending the support group. However, she was half as likely to endorse the negative coping strategies that she used after attending the support group. This suggested that she had begun to learn that negative or maladaptive coping strategies were ineffective. Not surprisingly, she also displayed patterns similar to the other participants. Though

she indicated that she did not engage in the strategy, “I kept quiet about the problem”, she indicated that it helped “a little” to not engage in this strategy. In addition, for the maladaptive strategy, “I didn’t do anything because the problem couldn’t be fixed”, she indicated that she did not do this, and that it helped “a lot” to not to do. This showed that Participant 4 had successfully gained an understanding that negative or maladaptive coping strategies were ineffective and that avoiding engaging in them would be effective.

It should be noted that Participant 4 had difficulty with her internet connection and therefore often had a bad connection. Perhaps this may have explained the lack of change reported in her coping strategies, both positive and negative.

Nonetheless, Participant 4 was present for the sessions in which we discussed coping strategies, problem-solving skills, cognitive restructuring, and mindfulness. During the fourth session in which we discussed coping skills and emotions, Participant 4 joined in on activities that focused on identifying emotions. During the sixth session, Participant 4 identified positive coping strategies. She said, “When I have a problem, if I can I just walk away and I try to read a book that makes me calm, so it gives me something out to focus on that makes me calm”. The importance of following her calming down with talking to the person and finding a solution was emphasized. Later, Participant 4 partook in learning about cognitive restructuring and mindfulness. Though there were no differences in her pre- and post-test *KIDCOPE* results, it seems that she still learned that negative or maladaptive coping strategies were ineffective.

***Participant 5.*** According to the results derived from the *KIDCOPE* measure, Participant 5’s use of positive or adaptive coping strategies remained the same before and after attending the support group. Furthermore, Participant 5 indicated an increase in her use of negative or maladaptive strategies. In other words, she indicated that she used 70% of the negative coping strategies before the start of the support group and used 90% after attending the support group.

Nevertheless, she appeared to decrease her endorsement of these negative strategies by 5% after attending the support group. It seemed unclear why Participant 5 showed no change in positive coping strategies and an increase in negative coping strategies. However, some insight into these results could be found within her engagement during the sessions.

During the fourth session in which we discussed coping skills and emotions, Participant 5 contributed well to activities that focused on identifying emotions. When asked to identify both negative and positive feelings she had regarding her sibling, she was able to identify both. In this activity, Participant 5 learned that it was important to balance both negative and positive emotions. Furthermore, when asked what coping strategies she used, Participant 5 indicated that she did not know what she could do when she had negative emotions. When suggesting that she could talk to a trusted adult, such as a parent, or friend, she said:

If I try to talk to my parents but I feel like they don't understand. They'll just say 'ok' and then it'll just be the way it always was. If I do ask them, then it's just back to reality. I don't talk to them about it. I have no one else I can talk to (no friend or other family members).

When encouraged to discuss with her parents with other strategies, such as writing what she wanted to say first, she responded "I guess I could try". This discussion may have alluded to evidence that Participant 5 was unable to establish positive coping strategies, as it seemed that she often did not perceive that she had support available to her. When asked if she tried the suggestions made, to write what she had to say to her parents on paper, she replied:

I tried it a few times, but it never really works. When I get angry about something I try to write down my feelings because I can't express them, but it never really works for me, and I end up just scribbling on the page.

In response, we went over ways that she could calm down first before writing her feelings, and that this was an important antecedent step to expressing herself, whether it be on paper or face to face.

Furthermore, when discussing 'Dear Rose' letters and giving advice to similar others in order to work on problem-solving skills and coping strategies, Participant 5 said that the hypothetical girl would need to get into trouble to receive attention from her parents. She seemed to overtly condone maladaptive coping strategies during the sessions. Though we had discussed this further, and she received many examples of positive coping strategies that she could use, it did not seem as though she had internalized them given her limited resources at home. Perhaps this served as evidence for her increase in negative or maladaptive coping strategies after the support group.

During the sixth session, Participant 5 continued to work on identifying positive coping strategies that she could use. For instance, she said that she could calm down by using a fidget spinner or drawing. Participant 5 also identified a difficult situation that had recently happened and was able to identify solutions along with the other group members. Subsequently, during the seventh session, Participant 5 participated in learning about cognitive restructuring and mindfulness. Furthermore, Participant 5 seemed proud during the last session in showing that she printed the coping strategies that we had discussed.

Thus, the evidence from the interactions during the support group sessions may have served as an explanation for the results obtained from the *KIDCOPE*, whereby Participant 5's use of positive or adaptive coping strategies remained stagnant, while her use of negative or maladaptive strategies increased. Though we had many discussions about coping strategies and problem-solving skills during the sessions, it seemed like Participant 5 required further intervention given her complex family life.

**Self-Esteem.** Increasing self-esteem was another goal that was targeted in the support group. This was due to evidence from previous literature indicating that TD siblings had shown a heightened risk of developing low self-esteem due to factors including lack of attention that was received from family members, having limited opportunities to express their emotions, and feeling isolated from peers in similar circumstances (D'Arcy et al., 2005; Evans et al., 2001; Gafoor, 2015; McCullough & Simon, 2011). During fifth session, the participants were thus asked to draw a picture of themselves and write their best qualities as homework (see Appendices M-O). Furthermore, other fun activities, such as playing self-esteem games, identifying their good qualities, and writing about their likes and stories aimed to contribute to an increase in self-esteem (see Appendix E).

**Participant 1.** During the first session, Participant 1 seemed to enjoy the “All About Me” icebreaker activity, which focused on sharing information about themselves, such as their likes and dislikes. Furthermore, they seemed to find commonalities with the other group members, such as enjoying reading and drawing.

Though Participant 1 was absent for the fifth session, which discussed self-esteem, a review of the session was given to them prior to the sixth session. Furthermore, they completed the homework, which was to draw a picture of themselves that included all their best skills and positive attributes. They gave consent for the picture to be shared, and it is included in Appendix M. In their drawing, they included positive attributes such as, “strong”, “responsible”, “interesting”, “smart”, “caring”, “awesome”, “kind”, and “fun”. When asked if they enjoyed the activity, they responded that they did. Though self-esteem was not overtly measured, the qualitative data suggested that Participant 1 learned more about self-esteem during the support group sessions.

**Participant 2.** During session one, Participant 2 also seemed to enjoy the “All About Me” icebreaker activity, which focused on sharing information about herself, such as her likes and dislikes. Furthermore, she found commonalities with the other group members.

During session five, we had focused on learning about self-esteem. When asked if she knew what self-esteem was, she replied that she had heard of it before. Later, she answered each self-esteem question correctly within the self-esteem game. After the lesson, she was shown ways that we could increase our own self-esteem. Within the list of examples, she chose “look in the mirror and tell yourself ‘I love you’” and “Create; build; cook; bake; garden; do art” as her favorite examples. When choosing one word to describe herself, she chose “creative” amongst a list of examples. Finally, when responding to the prompt “I’m great because...”, she responded, “I’m naturally gifted at drawing and painting, and others say I have a good sense of humour”.

She completed the homework, which was to draw a picture of herself that included all her best skills and positive attributes. She gave consent for the picture to be shared, however when asked for it to be sent via email, her parents said that she had lost the drawing. Nevertheless, during one of the sessions, she explained that in her drawing, she had included positive attributes such as, “I am fun”, “I am interesting”, “I am strong”, “I like to paint”, “I am kind”, and “I am funny”. When asked if she enjoyed the activity, she responded that she did. Though self-esteem was not overtly measured, the qualitative data suggested that Participant 2 had gained knowledge and perhaps increased her self-esteem after attending the support group.

**Participant 3.** During the first session, Participant 3 seemed to enjoy the “All About Me” icebreaker activity, which focused on sharing information about himself, such as his likes and dislikes. Furthermore, he seemed to find commonalities with the other group members, such as enjoying skateboarding and drawing. He seemed to be quiet in the beginning of the sessions but had begun to open up and answer more questions as the sessions progressed.

When asked if he knew what self-esteem was, he replied that he did not. Following the self-esteem lesson, Participant 3 successfully answered each question correctly about self-esteem. Within the list of examples of ways that we could increase our own self-esteem, he chose “treat others the way you would like to be treated” as his favorite example. When choosing one word to describe himself, he chose “caring” amongst a list of examples. Finally, when responding to the prompt “I’m great because...”, he responded, “Others think I’m great because I’m always nice to them and friendly, I always play with them. I sometimes say no to stuff I don’t like but yes to things that I want to do”.

He completed the homework, which was to draw a picture of himself that included all his best skills and positive attributes. However, he did not want to share the picture with the group. He agreed to send the picture via email, but his parents were unable to find the drawing. Nevertheless, it seemed that he enjoyed the self-esteem activities.

*Participant 4.* During the first session, Participant 4 seemed to enjoy the “All About Me” icebreaker activity, which focused on sharing information about herself, such as her likes and dislikes. Furthermore, she seemed to find commonalities with the other group members, such as enjoying reading and drawing.

When asked if she knew what self-esteem was, she replied that she did not. After learning about self-esteem, she answered the questions in the self-esteem game correctly. Subsequently, she was shown ways that we could increase our own self-esteem. Within the list of examples, she chose “don’t compare yourself to what you see in the media” as her favorite example. When choosing one word to describe herself, she chose “creative” amongst a list of examples. Finally, when responding to the prompt “I’m great because...”, she responded that she was not sure what to respond. Thus, it seems that she had difficulty thinking of positive attributes within herself.

When brainstorming her positive qualities together, she finally realized, “I’m good at tennis, swimming, and reading. I’m also good at listening”.

She completed the homework, which was to draw a picture of herself that included all her best skills and positive attributes. She seemed eager to share her artwork and volunteered to share it first. She gave consent for the picture to be shared, and it is included in Appendix N. In her drawing, she included positive attributes such as, “helpful”, “clever”, “good at trying”, “thoughtful”, “kind”, “good listener”, and “good helper”. When asked if she enjoyed the activity, she responded that she did. Though self-esteem was not overtly measured, the qualitative data suggested that Participant 4’s self-esteem had increased after attending the support group when compared to her responses at the start of the sessions.

***Participant 5.*** Participant 5 seemed to enjoy the “All About Me” icebreaker activity, which focused on sharing information about herself, such as her likes and dislikes. Furthermore, she seemed to find commonalities with the other group members, such as enjoying sports and drawing. However, she seemed to be reserved and quiet throughout the session. She would put her head down when asked a question, and often said that she would like to pass on the question. However, as the weeks progressed, she seemed to become more comfortable and open to sharing her experiences. She would volunteer first to answer the questions and made comments throughout the sessions. Furthermore, she seemed to have more confidence while answering questions that she did not know the answers to when the support group had begun. For instance, when asked in the first session what she said to others when they asked about autism, she replied, “I don’t know”. During the fifth session, when asked what we could do if we got teased or questioned by others, she replied, “Talk to someone about it. You can talk to a counselor, parents, or any adult that’s around”.

During the fifth session, we had focused on learning about self-esteem. When asked if she knew what self-esteem was, she replied that she did not. After the lesson, she was shown ways that we could increase our own self-esteem. Within the list of examples, she chose “don’t compare yourself with others, you are unique” as her favorite example. When choosing one word to describe herself, she chose “creative” amongst a list of examples. Finally, when responding to the prompt “I’m great because...”, she responded, “it makes me feel good when I aced something, when I get a good grade on a test, or something like that”.

She completed the homework, which was to draw a picture of herself that included all her best skills and positive attributes. She gave consent for the picture to be shared, and it is included in Appendix O. In her drawing, she included positive attributes such as, “I am helpful”, “I am creative”, “I am good at drawing”, “I am brave”, “I am smart”, “I am good at sports”, and “I am funny”. When asked if she enjoyed the activity, she responded, “I felt happy about drawing the self-esteem activity”. Though self-esteem was not overtly measured, the qualitative data suggested that Participant 5’s self-esteem had increased after attending the support group when compared to her responses at the start of the sessions.

***Research Question #3: Will children’s relationships improve with their sibling after attending a sibling support group?***

Throughout the sessions, another goal that was targeted was improving the relationship between the TD sibling and the sibling with ASD. Correspondingly, three questions in the *View of Siblings Questionnaire (VSQ pre and post)* administered before and after the start of the support group asked about the relationship between the TD sibling and the sibling with ASD (see Appendix I and J). Discussions and activities throughout the sessions focused on assisting the participants to develop an understanding for their sibling, as well as methods in which they could better communicate and interact with them that was mutually beneficial.

**Participant 1.** The following results regarding Participant 1's changes in their relationship with their sibling was observed throughout session two, three, and six, in addition to information gathered from the *VSQ*, the demographic questionnaire completed by their mother, and in email exchanges with their mother.

According to Participant 1's self-report on the *VSQ (pre and post)*, they got along with their brother "somewhat well", "played around and had fun" with them "often", and "disagreed or fought" with their sibling "sometimes". They also reported that they often felt angry with their brother. However, from the results taken from the demographic questionnaire, it seemed that Participant 1 had already established a good relationship with their sibling. Their mother had reported that they had a good relationship. Consequently, there was no report of change before and after the support group.

Nevertheless, it should be noted that Participant 1 was observed to be thoughtful when watching a video about people who have autism during the second session. When asked what they thought about people in the video saying they would not change having autism, Participant 1 said, "I felt the same way because so many of our inventions have been made by autistic people – it's really cool. So, I don't think I would change that". Furthermore, after watching the illusion video, Participant 1 said, "I have thought about my brother experiencing this but it's kind of hard to imagine it". Furthermore, in the third session, Participant 1 learned more about empathy and what it meant to understand someone from their perspective. Participant 1 also participated in balancing positive and negative emotions they had for their brother.

During the sixth session, Participant 1 spent time reflecting on a difficult situation they had with their brother. Participant 1 and the group thought of alternate solutions to the situation that they presented. Finally, after the mindfulness and cognitive restructuring session, it seemed

that Participant 1 had applied the information he had learned to their life in order to improve their relationship with their brother. The following meeting, Participant 1 expressed:

I tried the relaxation techniques and it quite helped. I didn't even notice it at first until my mom pointed it out. After we did the relaxation video, my brother and I hadn't argued at all for the rest of the evening. And usually something happens, we would have started arguing, but that didn't happen, and my mom pointed it out. So yeah, every time he gets angry, we get him to do the relaxation techniques. It helps a lot with him.

Their mother had also emailed the researcher expressing that "Participant 1 and their brother had the most peaceful, cooperative play together after the last session that I had seen in quite a while!".

Thus, although it did not seem that Participant 1 self-reported an improvement in their relationship with their brother, it should be noted that both Participant 1 and their parents had noticed an improvement in the relationship, nonetheless.

**Participant 2.** The following results regarding Participant 2's changes in her relationship with their sibling was observed throughout session two, three, five, and six, in addition to information gathered from the *VSQ*.

Based on Participant 2's self-report on the *VSQ* (*pre and post*), she got along with her brother "somewhat well", "played around and had fun" with him "sometimes", and "disagreed or fought" with him "often". She had also reported that she often felt angry with her brother. After attending the support group, she reported a change in how much she disagreed or fought with her brother, which had changed to "sometimes".

Additionally, Participant 2 seemed to be willing to find solutions when it came to getting along with her brother throughout the sessions. During the second session, she reflected on her and her sibling's differences and commonalities. She smiled throughout the interaction and

seemed responsive to the questions being posed. During another activity, she was able to find three differences, three commonalities, and three things that her brother was good at, while thinking of her brother's perspective of the world. Moving forward into session three, Participant 2 started to understand what empathy was, keeping her brother in mind. She was also given games and activities that she could do with her sibling and challenged to do so for homework as the weeks progressed.

As previously mentioned, Participant 2 began to balance her positive and negative emotions that she had for her brother. During the fifth session, she reflected on the "Dear Rose" letter and associated it to a moment she was also proud of her brother:

Can I say a time where my friends were proud of my brother? They came over and we went to play in a skating rink. My brother got on a skateboard and started doing it like he already knew how to do it for five years. My friend was just staring at him the whole time like "what". She was shocked. I wasn't really surprised; it happens a lot where he does stuff out of the blue and he's good at it. I was still proud of him.

During the sixth session, Participant 2 spent time reflecting on a difficult situation she had with her brother. She and the group thought of alternate solutions to the situation that she presented. She seemed to gain an understanding of how to better interact and communicate with her sibling, which may have contributed to the improvement of her relationship with her brother.

**Participant 3.** The following results regarding Participant 3's reflection of his relationship with his sibling was observed throughout sessions two and five, in addition to information gathered from the *VSQ*.

The results from Participant 3's self-report on the *VSQ (pre and post)* revealed that before the start of the support group, he got along with his sister "very well", "often played around and had fun" with her, and "sometimes disagreed or fought" with his sister. After attending the

support group, Participant 3 revealed a change in his relationship with his sister. He indicated that he “always played and had fun” with his sibling. From these results, it seemed that Participant 3 had already established a good relationship with his sibling, but perhaps the support group helped him develop a better play relationship with her.

Participant 3 also seemed to be willing to find solutions when it came to getting along with his sister throughout the sessions. During the second session, he reflected on their differences and commonalities. He was also able to find three differences, three commonalities, and three things that his sister was good at, while thinking of his sister’s perspective of the world. Participant 3 had also developed an understanding of what empathy was when thinking of his sister. He was also given games and activities that he could do with his sibling and challenged to do so for homework as the weeks progressed.

As previously mentioned, Participant 3 had begun to balance his positive and negative emotions that he had for his sister. During the session five, he reflected on the “Dear Rose” letter and associated it to a moment he was also proud of his sister:

A time when I was proud of my sister; when I was a kid, she really didn’t like roller coasters, and we went on and she really got scared, but then she really liked it. And now she always says let’s go to LaRonde. I always tell her that (how brave and amazing she is).

Thus, it seemed that the group was successful in helping Participant 3 become better able to play and get along with his sister.

**Participant 4.** The following results regarding Participant 4’s reflection of her relationship with her sibling was observed throughout sessions one and two, in addition to information gathered from the *VSQ*.

Based on Participant 4's self-report on the *VSQ (pre and post)*, she got along with her sister somewhat well, never played around and had fun with her, and often disagreed or fought. She also reported that she often felt angry with her sibling. After attending the support group, she reported that she had now often played around and had fun with her sister, which was two points higher than what she had previously indicated. This shift was also observed within the support group sessions.

During the first session, when asked what she would wish for if she had three wishes, one of her wishes was that her sibling "actually" play with her. Within the second session, she was able to find three commonalities, three differences, three things her sibling had difficulty with, and three things that her sibling was good at. However, she had expressed that it was easy to find differences, while it was difficult to find commonalities. In this session, she was guided to think of more commonalities and ways that she would play with her sibling. Later, she was also taught about empathy and viewing a situation from someone else's perspective, such as her sister's. When asked what she thought about a video whereby people with autism said that they would not cure it, she responded:

I thought the videos were pretty good, I thought they made interesting points. I liked that they said they wouldn't change even if they could. I never really heard it from their point of view before. I think my sibling would feel the same because she likes it. Whenever we ask her why she does something she says it's because I'm autistic and it's a special talent.

Thus, it seems that she had begun to gain an understanding of her sister's point of view. She was also given games and activities that she could do with her sibling and challenged to do so for homework as the weeks progressed. As previously mentioned, Participant 4 began to balance her positive and negative emotions that she had for her sister.

**Participant 5.** The following results regarding Participant 5's reflection of her relationship with her sibling was observed throughout sessions one, two, and five, in addition to information gathered from the *VSQ*.

On the *VSQ (pre and post)*, Participant 5 reported she got along with her sibling "okay", "sometimes played around and had fun" with him, and "often disagreed or fought". After the support group had ended, she had reported no change in her relationship with her sibling. Considering Participant 5's complex family situation and based on observations from the support group, perhaps Participant 5 had required further intervention that was not provided by the support group.

Accordingly, Participant 5 had reported within the first session that she had wished her brother did not have autism and could be more like her. She had also wished that she had more siblings:

Because just having one sibling and they're older and they don't want to hang out with you, and they just want to do teenage things. He doesn't like to hang out with me. If he's playing with something he just doesn't want to play with me and then I have to get out of the way.

Based on these observations, it seemed that Participant 5 and her brother had difficulty in their relationship with one another.

During the second session, she seemed to be aware that she was able to find many differences between her and her sibling, however had difficulty finding commonalities. When thinking of differences that she and her brother had, she seemed upset. She said, "It's always about what he wants. We have to watch his show, we have to play whatever games he wants to play, and it's annoying". Nevertheless, she reflected on what empathy was and how to think of her brother's perspective as well. When asked what she thought about an illusion video where

she was shown what it could be like to have autism, she responded, “it’s kind of hard to deal with when we’re not in his shoes”. When asked what she thought about a video whereby people with autism said that they would not cure it, she responded, “Well, I guess they didn’t want to cure it because having a world full of different people is better than having a world with people that are all the same”.

She was also given games and activities that she could do with her sibling and challenged to do so for homework as the weeks progressed. Participant 5 had begun to learn to balance her positive and negative emotions that she had for her brother with guidance. To practice, Participant 5 participated in giving advice when presented with the “Dear Rose” letters. She had also presented difficult situations that she had with her brother throughout the sessions and came up with solutions with the group. Thus, though it seems as though she had begun to work on her relationship with her brother, perhaps she had required further intervention.

***Research Question #4 and #5: Will children express an increase in open communication with their parents and/or peers after they attend a sibling support group? How will typically developing siblings perceive the sibling support intervention?***

Throughout the sibling support group, the participants had the opportunity to express their feelings and share their experiences, which facilitated the connection that they had formed with one another. Discussions and activities throughout the sessions focused on ways to cope with difficulties faced regarding their siblings, as well as ways to utilize their support networks (see Appendix D and E). Children were taught that they were not alone, despite each of them expressing loneliness, and that they had a support system they could confide in. At the end of the support group, the participants had the opportunity to exchange telephone numbers and *discord* accounts to keep in contact with one another, to which they all did. To evaluate intervention satisfaction, information was gathered from observations throughout the support group sessions,

and the *View of Siblings Questionnaire (VSQ)*, and the demographic questionnaire completed by parents).

**Participant 1.** At the start of the support group, Participant 1 expressed what they were looking forward to by attending a sibling support group. They said:

I think this group can help because everyone in this group probably has similar experiences to what I have and if I wanted to talk to my friends, it wouldn't make sense because none of them have siblings with autism.

This is consistent with Participant 1's answer within the *VSQ*. When asked what they would like to get out of being part of a sibling support group, they responded, "I would like to see other kids my age's experiences". Similarly, Participant 1's parents indicated consistent hopes for the group within the demographic questionnaire:

We hope that this group will allow our eldest to connect with peers who are living with some shared experiences. There have been times where it feels like we are living with a low level of trauma, and I think that it would be good for our eldest to be able to talk about all of this with understanding people outside of our family.

Furthermore, their parents had indicated that their relationship with Participant 1 was "very good".

Throughout the sessions, it should be noted that the participants often expressed similar situations and mentioned that they related to one another. During the sixth session, Participant 1 reflected on ways that they could ask for help and realized that it is often difficult for them to ask for help. They explained, "I'm honestly not sure why I can't ask for help, it just seems hard to come up to the person and ask for help". Subsequently, after being introduced with examples of how we can ask for help, they applied these techniques when participating in an activity with scenarios in which they needed to ask for help.

As previously mentioned, Participant 1 had indicated within the fourth session that they talked to no one when something bad happened. However, when giving advice in the “Dear Rose” letters, Participant 1 indicated that we could talk to parents when faced with difficult situations. Likewise, during the support system activity within the last session, Participant 1 thought about who they could confide in when they needed support. They indicated that they could find support from their parents, cousin, and grandmother. In reflecting on what they wished their parents knew, they said, “I’m grateful for my parents being there for me, because they’re always there for me. If I have something to tell them they always listen”. A positive comment that they wanted to say to their parents was, “I’m grateful for my brother; he always hangs out with me, which I’m happy about. I’m grateful for my parents accepting who I am”. Furthermore, when reflecting what they liked about the group, they said, “Usually I can’t talk to anyone about any stuff that happens at home because they don’t really understand what I’m talking about, but I’m really happy that we could do this, and everyone understood”. Within the *VSQ* that was administered after the support group, Participant 1 indicated that they got what they wanted out of being part of the support group. They also said, “I very much enjoyed the support group, thanks so much for doing it!”.

**Participant 2.** Participant 2’s mother indicated within the demographic questionnaire that their relationship with her was “Very close. I like to think we are more like friends most of the time”. However, though perhaps they may have had a good relationship, it seems that Participant 2 had difficulty communicating openly at times with her parents. In the fourth session, Participant 2 indicated that she did not talk to anyone when she had negative emotions. She agreed that when faced with a difficult situation, there are many different people that she could rely on for support. Consequently, during the last session, Participant 2 said, “I talk a lot with my parents”, and therefore said that her parents knew everything when asked what she

wished her parents knew. In reflecting on positive comments that she could say to her parents, she said, “my parents are very supportive, and I like that they respect my decisions, and they make me happy most of the time”.

Though it seemed as though Participant 2 had already developed a good communication with her parents, perhaps the support group enabled her to be even more open with them. Nevertheless, her parents had indicated that she had difficulty expressing herself with others at times. In an email exchange with Participant 2’s mother, she said, “I hope she opens up, she tends to keep things she’s feeling to herself at home. I’m hoping these sessions will get her out of her shell a little”. Within the observations during the sessions, it was noted that Participant 2 seemed to express herself well, share her experiences, and relate to other sibling’s experiences. Within the *VSQ* that was administered after the support group, Participant 2 expressed, “It was a helpful and nice to share our worries. Living with my brother with autism is challenging but I try to face it one day at a time, one situation at a time”. Thus, it seemed that Participant 2 had gained a peer network from the support group and had gained a space in which she could express her experiences in an understanding environment.

**Participant 3.** Participant 3’s mother indicated within the demographic questionnaire that her relationship with him was “Very close and confident”. This is consistent with what Participant 3 had said in the fourth session, when he indicated that he talked to his mother or parents when he had negative emotions. Correspondingly, during the support system activity within the last session, Participant 3 thought about who he could confide in when he needed support. He indicated that he could find support from his parents, his best friend, and his sister. In reflecting on what he wished his parents knew, he said that he was open with his parents and that they knew everything he wanted them to know. A positive comment that he wanted to say to

his parents was, “I’m grateful that my parents are always helping me and are kind and supportive”.

Additionally, when reflecting what he liked about the group, he said, “it was good to talk with people that know what autism is, because my friends don’t really know. But all of you know so I can talk to you and it’s easier”. Within the *VSQ* that was administered after the support group, Participant 3 indicated that he got what he wanted out of being part of the support group and was thankful. Though he seemed to have already established an open communication with his parents, he seemed to have benefitted from developing a peer network of individuals similar to him.

**Participant 4.** It should be noted that due to Participant 4’s poor network connection, her responses were limited regarding this topic. Participant 4’s parents indicated within the demographic questionnaire that their relationship with her was “Very good”. This is consistent with what Participant 4 said in the fourth session, when she indicated that she could talk to her parents when she had difficult emotions. In an email exchange, her mother apologized for the poor connection, but that she “certainly seems to be enjoying the sessions”. Correspondingly, during the support system activity within the last session, Participant 4 thought about who she could confide in when she needed support. She indicated that she could find support from her parents, her friends, and her sister. In response to the *VSQ* that was administered after the support group, Participant 4 indicated that she got what she wanted out of being part of the support group and was thankful.

**Participant 5.** Participant 5’s mother indicated within the demographic questionnaire that her relationship with her was good. Though she may have perceived that they had a good relationship, Participant 5 expressed concerns of her parents’ unresponsiveness when she required their support. As previously mentioned, Participant 5 expressed that if she tried to talk

to her parents, she felt like they did not understand her. Throughout all the sessions, she repeatedly expressed that she could not talk to anyone about her concerns. She also expressed that she did not have any friends.

Throughout the sessions, it should be noted that the participants often expressed similar situations and mentioned that they related to one another. As previously mentioned, when Participant 5 joined the group, she seemed reserved and avoided answering questions. However, as the weeks progressed, she seemed more eager to participate. When asking general questions to the group, giving the opportunity for anyone to answer, she had started volunteering first to answer them.

During the sixth session, Participant 5 reflected on ways that she could ask for help and realized that it is often difficult for her to ask for help. She explained:

Sometimes it's hard to explain the problem or the situation and they're not really trying to understand it, so that's kind of hard. And also, they never have free time. Even though it says, "do you have free time", no one really has any free time so that doesn't help either.

Subsequently, after being introduced with examples of how we can ask for help, she applied these techniques when participating in an activity with scenarios in which she needed to ask for help. She also expressed difficult situations that she was in throughout the sessions, and we brainstormed different solutions, to which she said she would apply. In consequence, she reported what happened when she talked to her mother:

I told my mom how I felt about it; I know he should get more attention, but I never get to spend time with them alone except for 1.5 hours a week on Thursday, which is not enough for me. Not to be greedy or anything. My mom understood and she wished that

she could put a babysitter with him for an afternoon and that I can spend time with her, but because of covid, she can't do that.

She expressed that she felt good after talking with her mother and was encouraged to continue to have more open discussions with her parents. Consequently, during the support system activity within the last session, Participant 5 thought about who she could confide in when she needed support. She indicated that she could find support from her parents, her friends, and the support group. In reflecting on what she wished her parents knew, she said:

I wish they felt how it was to be in my shoes because they don't see my brother every day and they don't have to deal with his behavior every day because they don't live together. And they don't see how he pushes me around – I just wish they could understand.

Thus, it seems that towards the end of the support group, Participant 5 had started to work on developing open communication between her and her parents, but she required further intervention that perhaps was not sufficient within the support group. As she had a more complex family situation, perhaps Participant 5 would have required further intervention. Nevertheless, it seems as though the sibling support group was successful in providing her with a peer network, as shown in the observations from the sessions.

In response to the *VSQ* that was administered after the support group, Participant 5 indicated that she would have hoped to receive more information on managing her brother's emotions and behaviors. Thus, it seemed that she required further intervention that was beyond the expectations of the sibling support group.

### **Discussion**

This study provided evidence that implementing an online sibling support group led to participants' reported improvements in their relationship with their sibling with ASD. Qualitative results indicated that all participants improved their understanding and knowledge of their sibling's

ASD, benefitted from working on their self-esteem, developed a peer network, and developed their communication skills. Furthermore, most of the participants (60%) increased their use of adaptive coping strategies, while some of the participants (40%) decreased their use of maladaptive coping strategies. The following will address the results of these themes and how it supports and extends the literature reviewed.

### **Knowledge About Their Sibling's ASD**

As previous research has shown, increasing TD siblings' knowledge about their sibling's disorder has been critical in eliminating confusion and stress related to their siblings' symptoms of unpredictable behaviors, ultimately leading to feelings of embarrassment or in some cases, poor psychosocial adjustment (Angell et al., 2012; Corsano et al., 2017; Petalas et al., 2012). In line with these findings, the participants' reports during the sibling support group sessions reflected these feelings of stress, confusion, embarrassment, and so on. Therefore, similar to sessions outlined by previous research, two sessions were targeted to increase knowledge of ASD. In accordance with previous research that has both examined the effectiveness of sibling support groups and measured the knowledge about their sibling's disorder, all five participants successfully increased their knowledge of ASD after the intervention (Brouzos et al., 2017; D'Arcy et al., 2005; Dyson, 1998; Evans et al., 2001; Gafoor, 2015; Gettings et al., 2015; Granat et al., 2012; Hansford, 2014; Jones et al., 2020; Kryzak et al., 2015; McCullough & Simon, 2011; Smith & Perry, 2004; Tudor & Lerner, 2015; Venegas, 2015). In addition, all five participants demonstrated an increase in their understanding of ASD in general, and perhaps their understanding of their sibling's diagnosis as observed by their interactions during the sibling support group sessions. While each of the participants seemed to express confusion regarding their sibling's disorder at the start of the support group, all successfully learned about the definition, characteristics, facts, and myths about ASD after the intervention. This was made

evident through their participation in the relevant games and activities, such as the illusion activity during session two, which was also well-liked by participants within McCullough and Simon's (2011) research. These results parallel each of the findings from previous research mentioned above, confirming that the sibling support group was effective in increasing neurotypical sibling's knowledge of ASD.

### **Coping Strategies and Problem-Solving Skills**

Given that providing TD siblings with coping strategies and problem-solving skills has been shown to mediate adjustment problems when measured, this study measured the acquisition of coping strategies and problem-solving skills from observations of the support group sessions in addition to results from the *KIDCOPE* (Brouzos et al., 2017; D'Arcy et al., 2005; Evans et al., 2001; Gafoor, 2015; Giallo & Gavida-Payne, 2008; Jones et al., 2020; Kyzak et al., 2015; Roberts et al., 2015).

Throughout sessions four, six, and seven, the participants learned various coping strategies, how to regulate their emotions, problem-solving strategies, and elements of restructuring cognitions. Jones et al. (2020), Brouzos et al. (2017) and Hansford (2014) showed that teaching participants about deep breathing and relaxation techniques, such as mindfulness, is beneficial in a sibling support group program. As such, children with the sibling support group responded positively when being taught these techniques. Furthermore, Brouzos et al. (2017), Evans et al. (2001), and Gafoor (2015) demonstrated that facilitating children's ability to balance positive and negative emotions by considering both and accepting them was also beneficial. Similar to these findings, the participating children in this intervention showed that they achieved this ability throughout each session. For instance, many of the participants were observed to reflect on the inefficacy of their maladaptive coping strategies and replace them with adaptive

ones. Finally, the participants learned valuable problem-solving strategies, as outlined by Hansford (2014) with their “COPE” method.

The results of the *KIDCOPE* indicated mixed findings among the five participants, which contrasts the reviewed literature that found a significant reduction in maladaptive coping/adjustment difficulties and behavioral problems in each study. While three of the participants showed an increase within the *KIDCOPE* of their positive or adaptive coping strategies, and a decrease of their negative or maladaptive coping strategies, two participants did not. However, observations from the support group sessions provided evidence that it was beneficial in helping the participants to develop the tools to replace maladaptive coping strategies with adaptive ones. While participants indicated when they did not engage in the maladaptive strategy in the *KIDCOPE*, they also reported that it had helped them to not do it. Many of the participants reported that not engaging in maladaptive strategies, such as “I yelled, screamed, or got mad”, had helped to not use the strategy. This suggested that the participants had concurrently learned that maladaptive coping strategies were ineffective, while avoiding engaging in them would be effective.

### **Self-Esteem**

Previous research has shown that there is a heightened risk for children who have a sibling with disabilities to develop low self-esteem (Evans et al., 2001). D'Arcy et al. (2005) Evans et al. (2001), Gafoor (2015), and McCullough and Simon (2011) identified that some possible explanations could be the lack of attention that they receive from family members, having limited opportunities for affective expression, and feeling isolated from peers in similar circumstances. Though previous research has reported mixed findings in the evaluation of self-esteem, it has also shown that most children enjoyed the support groups and felt that it had positive outcomes (D'Arcy et al., 2005). Although self-esteem was not overtly measured, the

sibling support group provided multiple opportunities for the participants' self-esteem to grow. For instance, during the fifth session, the children participated in activities regarding self-esteem, such as identifying their favorite positive affirmations. They were also given homework to draw a self-portrait that included all their best skills and positive attributes. The participants were given the opportunity to both work on their self-esteem and learn more about maintaining a good self-esteem simultaneously.

### **Sibling Relationship**

Corsano et al. (2017) found that having a brother with ASD had a significant impact on their social life and relationships. The reports gathered from participants during the support group sessions reflected these findings. Thus, this study sought to improve the relationship between the TD sibling and the sibling with ASD. Other previous research had found that a recurrent challenge for the TD sibling was feeling like they had restrictions on their own life activities as they had to be there for their brother with ASD (Corsano et al., 2017; Moss et al., 2019). Consistent with these findings, many of the siblings shared their experiences in their struggle between balancing the responsibilities of their family, and their social lives. Within this study, discussions and activities targeted the development of empathy and managing their sibling relationships. The *View of Siblings Questionnaire (pre and post)* as well as parent and sibling reports revealed an improvement in the sibling relationship of Participant 1, 2, 3, and 4. They seemed to have gained an understanding of how to better interact and communicate with their sibling, which may have contributed to the improvement of their sibling relationships. This is in line with research by Zucker et al. (2021), who emphasized the importance of a sibling support group as being a protective factor against poor mental and social health outcomes and as successful in mediating the challenges that come with this complex sibling relationship. With the majority (80%) of participants demonstrating an improvement in their sibling relationships, these

result point to the benefit that the current sibling support group had on the relationships between the participants and their siblings.

### **Facilitating Open Communication, Developing a Peer Network, and Intervention**

#### **Satisfaction**

As previous research has shown that siblings have consistently reported that they were unable to communicate with parents, thus feeling distant, alone, and unseen, the goal of facilitating communication was apparent (Dansby et al., 2018; Corsano et al., 2017; Petalas et al., 2009). Equally, allowing the participants to develop a peer network was essential in beginning their development of open communication. Consistent with findings from Brouzos et al. (2017) and Jones et al. (2020), the sibling support group included icebreaker activities within the first session. This served to foster a safe environment that allowed children to express their experiences and ask questions. In line with findings by D'Arcy et al. (2005), the sibling support group found that participants increased their willingness to share experiences about their siblings after attending the support group. It seemed that the participants were excited that they were able to share their experiences with similar peers and indicated an improvement in their communication skills by describing both positive and negative experiences with their siblings. Equal to findings by Scelles et al. (2012), it seemed that children felt relieved when their worries and questions were acknowledged and addressed. Finally, Brouzos et al. (2017) included an activity that allowed children to identify important people in their support group, of whom they could turn to when needed. In this support group, children seemed to enjoy the “My Support System” activity (see Appendix E). In line with previous research, the sibling support group thus showed evidence for the facilitation of open communication and the development of a peer network (D'Arcy et al., 2005; Evans et al., 2001; Gettings et al., 2015; Kyzak et al., 2015; Roberts et al., 2015).

These goals lead to the observations of intervention satisfaction within the participants. Previous research has shown that sibling support groups have reported many benefits and high satisfaction when children and parents were interviewed (Brouzos et al., 2017; D'Arcy et al., 2005; Dyson, 1998; Evans et al., 2001; Giallo & Gavida-Payne, 2008; Granat et al., 2012; Hanford, 2014; Kyzak et al., 2015; Roberts et al., 2015; Smith & Perry, 2004; Venegas, 2015). In line with these findings, it seemed that the majority (80%) of the participants were satisfied with the intervention. Consistent with findings by Scelles et al. (2012), the children reported intervention satisfaction, and the parents reported feeling pleased with the group as they were aware of their possible lack in attention and time given to their TD child.

### **Limitations and Future Directions**

As a response to the restrictions imposed by the COVID-19 pandemic, this study was designed as an online intervention. Previous research by Banbury et al. (2018), Gettings et al. (2015), Giallo and Gavida-Payne (2008) reported benefits to providing an intervention online, as it reduced many barriers such as geographical barriers, time constraints, distance, insufficient funds, lack of respite care if caring for someone else, and transportation. They also reported success in providing benefits for their participants. Though the participants benefitted from an online intervention in many ways, it did not come without its challenges. Participants 1 and 3 were absent for two sessions due to unanticipated circumstances related to the pandemic and having to care for their other sibling. Furthermore, technological difficulties were unavoidable throughout the sessions. Though measures were taken to ensure that the participants would avoid these issues, Participant 4 had the most difficulty with her internet connection and therefore it was difficult to observe responses from her during the sessions. Though her parents were notified, they were unable to improve the quality of her internet connection during the sessions.

Future studies should aim to work towards eliminating the challenges that come with technology, though they are perhaps unavoidable.

The recruitment of participants presented its challenges. Despite many clinics and organizations agreeing to post the recruitment flyer, the sample size of the study was small, with only five children available to participate. Thus, conclusions derived from this study are not generalizable and more complex quantitative analysis was not possible. Future studies on this topic should include a larger sample size in order to obtain generalizability. Furthermore, though qualitative findings have shown to provide rich data, this data may only be applicable to the participants found within this study. Future studies should investigate whether the benefits achieved from this sibling support group would be retained on a later occasion.

Finally, four items within the *View of Siblings Questionnaire (VSQ-pre and post)*, found within questions four to seven, had to be omitted from the study as the participants were unable to understand and respond to them. Future studies should revise or replace this measure altogether in order to accurately measure sibling's concerns prior to the support group, and whether they perceive any changes to their concerns after attending a sibling support group.

### **Implications**

Though this study faced its challenges relating to recruitment during a global pandemic and occasional technological difficulties, the findings gathered from the sample are important. This research provides insights into the experiences of children who have a sibling with autism, in addition to new experiences faced by them as a result of the COVID-19 pandemic. These results point to implications of sibling support group, especially with the unexpected and continuous changes that were brought by the pandemic. As such, this research revealed that implementing a sibling support group online is not only feasible but could yield numerous benefits similar to conducting the support group in person, especially during the current time of

limited social interactions. The results point to the importance of the implementation of a sibling support group as it was clear that many of the participating TD siblings required and/or wanted such an intervention and improved on several goals that served to improve their lives.

Furthermore, most of the participants were satisfied with the support group. As TD siblings are often not provided with the same attention as their siblings with ASD, these results point to implications of providing support in general for children who have a sibling with ASD.

### **Conclusion**

Overall, observations of the five participants and data gathered both quantitatively and qualitatively showed that there was improvement in the targeted goals of the study. Thus, the results showed that all participants improved their understanding and knowledge of their sibling's ASD, and benefitted from developing a peer network, working on their self-esteem, and developing their communication skills. The majority of participants reported satisfaction in their attendance of the sibling support group and an improvement in their sibling relationships. In addition, most of the participants (60%) increased their use of adaptive coping strategies, while some of the participants (40%) decreased their use of maladaptive coping strategies. The support that was provided within the group seemed helpful for the participants in allowing them to consider their own experiences and relate to others with similar experiences. The participants seemed excited to be a part of something that was about themselves. The knowledge gained from the current study is useful for parents that have both a TD child and a child with ASD, intervention specialists, psychologists, and researchers.

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**Appendix A**

**Child's Assent Form (10 to 13-years-old)**



## **INFORMATION AND ASSENT FORM FOR CHILDREN (10-13 YEARS OLD)**

**Study Title: A Support Group for Siblings of Children with Autism**

**Researcher: Stephanie da Costa**

**Researcher's Contact Information: [stephanie.dacosta@mail.concordia.ca](mailto:stephanie.dacosta@mail.concordia.ca)**

**Faculty Supervisor: Miranda D'Amico**

**Faculty Supervisor's Contact Information: [miranda.damico@concordia.ca](mailto:miranda.damico@concordia.ca)**

**Source of funding for the study: N/A**

Research studies help us learn new things. We can test new ideas. We ask a question and try to find the answer. This paper talks about our research and gives you a choice to take part in it. You can ask questions to Stephanie (the person doing the research) at any time.

### **A. PURPOSE**

We are doing research to find out more about what happens when children take part in a support group. Only children who have a brother or sister with autism spectrum disorder (ASD), like you, will be asked to take part. A support group will give you and other children a chance to share your experiences about your brother or sister and to talk about things or situations that are important to you.

### **B. PROCEDURES**

If you choose to take part in the support group, you will be asked to share the private experiences you have of your sibling (brother or sister) who has autism with other children like you who also have a sibling who has autism. When you share these things, Stephanie (researcher), Miranda (Dr. D'Amico, supervisor), and other children who also have a sibling will be there listening to you. You will also be asked to take part in group activities and to try to be honest.

We will also ask you to answer questions before we start our meetings, and after we have ended our meetings.

If you take part in the study, Stephanie, Miranda, and the other children will all video chat (on Zoom) for 1 hour a week, for 8 weeks total. The meetings will be video recorded.

### **C. RISKS AND BENEFITS**

Some of the things we talk about might make you uncomfortable or the questions might be hard to answer. We will try to make sure no bad things happen. You can say ‘no’ to what we ask you to do for the research at any time, or not answer. We think being in this research may help you because you will get to learn about autism, find ways to talk about difficult stuff with people you love like your mom or dad, and learn how to calm yourself down when you feel angry, sad, or don’t know what to do.

### **D. CONFIDENTIALITY**

If you take part in the study, everything will be kept confidential. Confidentiality means not telling anyone the things you've told us. We'll keep it private, locked up, and nobody will know except the people doing the research and the other children in the meetings. We also will not tell anyone your name. Even if your parents or teachers ask, I will not tell them about what you say or do in the study. We will only tell someone if we are really worried that you or someone else can get hurt.

It is important that you also do not tell other people what the other children in the meetings say. At the beginning of each meeting, we will remind you about confidentiality, what it means, and why it is important to keep it for others.

### **E. CONDITIONS OF PARTICIPATION**

You do not have to take part in the research. It is really up to you. If you decide to take part, you can stop at any time. You can also ask that whatever you said not be used for the research, and your choice will be respected. If you decide that you don’t want us to use what you say, please tell Stephanie (the researcher) before May 31, 2021 (this will change according to when intervention starts, giving the participant 3 weeks’ time post-intervention). No one will be upset if you don’t want take part in the research, if you don’t want to continue, or if you ask us not to use what you say.

### **F. PARTICIPANT’S DECLARATION**

If you want to be in the research, please write your name below. This shows that we talked about the research, we answered your questions, and that you want to take part.

NAME

---

SIGNATURE

---

DATE \_\_\_\_\_

If you have more questions about the research, please ask Stephanie or Miranda.

If you have concerns about ethical issues in this research, please contact the Manager, Research Ethics, Concordia University, 514.848.2424 ex. 7481 or [oor.ethics@concordia.ca](mailto:oor.ethics@concordia.ca).

**Appendix B**  
**Parent Consent Form**



## **INFORMATION AND CONSENT FORM**

**Study Title: A Support Group for Siblings of Children with Autism**

**Researcher: Stephanie da Costa**

**Researcher's Contact Information: [stephanie.dacosta@mail.concordia.ca](mailto:stephanie.dacosta@mail.concordia.ca)**

**Faculty Supervisor: Miranda D'Amico**

**Faculty Supervisor's Contact Information: [miranda.damico@concordia.ca](mailto:miranda.damico@concordia.ca)**

**Source of funding for the study: N/A**

You and your child are being invited to participate in the research study mentioned above. This form provides information about what participating would mean. Please read it carefully before deciding if you want yourself and your child to participate or not. If there is anything you do not understand, or if you want more information, please ask the researcher.

### **A. PURPOSE**

The purpose of this study is to explore the outcomes of a support group for typically developing children who have a sibling with autism spectrum disorder (ASD). Children between the ages of ten and thirteen will participate together in weekly support group sessions conducted on Zoom over a period of eight weeks. The research questions will explore how the children perceive the sibling support group, whether their knowledge of ASD increases after they attend a support group, and whether the participants perceived an increase in their coping strategies, problem-solving skills, and self-esteem after they attend a sibling support program.

### **B. PROCEDURES**

If you participate, you will be asked to respond and communicate through e-mail pertaining to the research. You will also be asked to fill out a questionnaire prior to the start of the support group sessions.

In total, your participation in this study will take approximately 45 minutes.

If your child participates, they will be asked to answer questionnaire before the sessions have begun, and after the sessions have ended. In addition, they will be asked to attend 8 weekly Zoom sessions, each lasting approximately 1 hour. Each Zoom session will include the presence of other children who have siblings with autism, Stephanie, and Dr. Miranda D'Amico. The topics of each session include learning about autism, working on coping skills and emotions, learning how to handle situations that arise from peers that involve their sibling, working on

problem-solving skills, and learning how to reflect using cognitive strategies to address our thoughts and feelings, and mindfulness. Each Zoom session will be video recorded. The video recording will be for analysis purposes only and it will not be shown for any publications or presentations.

### **C. RISKS AND BENEFITS**

This research may provide benefits for your child who is participating. This may include providing them with knowledge about autism, providing coping strategies and problem-solving skills, and learn ways to facilitate open communication within your family. It will also provide a safe space for your child to talk about the experiences they have with their sibling. However, there is the possibility that your child may get upset and leave in the middle of a Zoom session or require some sort of intervention. Should such a situation arise, Stephanie will contact the emergency contact (parent) by phone.

Both the researcher (Stephanie) and supervisor (Dr. Miranda D'Amico) will be present during the group Zoom sessions with all of the participants. Stephanie will act as a group facilitator and is pursuing this study for her Master's thesis. Stephanie has extensive experience working with children with and without autism as a specialized educator within daycares as part of Resi Kids Inc., thereby integrating disabled children into the childcare facilities. Dr. Miranda D'Amico will supervise the sessions and she has extensive research in this area as she is the research co-director of the Centre for the Arts in Human Development (CAHD) at Concordia University.

### **D. CONFIDENTIALITY**

If both you and your child consent to participate in this research, we will gather demographic information and information about the relationship that your children have with one another.

We will not allow anyone to access the information, except people directly involved in conducting the research. We will only use the information for the purposes of the research described in this form.

The information gathered will be confidential. That means that the research team will know the participants' real identity, but it will not be disclosed. Confidentiality will also be explained to your child as well as the other children participating at the beginning of each session.

We will protect the information by keeping all your information in encrypted files on the researcher's laptop.

We intend to publish the results of the research. However, it will not be possible to identify you or your child in the published results.

We will destroy the information five years after the end of the study.

## **E. CONDITIONS OF PARTICIPATION**

You do not have to participate in this research. It is purely yours and your child's decision. If you do participate, you and your child can stop at any time. You can also ask that the information you provided not be used, such as direct quotes, and your choice will be respected. At the time of withdrawal, all of the participant-specific questionnaires that your child completes, and demographic data completed by a parent will be destroyed. However, please note that it is impossible to obtain complete withdrawal from a group session given that what your child may have shared may influence other participants' answers, making it not possible to completely remove the data. Video-recordings of group sessions will remain in secure storage because the videos contain recordings of group sessions. If you decide that you don't want us to use yours or your child's information, you must tell the researcher up to three weeks after the support group sessions have finalized (21 days). There are no negative consequences for not participating, stopping in the middle, or asking us not to use your information.

## **F. PARTICIPANT'S DECLARATION**

I have read and understood this form. I have had the chance to ask questions and any questions have been answered. I agree to participate in this research under the conditions described.

Please note that signatures from both parents/guardians are required if there are two parents/guardians.

NAME OF PARENT/GUARDIAN 1 (please print)

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SIGNATURE OF PARENT/GUARDIAN 1

---

DATE \_\_\_\_\_

NAME OF PARENT/GUARDIAN 2 (please print)

---

SIGNATURE OF PARENT/GUARDIAN 2

---

DATE \_\_\_\_\_

**EMERGENCY CONTACT**

NAME OF PARENT/GUARDIAN \_\_\_\_\_

PHONE NUMBER (please specify cell/home/work)  
\_\_\_\_\_

If you have questions about the scientific or scholarly aspects of this research, please contact the researcher. Their contact information is on page 1. You may also contact their faculty supervisor.

If you have concerns about ethical issues in this research, please contact the Manager, Research Ethics, Concordia University, 514.848.2424 ex. 7481 or [oor.ethics@concordia.ca](mailto:oor.ethics@concordia.ca).

**Additional Resources**

The following is a list of additional resources that you can visit should you have additional concerns about your typically developing child who has a sibling with Autism Spectrum Disorder (ASD). Your local CLSC or CIUSS in Montreal and surrounding areas is a good resource centre to use to inquire about ways that they can help with your child.

- **ID-ASD PROGRAM**
  - The ID-ASD program combines the services intended to meet the needs of individuals suffering from intellectual disability, global development delay or by autism spectrum disorder. The services of this program aim to reduce the impact of the disability on the person and his family, compensate for the incapacity and support integration and social participation. The program's mandate is to guarantee this clientele access to services intended for the general population as well as access to specialised and ultra-specialised services.  
<https://ciusss-ouestmtl.gouv.qc.ca/en/care-services/dorval-lachine-lasalle-territory/for-everyone/intellectual-disability-and-autism-spectrum-disorder-id-asd/#c45903>
- OTHER CURRENT ONLINE SUPPORT GROUPS (due to accommodations for the pandemic)
  - **Kerry's Place: Autism Services/Services en Autisme**  
Kerry's Place is based in the Ontario region; however, it is possible to participate in sibling support group sessions through Zoom. They offer a chance for siblings of children with an ASD to meet other siblings and talk about the good and not so good parts of living with a brother or sister with special needs. It is an opportunity to chat, play games, and do activities.  
<https://www.kerrysplace.org/contact-us/>

- COMMUNITY ORGANIZATIONS PROVIDING SUPPORT TO FAMILIES AND LOVED ONES
  - **PABEMSOM**  
Covering the territory of South West Montréal—including Lachine, LaSalle, and Verdun—PABEMSOM (Parents et amis du bien-être mental du Sud-ouest de Montréal) aims to bring together parents and families in distress upon finding out a loved one is suffering from a mental disorder.  
[www.pabemsom.org](http://www.pabemsom.org)
  - **Friends for Mental Health**  
Friends for Mental Health is a non-profit organization operating in the West Island whose purpose is to provide support and other resources—such as counselling, training, conferences, support groups—to those close to a person with a mental health disorder.  
[www.asmfmh.org](http://www.asmfmh.org)
  - **AMI-Québec**  
AMI-Québec is a non-profit organization that has many programs to help families cope with mental illness in a loved one. Family members can attend support groups (including one for family members only), workshops, or book an appointment with one of our counselors (for family members only).  
[www.amiquebec.org](http://www.amiquebec.org)

**Appendix C**  
**Recruitment Flyer**



# Take part in an online support group!

## The Goal:

To provide a support group for individuals who have a brother or sister with autism spectrum disorder (ASD). The participants will be a part of a group where they share their experiences, talk about their sibling relationships, and be part of a peer group that they can relate to.

## Who?

If you have a child who is between 10 – 13 years old, and would like to participate in a peer support group.

## What's involved?

The support group will be conducted virtually through Zoom over a period of 8 weeks. The 8 weekly sessions will last approximately 1 hour.

If you and your child are interested,  
please contact for more information

E-mail: [stephanie.dacosta@mail.concordia.ca](mailto:stephanie.dacosta@mail.concordia.ca)

## **Appendix D**

### **Overview of Sibling Support Group Intervention Sessions**

### ***Session 1: Introduction***

This session promoted open communication about various topics, including their sibling, and allowed the participants to start developing comfort with their peer network.

15 – 20 min

The group members were asked to announce their name while saying one interesting fact about themselves (suggestions: favorite movie, favorite candy, favorite hobby, favorite school subject, special talent, etc.) (Brouzos et al., 2017).

After the brief introduction of the members of the group, the group leader briefly informed the participants about the purpose of the support group, the topics of each sessions including the issues they will talk about, and the ways in which they are expected to participate. We also discussed the rules of the group (see Appendix E). They then completed pages from the “All About Me” Booklet (based on Gafoor, 2015; Teachers Pay Teachers, n.d.).

10 min

The group members were asked to share their feelings and expectations of the group. The group leader reflected on the expressed feelings with respect to allow the members to feel safe (Brouzos et al., 2017). They were also asked to share information about their family and siblings.

20 min

Members paired up and shared information about themselves including their families. The other person listened and wrote down what they said in order to repeat back to the group (age, interests, school, sibling with autism: age, level of closeness, school, etc.) (Brouzos et al., 2017). They used information that is written already in the “All About Me” booklet (Appendix E). They also found 3 things that they have in common with that person (Kryzak et al., 2015).

10 min

The pairs shared the information they learned from their group to all of the members.

10 min

Same/Different activity: Each sibling came up with 3 ways that they are the same and different from their sibling with autism (Hansford, 2014). They then presented. The leader asked whether it was difficult to find similarities between themselves and their brother/sister or another sibling in the group.

Conclusion

Message of the week.

Homework

Children were encouraged to speak to their parents and write a reflection about the session and how they felt about being a part of a support group (Brouzos et al., 2017).

### ***Session 2: Let's Learn About Autism***

This session allowed children to start learning about Autism Spectrum Disorder, including its definition, facts, myths, challenges, and more (Brouzos et al., 2017). It was accompanied by various activities that made learning fun and interactive.

5 min	Review of previous week and introduction to this week's theme (including reminder of rules of the group).
10 min	We discussed people's differences. Various images of flowers were shown in order to demonstrate that no flower is "worse", just different and that we may embrace these differences. I explained that each one of us is unique and special. Differences may not be visible at first glance.
10 min	Children were shown pictures of famous people who have ASD including brief information about them. There was an emphasis on showing that people with ASD have both strengths and weaknesses. The children then wrote down three strengths and three weaknesses of their sibling.
20 min	The group members shared what they wrote about their sibling's strengths and weaknesses. The leader helped siblings relate weakness of siblings to characteristics of autism and encouraged them to talk about emotions that relate to the strengths and weaknesses of their sibling.
15 min	Children were shown illusion videos of what it is like to experience autism (McCullough & Simon, 2011). <ul style="list-style-type: none"> <li>• <a href="https://www.youtube.com/watch?v=DgDR_gYk_a8">https://www.youtube.com/watch?v=DgDR_gYk_a8</a></li> <li>• <a href="https://www.youtube.com/watch?v=IApo5TBR7jc">https://www.youtube.com/watch?v=IApo5TBR7jc</a></li> </ul>
10 min	Discussion about videos. Message of the week.

***Session 3: Let's Learn About Autism (Cont'd)***

The children continued to learn about autism spectrum disorder, including its definition, facts, myths, challenges, and more (Brouzos et al., 2017). It was accompanied by various activities that will made learning fun and interactive.

5 min	Review of previous week and introduction to this week's theme (including reminder of the group rules).
10 – 15 min	Children broke into pairs and write down everything they knew about autism (Brouzos et al., 2017). This included the common characteristics and how many people they knew with the diagnosis (Guzman, 2009). They were also be asked about how their experiences may differ from their sibling regarding school, family, friends, etc. (D'Arcy et al., 2005; Smith & Perry, 2004).
5 – 10 min	The groups presented their ideas, and the group leader confirmed whether these conceptions were true.
20 min	The group leader gave a small lesson on the definition, diagnosis, characteristics, facts, treatment, and myths about ASD.
20 min	We played a Jeopardy style game on definitions, facts, and myths about ASD. (Jones et al., 2020). <ul style="list-style-type: none"> <li>• <a href="https://www.playfactile.com/edit/learnasd">https://www.playfactile.com/edit/learnasd</a></li> </ul>
10 min	Discussion about game. Message of the week.

#### ***Session 4: Working on Coping Skills and Emotions***

In this session, group members continued to work through some of their feelings of resentment, guilt, embarrassment, and even anger that they may have felt towards their sibling with autism. However, group members also revealed positive emotions and feelings they had towards their sibling (Brouzos et al., 2017). They also worked on their coping skills through various activities.

5 min	Review of previous week and introduction to this week's theme (including reminder of the group rules).
10 min	The group leader asked questions that elicited answers about their sibling's challenging behaviors (Appendix E)
10 min	We played a game in which we identified people with various positive and negative emotions: <ul style="list-style-type: none"> <li>• <a href="https://create.kahoot.it/share/emotions/7966b97b-75ed-4fb1-b637-f96115f93821">https://create.kahoot.it/share/emotions/7966b97b-75ed-4fb1-b637-f96115f93821</a></li> </ul>
10 min	The group members each thought of instances where they had felt positive and negative emotions in general, and then regarding their sibling with autism or their parents (see examples in Appendix E). They wrote all of the positive emotions on the top of the paper, and all of the negative emotions on the bottom of a paper (see Appendix E; Guzman, 2009). The group leader allowed the children to accept those emotions.
15 min	Group discussion.
20 min	Children were presented with "Dear Rose" letters, and they were asked to act like experts and give advice to the children writing the letters (Dyson, 1998; Gafoor, 2015; Venegas, 2015). They were also presented with various scenarios and asked how they would feel.
10 min	The members talked about who they can talk to when they are experiencing good and bad times (Giallo & Gavidia-Payne, 2008).
Conclusion	Message of the week.

### ***Session 5: Relationships with Others***

Children thought about feelings that arose regarding their sibling and thought of helpful ways of dealing with them. These situations reflected ones that children may experience outside of the home, such as with friends, at school, or other contexts. The focus was on the experiences of TD siblings and will hopefully contributed to an increase in their self-concept and self-esteem.

5 min	Review of previous week and introduction to this week’s theme (including reminder of the group rules).
5 min	The group leader will ask various questions to introduce theme and stimulate conversation (see Appendix E).
10 min	<p>We will watch an animation that shows the perspective of someone who has autism.</p> <ul style="list-style-type: none"> <li>• <a href="https://www.youtube.com/watch?v=CKMmflQy2pk">https://www.youtube.com/watch?v=CKMmflQy2pk</a></li> </ul> <p>Group discussion</p>
10 min	Children will be introduced hypothetical situations and look at more “Dear Rose” letters, this time about contexts involving others (Dyson, 1998; Gafoor, 2015; Venegas, 2015). They will act as experts and give advice to the children writing the letters (see Appendix E).
10 min	Children will break into pairs and talk about their fears, thoughts, and concerns regarding their siblings with ASD (Brouzos et al., 2017). They will be presented with various hypothetical scenarios that ask for advice and whether it has happened to them. The leader will emphasize that they should not feel guilty, embarrassed, or ashamed from having these thoughts and that it is a safe space to express them. Having negative feelings is normal. We will then discuss these as a group.
10 min	The group leader will introduce the topic of self-esteem. Children will be presented with examples of how they can boost their self-esteem and choose their preferred methods.
10 min	<p>We will play a game to learn about self-esteem:</p> <ul style="list-style-type: none"> <li>• <a href="https://create.kahoot.it/share/self-esteem/2796d468-8f2e-4f97-8033-383418092662">https://create.kahoot.it/share/self-esteem/2796d468-8f2e-4f97-8033-383418092662</a></li> </ul>
10 min	The participants will be presented with examples of compliments and reflect why they think they are great using some examples.
Homework	Group members will be asked to either think about their sibling’s favorite activities, or to interview their sibling about them. They will also be asked to draw a self-portrait that includes all their best skills and positive attributes.

### ***Session 6: Problem-Solving Skills***

The children were encouraged to think of problem-solving skills. They were presented with various coping strategies and given opportunities to implement the strategies hypothetically, as well as in their own lives.

5 min	Review of previous week and introduction to this week's theme (including reminder of the group rules).
20 min	The group members were presented with various problem-solving strategies. They were introduced to COPE: clarify the problem, option list, pick the best idea, evaluate. They were also presented with the problem-solving wheel, other examples of coping strategies, and examples of how we can ask for help.
10 min	Discussion about the group members' coping strategies.
15 min	The members were then presented with hypothetical scenarios about asking a question. Group members were asked to use the problem-solving map to problem-solve and find the best solution. We discussed as a group.
10 min	The group members wrote down difficult situations they had or continued to have with their sibling or parents. They were also asked to provide their solutions or potential solutions (Gafoor, 2015).
10 min	The group members shared their stories, and discussed solutions for each other (Gafoor, 2015).
Conclusion	Message of the week.
Homework	Worksheet given to participants to complete ( <a href="https://www.therapistaid.com/worksheets/cbt-for-kids.pdf">https://www.therapistaid.com/worksheets/cbt-for-kids.pdf</a> )

### ***Session 7: CBT and Mindfulness***

The children are encouraged to think about coping strategies they could use when faced with difficult situations. They will learn aspects of mindfulness, CBT (cognitive behavioral therapy) and various relaxation techniques that will be appropriate for their age group.

5 min	Review of previous week and introduction to this week's theme (including rules of the group).
10 min	Introduction of CBT and Mindfulness. Examples are provided.
5 min	<p>Video on Thoughts, Actions, Feelings (0:41 – 1:45):</p> <ul style="list-style-type: none"> <li>• <a href="https://www.youtube.com/watch?v=PcFmrVZ0e-I">https://www.youtube.com/watch?v=PcFmrVZ0e-I</a></li> </ul> <p>Worksheet looked over with participants and discussed.</p> <ul style="list-style-type: none"> <li>• <a href="https://www.therapistaid.com/worksheets/cbt-for-kids.pdf">https://www.therapistaid.com/worksheets/cbt-for-kids.pdf</a></li> </ul>
10 min	<p>The group leader asked questions about the various thinking traps. As a group, they came up with solutions/adaptive thoughts (see Appendix E).</p> <ul style="list-style-type: none"> <li>• “Thinking Traps” (0 – 1:06) <a href="https://www.youtube.com/watch?v=IDcSTuNgZX0">https://www.youtube.com/watch?v=IDcSTuNgZX0</a></li> </ul> <p>The group members discussed thinking trap activities together. They were presented with various examples on how to challenge a thought.</p>
2 min	The group members were given 10 reminders for when they are having a hard day. Each member took a turn reading them.
10 min	<p>Various relaxation technique activities were introduced (CBT or mindfulness). The group members practiced directing their attention away from unpleasant stimuli and towards something that they found less threatening.</p> <ul style="list-style-type: none"> <li>• “Everyday mindfulness” <a href="https://www.youtube.com/watch?v=QTsUEOUaWpY">https://www.youtube.com/watch?v=QTsUEOUaWpY</a></li> <li>• “3 minutes body scan meditation” <a href="https://www.youtube.com/watch?v=ihwcv_ofuME">https://www.youtube.com/watch?v=ihwcv_ofuME</a></li> </ul>
5 min	Group discussion.
Conclusion	Message of the week.
Homework	Group members were encouraged to practice relaxation techniques at home. They were also encouraged to write down any problem they encountered and to find solutions before acting.

**Session 8: Goodbyes**

The group members reflect on their journeys and say goodbye to each other in the final session. The children will have the opportunity to keep in contact with the participants and reflect on ways that they can maintain their newly learned skills.

5 min	Review of previous week and introduction to this week's theme (including rules of the group).
15 min	Review Game of everything that was learned in the previous sessions: <ul style="list-style-type: none"> <li>• <a href="https://create.kahoot.it/share/final-quiz/ae78e21a-f6b9-4aeb-b1aa-5ff9a9f2a84a">https://create.kahoot.it/share/final-quiz/ae78e21a-f6b9-4aeb-b1aa-5ff9a9f2a84a</a></li> </ul>
15 min	My support system activity: Members completed the activity based on who they could turn to in their support system. They also discussed ways in which they could ask for help if this was something that was difficult for them to do (Kryzak et al., 2015). They discussed with the group what they had written.
10 min	Group members made a list of things that they wish their parents knew about being a sibling and discuss ways they can talk to their parents about them. They also wrote a letter to their parents and sibling about the positive things their families bring to their lives (Hansford, 2014).
10 min	Group members shared what they liked about the group. They exchanged ways to keep in contact.
Conclusion	Goodbyes.

**Appendix E**  
**Activities of the Support Group**

## **Session 1**

### **Rules of the Support Group**

(Based on Guzman, 2009)

1. Confidentiality: what is said in the group, stays in the group. The only exceptions are if a group member says they want to hurt someone else, if a group member is being hurt by someone else, or if a group member wants to hurt himself or herself.
2. Be respectful of others when they are speaking and sharing their ideas
  - a. No insults, teasing, or bullying
  - b. If you would like to speak, please raise your hand
  - c. Only one person may speak at a time
3. Members are allowed to say they do not want to answer the question and pass to the next

## **Session 1**

### **All About Me Booklet**

(Based on Gafoor, 2015; Teachers Pay Teachers, n.d.)

Children may have access online through this link and can edit online if they wish:

[https://docs.google.com/presentation/d/1ryXzoE6M8-W9VjiBa0eS23\\_yCKQhngQT91AisGzGSQo/edit?usp=sharing](https://docs.google.com/presentation/d/1ryXzoE6M8-W9VjiBa0eS23_yCKQhngQT91AisGzGSQo/edit?usp=sharing)

The following shows the contents of the booklet which will be viewed and sent as a PDF document.

# ALL ABOUT \_\_\_\_\_

I'm \_\_\_\_\_ years old. 

My birthday is \_\_\_\_\_.

My favorites

- 
- 
- 
- 
- 
- 
- 

 My family 

I'm from 

I live in \_\_\_\_\_

I like to eat ... 

I like to



I am



Something interesting about me



MY FRIENDS



I SPEND MOST OF MY  
FREE TIME AT...

MY SIBLING'S  
DIAGNOSIS

THE PERSON I ADMIRE

IF I COULD HAVE 3  
WISHES, I WOULD WISH

1.

2.

3.



**Session 4**

**Emotions**

**Positive Emotions I have for my sibling...**

**Negative Emotions I have for my sibling...**

## Session 4

### Discussion Questions (Venegas, 2015)

1. How many of you are sometimes embarrassed or bothered when going out in public with your sibling with autism because of the way they sometimes act? (i.e., hand flapping, rocking, spinning in circles, laughing, or crying for no apparent reason)
  - a. Who can explain/describe/act out some of the behaviors your sibling does?
2. If your sibling engages in hand flapping, what are some other things you can teach your sibling to do or something you can give them to prevent them from hand flapping?
  - a. Possible Suggestions: Give them a toy to play with, hold their hand, Play a hand game with them (i.e., patty-cake)
3. If your sibling engages in rocking their body back and forth or spinning in circles, what are some things you can teach your sibling to do or things you can give them to prevent it?
  - a. Possible Suggestions: Have them play a game with you to give them something else to do

## Session 4

### Dear Rose Letters (Sibling)

(Based on Dyson, 1998; Gafoor, 2015; Meyer et al., 1985; Venegas, 2015)

“Dear Rose” is an activity where children can offer advice to similar others who have written to the fictional character. Children respond to letters by helping in a way that they themselves would deal with the situations, thus working on their problem-solving skills. “Dear Rose” is based on a Sibshops by Meyer et al. (1985).

1. Dear Rose,

Sometimes I feel invisible. My brother has autism and has a lot of needs that seem to take up all of my parents’ time. It seems the only time they pay attention to me is when I get into trouble, and that's no good. My brother gets all the attention! It never seems like what I do is as important as what my brother does.

(signed) Ms. Invisible

2. Dear Rose,

I am so mad! For the fifth time tonight, my brother has bugged me while I've been trying to do my homework. He is always bugging me! Especially when my friends come over.  
Help!

(signed) Fuming

3. Dear Rose,

I am beginning to feel like Cinderella. My parents make me take care of my brother who has autism. I never get to go out with my friends. What can I do?

(signed) Cinderella

## Session 5

### Discussion Questions (from Venegas, 2015)

1. How many of you have been teased, bullied, or just questioned about having a sibling with autism?
  - a. What do some kids say or ask?
2. Who can think of ways you can deal with being teased or bullied by other kids?
  - a. Possible Suggestions: Tell them they don't know your sibling and that he has autism so he can't talk well, or he has a hard time playing with or being around a lot of people, if they ask you a question about your sibling that you don't know the answer to, tell them you will check with your parents and get back to them.
3. Who can think of reasons you shouldn't hit or hurt your sibling with autism when they hit or hurt you?
  - a. Possible Suggestions: Your sibling is not hitting or hurting you due to personal reasons, but it could be because they have a hard time talking with others or they may feel uncomfortable or unhappy in certain situations.
4. Is there anyone that feels like they have less time for their friends?
  - a. What are ways in which we can try to plan better so we can have time for everyone in our lives?

## Session 5

### Questions about Problem-Solving

(Based on Venegas, 2015)

1. Raise your hand if your sibling with autism sometimes makes you upset.
  - What types of things does he/she do to make you upset?
2. Raise your hand if your sibling with autism has broken anything of yours.
  - What did you do when this happened?
3. Raise your hand if you feel you don't get very much time or many chances to play with your friends.
  - Do you sometimes want to invite them over to your house, but you are afraid to because of your sibling with autism?
  - Are you sometimes not allowed to invite them over because of your sibling with autism?
4. How many of you sometimes feel that you and your family cannot go certain places because of your sibling with autism?
  - What do your parents usually tell you when that happens? How does that make you feel?

**Session 5****“Dear Rose” involving others (school context)**

1. Dear Rose,

My name is Paula, I am 9 years old, and I am in the 4<sup>th</sup> grade. I have a brother who has something called autism. We go to the same school, but he is in 2<sup>nd</sup> grade. My classmates know that he is my brother, and they always ask me what is wrong with him because he does not talk and does not like to look at anyone in the eyes. I don't know what to say and I get really embarrassed. What can I do?

(signed) Confused

2. Dear Rose,

My name is Lily, and I am in the 6<sup>th</sup> grade. I go to the same school as my brother who has autism, and we take the bus together. My parents say that they want us to stick together on the school bus and that I have to walk with him home. Sometimes, I feel like my friends don't understand my brother and I always have to make excuses for him or explain to them what he does. Lately, I haven't felt like walking with him anymore and would rather walk with my friends. What should I do?

(signed) Caught Between

## Session 5

### Scenarios

#### Scenario #1: Anger

You have been waiting for the past couple of months for the newest video game to come out in stores. You saved your allowance and your birthday money to buy it. The day has finally come, and you come home after buying the game in the store. You unwrap the box and leave your game out on the kitchen table. You come back, ready to play the game, and find that it is broken in half. Your mom tells you that you should be more careful about leaving things where your brother or sister can get to them.

Discussion Questions:

- Has this happened to you?
- How did you feel?
- If it has not happened, how would you feel?

#### Scenario #2: Proud

You are having a slumber party at your house with a couple of your friends. It is usually hard for your brother or sister to talk and hang out with your friends but today your friends tell you that they want to ask your brother or sister something. They tell you that they heard from one of their younger siblings that your brother or sister is great with calendars and dates. You go get your brother or sister. Your friends start to call out different dates, including month, day, and year, and to your surprise, your sibling is able to tell them what day of the week it is! Your friends are amazed, and they give your sibling high fives.

Discussion Questions

- Has anything like this happened to you?
- How did you feel?

- If it has not happened, how do you think you would feel?

**Ways to expand what siblings say (Meyer et al., 1985)**

1. Identify the problem
2. Ask if anyone else seems to have the same problem: “what happens to the rest of you?”
3. Ask why the problem exists and why it bothers them
4. Ask what solutions they have come up with
5. Ask if it has worked
6. Brainstorm other ways to solve the problem

## Session 6

### Asking a Question Scenarios

#### **Scenario 1: Teacher**

You need to ask your teacher for help, but they are working at their desk. You're not sure if they are too busy. What could you do?

#### **Scenario 2: Homework**

You didn't do your homework. Your teacher was upset with you. What should you do?

#### **Scenario 3: Birthday Party**

Your friend invited you to their birthday party on the weekend. You are not sure whether you can go because your family is always busy on the weekend. What should you do?

#### **Scenario 4: Work**

You started to do your work, but you weren't sure if you were doing it right. What should you do?

## Session 6

### Problem Solving Scenarios

From: <https://www.home-speech-home.com/problem-solving-scenarios.html>

#### Scenario #1

You have been waiting all day for lunch to come because you are starving. Finally, class gets over and you get to go to lunch. Except when you go to get to your lunch, it's not there. You probably left it at home. What could you do?

#### Scenario #2

There is a guy in your class who is always mean to you. He always bumps you when he walks by, and he calls you names. He knocks stuff out of your hands and makes you feel stupid. You don't think you can take it anymore. What could you do?

#### Scenario #3

You rode the bus to school today and on the way in people are pointing and laughing at you. You go in the bathroom and see that you have pink gum all over the back of your pants. What could you do?

#### Scenario #4

You are eating dinner at a fancy restaurant with your parents and their friends. You have a really messy dinner and accidentally flip a noodle into the lady's lap. They are busy talking and don't notice it. What could you do?

#### Scenario #5

You started to do your work, but you weren't sure if you were doing it right. What should you do?

#### Scenario #6

You didn't do your homework. Your teacher was upset with you. What should you do?

## Session 7

### Example of Cognitive Restructuring

- You are going to take a test, but you are saying to yourself “it’s too hard, I can’t do it”.
- Instead, what can you say to yourself?
  - Tests are hard. They’re supposed to be, but I’ll try my best.
  - I’ve studied my best and I’ll just do my best. That’s all that matters.
- You can learn to change what you say to yourself.
- Your body will calm down, you will learn to do some breathing, and learn ways to keep your body calm.
- Important: you have to do the things you’re afraid to do. Even if you don’t want to do that test, and don’t go to school, you’ll never get over that fear and keep saying you can’t do it.
- Our bodies are designed to get used to bad feelings, just like we get used to cold water in the pool.

## Session 7

### Situations for thinking traps

**Goal:** When you notice you've fallen into a trap, try changing your thinking by asking yourself whether it is helpful or not. You can also think about what the evidence is for and against the thought. Just because you think a thought, it doesn't make it true.

#### Situation #1

You sit down and start studying

Thinking trap: what if I get the wrong answer? There's no point in trying

Emotion: anxious; Behavior: turn on the TV, don't study

Adaptive thought: I am going to try my best to get the right answer.

#### Situation #2

It is your first day of school and you don't know many people in the class.

Thinking trap: What if no one likes me?

Emotion: Worried, shy, scared; Behaviors: sit alone, do not talk to anyone

Adaptive thought: I am going to be myself and surely, I will make friends.

#### Situation #3

You walk by two people, and they start laughing.

Thinking trap: They are laughing at me.

Emotion: embarrassed; Behaviors: walk faster, get upset, don't talk to them anymore

Adaptive thought: They don't understand me or my sibling. I can try to talk to a teacher or my parent about my feelings and what I can do in the situation.

## Session 8

### My Support System

Source: <https://www.teacherspayteachers.com/FreeDownload/Identifying-Supports-My-Support-System-5115039>

**DIRECTIONS:** Read the descriptions below for numbers 1 through 12. Think about family, friends, and adults in your school who match these descriptions. Write the name of at least one person on the corresponding numbers inside the rainbow and sun rays. These people are part of your support system who you might choose to talk to about your feelings, problems, or worries.

#### Someone who...

- 1 = I trust
- 2 = helps me
- 3 = believes in me
- 4 = makes me smile a lot
- 5 = helps solve my problems
- 6 = I like to share my news with
- 7 = makes me feel good about myself
- 8 = makes me feel safe and comfortable
- 9 = cheers me up when I am down
- 10 = helps make my worries smaller
- 11 = I can share my feelings with
- 12 = listens when I need to talk



**Appendix F**

**Sample of Demographic Questionnaire for Parents**

### Demographic Questionnaire for Parents

1. Please circle the appropriate marital status

Single      Married      Divorced/Separated      Other: \_\_\_\_\_

2. Please indicate you and your partner's education level and occupation

Mother: \_\_\_\_\_

Father: \_\_\_\_\_

Guardian: \_\_\_\_\_

3. How many children are there in your home? \_\_\_\_\_

4. Please indicate the ages and genders of your children.

\_\_\_\_\_  
\_\_\_\_\_

5. Please indicate the number of children in your family with a disability. \_\_\_\_\_

a. Age: \_\_\_\_\_

b. Gender: \_\_\_\_\_

6. Please indicate the age at which your child was diagnosed with their disability.

\_\_\_\_\_

7. Please describe the medical diagnosis that was given to your child who has a disability.

\_\_\_\_\_  
\_\_\_\_\_

8. Please describe symptoms that your child with their disability often displays.

\_\_\_\_\_  
\_\_\_\_\_

9. Is there anything else you would like to share with us about your child with special needs? \_\_\_\_\_

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10. Please indicate the number of adults living in your home and their relationship with your child participating in the study.

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11. Please fill out the following information about your child participating in the study.

a. Age: \_\_\_\_\_

b. Gender: \_\_\_\_\_

c. Birth order within the family:        1        2        3        4        5        6

d. Does s/he attend the same school as your child with special needs? \_\_\_\_\_

e. Is there anything else you would like to share with us about your child?

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12. Please describe your child's current interests (e.g., space, superheroes, etc.)

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13. Have you previously attended classes or orientations for parents who have a child with autism?

\_\_\_\_\_ **no** \_\_\_\_\_ **yes** if yes, please explain \_\_\_\_\_

---

14. Have you previously attended classes or orientations for parents who have a child with autism and a typically developing child?

\_\_\_\_\_ **no** \_\_\_\_\_ **yes** if yes, please explain \_\_\_\_\_

---

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

---

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16. Are there any major concerns, stressors, or problems that your typically developing child(ren) are facing? \_\_\_\_\_

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17. Has your typically developing child ever participated in a sibling support group for children who have a sibling with autism?

\_\_\_\_\_ **no** \_\_\_\_\_ **yes** if yes, please explain \_\_\_\_\_

---

18. How did your other child/children react to the diagnosis? When do you think they noticed there was a difference? \_\_\_\_\_

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19. How does your child understand the diagnosis? How is it discussed at home? Is the word "Autism" mentioned? \_\_\_\_\_

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20. What is your relationship like with the child that is participating in the group?

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21. What is the relationship of your two children? How do they get along? \_\_\_\_\_

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22. Do you have any concerns or issues about your child with ASD? Your other child? How do you handle these concerns or issues? \_\_\_\_\_

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**Appendix G**

**Sample of Knowledge Questionnaire About Autism for Siblings**

### Knowledge Questionnaire About Autism for Siblings

Directions: You are going to read some questions about autism. I want you to answer as best you can by circling, either True or False. If you don't know the answer, you can circle Not sure.

1. People with autism have difficulty communicating. (Ilg et al., 2012)
  - a. True
  - b. False
  - c. Not sure
2. Kids with autism often go to special classes at school so they can learn. (Adapted from Perry, 1989).
  - a. True
  - b. False
  - c. Not sure
3. Kids with autism have lots of friends they like to play games with. (Adapted from Perry, 1989).
  - a. True
  - b. False
  - c. Not sure
4. The symptoms of autism are very different from one person to another. (Ilg et al., 2012).
  - a. True
  - b. False
  - c. Not sure
5. Most kids with autism still be different when they grow up. (Adapted from Perry, 1989).
  - a. True
  - b. False

- c. Not sure
6. Kids with autism often have language delays. (Ilg et al., 2012)
- a. True
  - b. False
  - c. Not sure
7. Kids with autism like to be by themselves a lot. (Adapted from Perry, 1989).
- a. True
  - b. False
  - c. Not sure
8. Kids with autism usually adapt to changes easily. (Ilg et al., 2012)
- a. True
  - b. False
  - c. Not sure
9. Kids with autism been that way since they were very young. (Adapted from Perry, 1989).
- a. True
  - b. False
  - c. Not sure
10. Autism common enough that there are lots of people on your street (or in your building) with a kid with autism in the family. (Adapted from Perry, 1989).
- a. True
  - b. False
  - c. Not sure
11. Kids with autism get that way because of the way their parents treat them. (Adapted from Perry, 1989).

- a. True
  - b. False
  - c. Not sure
12. Kids with autism do funny things like flapping their hands or bouncing up and down in their chair. (Adapted from Perry, 1989).
- a. True
  - b. False
  - c. Not sure
13. If a kid has a brother or sister with autism does that mean, there's something wrong with him/her too? (Adapted from Perry, 1989).
- a. True
  - b. False
  - c. Not sure

**Appendix H**  
**Sample of KIDCOPE**

### KIDCOPE

Please remember an event that happened recently (within the last month) concerning your sibling with autism. Perhaps you can remember a time where you were embarrassed, or they did something upset you. Once you have the memory, please read each of the coping strategies and circle *yes* if you used it, or *no* if you did not use it. If *yes*, you used it, please indicate how much that strategy helped by circling *not at all*, *a little*, or *a lot*.

	Did you do this?		How much did it help?		
	Yes	No	Not at all	A little	A lot
1. I just tried to forget it	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2
2. I did something like watch TV or played a game to forget it.	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2
3. I stayed by myself	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2
4. I kept quiet about the problem	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2
5. I tried to see the good side of things.	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2
6. I blamed myself for causing the problem.	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2
7. I blamed someone else for causing the problem.	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2
8. I tried to fix the problem by thinking of answers.	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2
9. I tried to fix the problem by doing something or talking to someone.	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2
10. I yelled, screamed, or got mad.	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2
11. I tried to calm myself down.	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2
12. I wished the problem had never happened.	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2
13. I wished I could make things different.	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2
14. I tried to feel better by spending time with others like family, grownups, or friends.	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2
15. I didn't do anything because the problem couldn't be fixed.	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2

**Appendix I**

**Sample of View of Sibling Questionnaire (Pre)**

### View of Sibling Questionnaire (Pre)

1. How well do you get along with your brother/sister with autism? (Venegas, 2015)
  - a. Very well
  - b. Somewhat Well
  - c. Okay
  - d. Not very well
  
2. How often do you play around and have fun with your sibling? (Buhrmester & Furman, 2008)
  - a. Always
  - b. Often
  - c. Sometimes
  - d. Never
  
3. How often do you and your sibling disagree or fight with each other? (Buhrmester & Furman, 2008)
  - a. Always
  - b. Often
  - c. Sometimes
  - d. Never
  
4. Here are some examples of concerns that someone may have about their brother/sister with autism. Please indicate whether this is one of your concerns and indicate any other concerns you may have about what your brother/sister does. (Gettings et al., 2015)

Concern	Please describe
a. You often feel angry with your brother/sister in regard to their disorder.	

b. You get teased at school because you have a brother/sister with autism.	
c. You don't know what to say when other kids make fun of your brother/sister with autism?	
d. You don't know how to explain that your brother/sister has autism to other people.	
e. You feel like your brother/sister with autism takes up a lot of your mother's/father's time.	
f. Other concerns.	
g. Other concerns	

## 5. Thinking about your answers to question 1 –

Using a scale of 0 to 10, where 0 means no concern at all and 10 means the most concern possible, what rating would you give each of your concerns? (Gettings et al., 2015)

Concern #	a	b	c	d	e	f	g
Rating of concern (0 to 10)							

6. Considering any **advantages or disadvantages** there might be, tell me how you consider that each of the things your brother/sister says or does that you pointed out in question 1 affect:

- a. you in particular
- b. your brother or sister (with autism)
- c. your parents
- d. anyone else at home not already mentioned
- e. you as a family

(Gettings et al., 2015)

	Description relating to each concern (1 to 5)
a	
b	

c	
d	
e	

7. We would like to know if you have talked to anyone properly about the things you're concerned about and if so, then how regularly you do so. Please tick in the box as appropriate. (Gettings et al., 2015)

Concern	Many times per day	Many times per week	Many times per month	Many times per year	As a 'one off' occasion	Never
a						
b						
c						
d						
e						
f						
g						

8. If answered never, then please give the reason(s) why. (Gettings et al., 2015)

Concern	Reason for not talking to someone about this concern
a	
b	
c	
d	
e	
f	
g	

9. What would you like to get out of being part of a sibling support group? (Gettings et al., 2015)

10. What would you like help with in particular? (Gettings et al., 2015)

11. What in particular would you like information about? (Gettings et al., 2015)

**Appendix J**

**Sample of View of Sibling Questionnaire (Post)**

### View of Sibling Questionnaire (Post)

1. How well do you get along with your brother/sister with autism? (Venegas, 2015)
  - a. Very well
  - b. Somewhat Well
  - c. Okay
  - d. Not very well
  
2. How often do you play around and have fun with your sibling? (Buhrmester & Furman, 2008)
  - a. Always
  - b. Often
  - c. Sometimes
  - d. Never
  
3. How often do you and your sibling disagree or fight with each other? (Buhrmester & Furman, 2008)
  - a. Always
  - b. Often
  - c. Sometimes
  - d. Never
  
4. At the start of the support group, you mentioned whether some things you have noticed your brother/sister with autism does or say that you were most concerned about, and general things about them that concern you.

You rated your concerns using a scale of 0 to 10, where '0' means no concern at all and '10' means the most concern possible.

What rating would you give each of your concerns now?

Concern #	a	b	c	d	e	f	g
Rating of concern (0 to 10)							

5. Considering any **advantages or disadvantages** there might be, tell me what changes, if any, there are in how you consider that each of the things your brother/sister does or says that you pointed out in question 1 affect:
- you in particular
  - your brother or sister (with autism)
  - your parents
  - anyone else at home not already mentioned
  - you as a family

(Gettings et al., 2015)

	Description relating to each concern (1 to 5)
a	
b	
c	

d	
e	

6. We would like to know if there have been any changes with regard to talking to someone properly (apart from talking to people in the support group) about the things you're concerned about. Please tick in the box as appropriate. (Gettings et al., 2015)

Concern	Many times per day	Many times per week	Many times per month	Many times per year	As a 'one off' occasion	Never
a						
b						
c						
d						
e						
f						
g						

7. Let's compare your answer, above, to what was happening before the support group. If there are any changes, what do you think are the reason(s) for those? If there has been no change in relation to talking to someone about one or more of your concerns, what do you think are the reason(s) for that?

Concern	Reason for any differences or reasons for no change
a	
b	
c	
d	
e	
f	
g	

8. Did you get what you wanted out of being part of the support group? (Gettings et al., 2015)

9. Did you get the particular help you identified before/at the start of the support group? (Gettings et al., 2015)

10. Did you receive the information you said you wanted in particular? (Gettings et al., 2015)

**Appendix K**

**Sample of Certificate of Completion**



CERTIFICATE OF PARTICIPATION

CHILD'S NAME

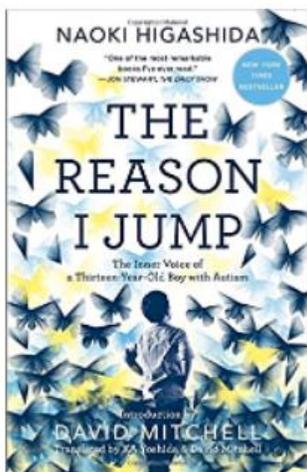
IS THANKED FOR THEIR  
OUTSTANDING PARTICIPATION IN  
THE SIBLING SUPPORT GROUP

DATE: JULY 27, 2021

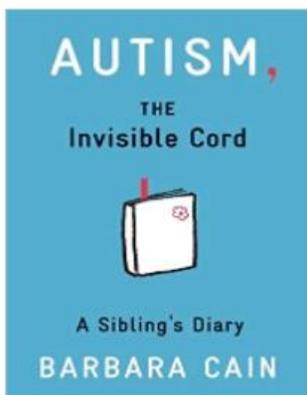
**Appendix L**

**Sample of Reading List in Thank You Letter**

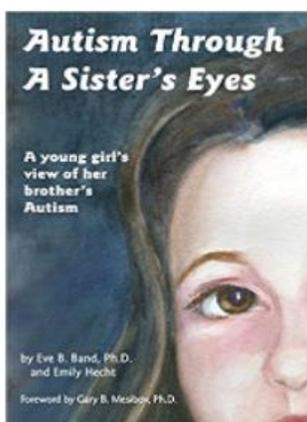
**Cool books you can add to your reading list!**



Naoki Higashida was only a middle-schooler when he began to write *The Reason I Jump*. Autistic and with very low verbal fluency, Naoki used an alphabet grid to painstakingly spell out his answers to the questions he imagines others most often wonder about him: why do you talk so loud? Is it true you hate being touched? Would you like to be normal? The result is an inspiring, attitude-transforming book that will be embraced by anyone interested in understanding their fellow human beings, and by parents, caregivers, teachers, and friends of autistic children. Naoki examines issues as diverse and complex as self-harm, perceptions of time and beauty, and the challenges of communication, and in doing so, discredits the popular belief that autistic people are anti-social loners who lack empathy. This book is mesmerizing proof that inside an autistic body is a mind as subtle, curious, and caring as anyone else's.



Barbara Cain's *Autism, the Invisible Cord: A Sibling's Diary* is an award-winning work of fiction that is sure to resonate with many. Written for the middle-grade and young teen audience, this book is narrated by Jenny. Jenny's brother, Ezra, is both her best friend and the biggest obstacle between herself and a "normal life." Over the course of the book, Jenny describes taking care of her brother, being his champion, and learning much about herself in the process.



*Autism Through a Sister's Eyes* is an informative, non-fiction book written by a clinical psychologist and a 10-year-old girl, Emily, whose brother is on the Autism Spectrum. The book explores the many feelings and questions a sibling might have about their brother or sister with autism. *Autism Through a Sister's Eyes* is written in Emily's voice, and features chapters on what are autism and Asperger's Syndrome, learning to cope, and talking with others.



Boy Alone: A Brother's Memoir is another non-fiction book that's likely to be helpful to other siblings of those on the Autism Spectrum. This "unforgettable memoir" documents the confusion, anger, and ultimately, overwhelming love that author Karl Taro Greenfield felt growing up with his non-verbal autistic brother, Noah.



Bridget and Carlton are as close as any sister and brother. But their relationship is particularly special. Carlton has autism and is almost completely nonverbal. He's smart, funny, creative, and loving. He has immense challenges in speaking full sentences. Bridget's fierce loyalty to and compassion for her brother led to an unbreakable bond that has helped the siblings cope with divorce and homelessness. Carlton's devotion to his family is loud and clear, even in his silence.

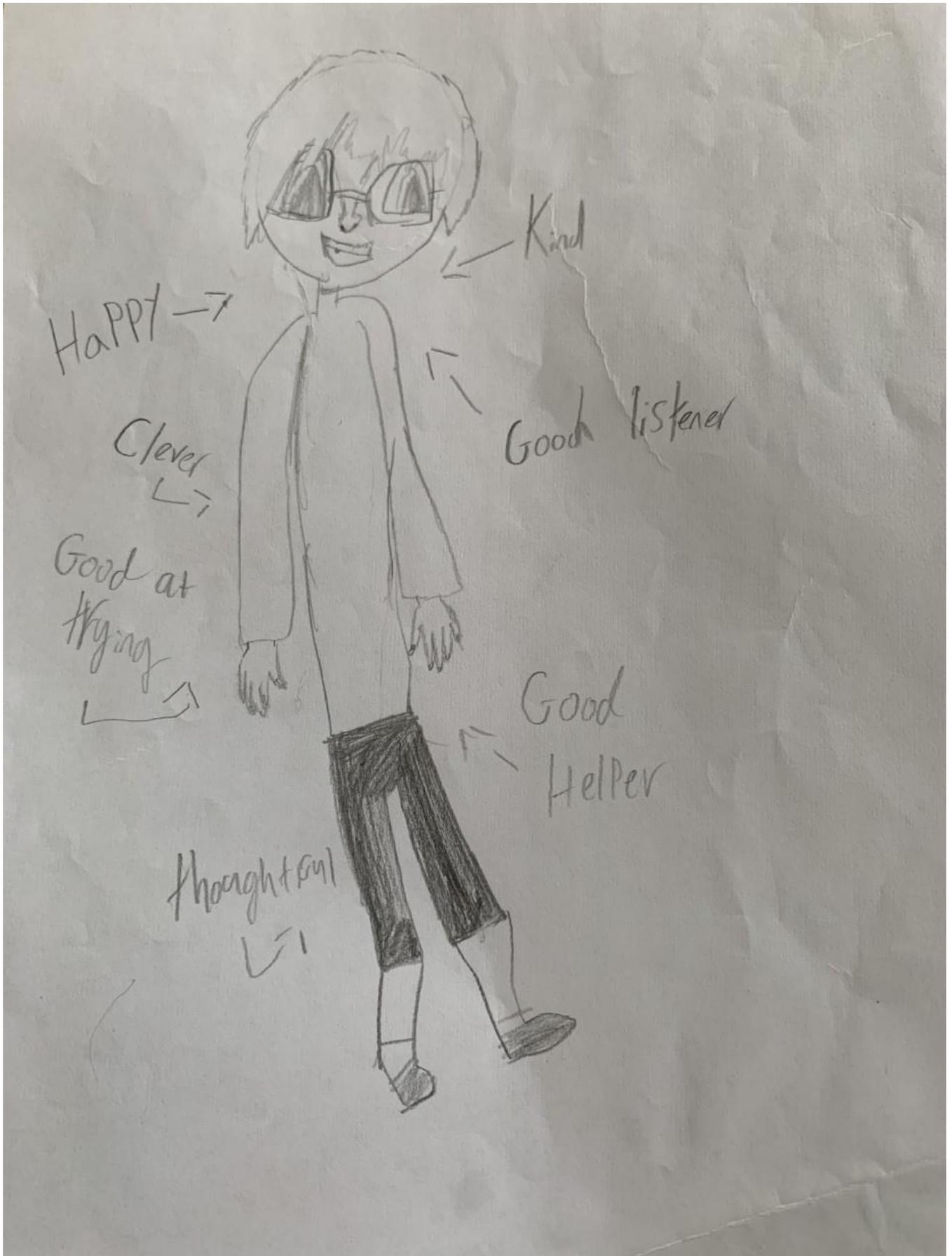
**Appendix M**

**Participant 1's Self-Esteem Portrait**



**Appendix N**

**Participant 4's Self-Esteem Portrait**



Happy →

Clever  
↳

Good at  
trying  
↳

Thoughtful  
↳

Kind  
←

Good listener  
←

Good  
Helper  
←

**Appendix O**

**Participant 5's Self-Esteem Portrait**

I am smart

I am good at drawing

I am brave



I am funny

I am creative

I am helpful